# Measuring and understanding individual and community health status in eastern Democratic Republic of Congo from a person-centered perspective

By

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## PREFACE

In the early morning of November 5, 2017, the second day of Jean and Françoise Macq's mission in South Kivu to support the implementation of field activities as part of the research for development project under which this thesis was conducted, an almost full-day military clash between the government forces and the guard of a rebel army officer erupted in Bukavu. It was within a 2-km radius of the beautiful Orchid hotel in the Muhumba bay where an apartment was booked for the two-month stay Françoise and Jean had planned. Even for Kivu residents who survived several war episodes, every single gunshot in the nearby is devastatingly stressful, let alone people like Françoise and Jean who were experiencing, for the very first time, a live armed clash for a whole day.

As owe a great part of the success of this project to Françoise's and Jean's resilience, many Congolese owe their health and lives to the resilience of the health system in conflict and post-conflict settings in the Democratic Republic of Congo (DRC) where family and societal structures have been shattered by decades-long sociopolitical instability and conflict. It would be an illusion to pretend understand the health system resilience in the Kivu without a clear comprehension of how each person's health is at the center of a complex interplay between biological, psychosocial and contextual resources and challenges. The development process of sustainable health systems responsive to each person's own experience of health in low-income and post-conflict settings will remain an elusive goal unless we collectively embrace a person-centered view of health. And if we can't measure health with person-centered lenses, we cannot understand it...

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"For is God who works in you both, to will and to do for His good pleasure." Phil 2.13

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## **SUMMARY OF THE THESIS**

### Introduction

The importance of viewing individual and community health through person-centred lenses has been increasingly recognised in recent decades. Akin to many low- and middle-income countries (LMIC) where public health services are still overwhelmingly burdened by infectious diseases and reproductive, maternal and child health problems, in the Democratic Republic of Congo (DRC) the design, monitoring and evaluation of health systems programs and performance are culturally framed around specific disease-based or mortality-based indicators. The lack of a person-centred thinking in many LMIC is partly due to limited evidence on how health can be measured and monitored, particularly at primary healthcare level, using person-centred tools.

#### Aim of the thesis

The aim of this thesis was to describe the typology of population health (Study I), examine the link between health capital (also interchangeably referred to as level of healthcare need hereafter) and health service utilisation (Study II), and analyse the feasibility of monitoring health at community level from a person-centred perspective in a low-income and post-conflict setting (Study III).

#### Methods

We conducted three population-based observational studies among adults with diabetes, hypertension, and mothers of infants with acute malnutrition (referred to as 'tracer group'); informal caregivers (of participants with diabetes and hypertension) and helpers of mothers of children acutely malnourished; and randomly selected neighbours in six health areas (four rural and two semi-urban) spanning four health zones of the South Kivu province in eastern DRC. We used the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS) to measure an individual's health from a person-centred standpoint. The baseline health capital variable was defined as a hierarchical gradient of healthcare need representing varying levels of cognitive, functional and social performance and (dis)ability. The health capital variable was derived from a cluster analysis following a principal component analysis of the WHODAS domain scores (Study I). In a cross-sectional

study, we examined how the health capital levels were associated with utilisation of modern health facilities at baseline (Study II). We then longitudinally studied how the overall individual health, expressed as the summary score of the six WHODAS domains (cognition, mobility, self-care, getting along with others, ability to execute domestic, work or school tasks, and social participation) changes over a two-year period and what are the factors influencing the magnitude of the probability of change and its direction.

#### Results

In Study I, 1266 study participants were interviewed, with an average age of 48.3 [Standard Deviation (SD): 18.7] years. Three hierarchical health clusters were identified: 69.7% respondents were in cluster 1 of minor dependency (or low level of healthcare need), 21.1% in cluster 2 of moderate dependency and 9.2% in cluster 3 of high dependency (or high level of healthcare need).

In study II, 82% (n = 413) of the participants who reported having fallen sick in the 30 days prior to the baseline interview (N = 504) utilized modern health facilities in the first resort. The prevalence of modern health facility utilization was higher by 27% [adjusted prevalence ratio (aPR): 1.27; 95% CI: 1.13–1.43; p < 0.001] and 18% (aPR: 1.18; 95% CI: 1.06–1.30; p = 0.002) among participants with middle and higher health needs, respectively, compared to those with low healthcare needs. Using the lowest health need cluster as a reference, participants in the middle healthcare need cluster tended to have a higher hospital utilization level.

In Study III, among the 1120 participants with validated data on tracer group status and WHODAS at baseline; 725 (64.7%) were interviewed at both follow-up visits, corresponding to 1450 person-visits. The overall risk of decline in health capital was 45.7%. Participants in the high healthcare need cluster had a lower absolute risk (15.4) of decline in health capital than those in the middle (33.3%) and low healthcare care need clusters (53.8%). The decline in health capital was not significantly associated with the enrolment status (tracer group variable), but was strongly linked to the baseline health capital. In fact, the risk of decline in health capital was lower in participants in the middle (adjusted RR: 0.46; 95% CI: 0.37– 0.57, p<0.001) and low (adjusted RR:0.21; 95% CI: 0.14–0.31; p<0.001) health capital cluster than in those in the high health capital cluster. We also found that each five-years increase in a participant's age was expected to increase the risk of decline in health capital by 4% (RR: 1.04, 95% CI: 1.02–1.06, p<0.001). The direction of the association between decline in health capital and rural location was unclear.

## Conclusion

In these population-based studies examining the feasibility and usefulness of measuring health from a person-center perspective, we showed that health status clustering has the potential to adequately discriminate individuals based on the levels of health needs and to increase the likelihood of appropriate healthcare service provision to all, including to those with vulnerabilities who could be easily overlooked by usual disease-based classifications of a population health. Although an individual's disease label is a significant predictor of their baseline health status cluster, it had little effect on the change in health capital over a two-year follow-up period. Therefore, assessing each person's healthcare need level with multidimensional person-centered tools, in additional to traditional mono-pronged assessments based on disease indicators, can help better fit health care services to people's needs and specific contexts. Further studies will be necessary to better understand the dynamic of individual and population health over longer time periods and the cost-effectiveness of such person-centered approaches in the health services organization at primary and higher levels of health systems in low-income countries.

## LIST OF PUBLICATIONS

- 1. E. B. Malembaka *et al.*, A new look at population health through the lenses of cognitive, functional and social disability clustering in eastern DR Congo: a community-based cross-sectional study. *BMC public health* **19**, 93 (2019).
- 2. E. B. Malembaka *et al.*, Are people most in need utilising health facilities in post-conflict settings? A cross-sectional study from South Kivu, eastern DR Congo. **13**, 1740419 (2020).
- 3. E.B. Malembaka *et al.*, A two-year longitudinal assessment of people's healthcare status and needs from a person-centred perspective at community level in South-Kivu, DR Congo: lessons learned. [To be submitted to a peer-reviewed journal]

## **ACRONYMS AND ABBREVIATIONS**

| ABM     | Agent-Based Modelling  |
|---------|--|
| AOR     | Adjusted Odds Ratio  |
| ARES    | Académie de Recherche et d'Enseignement Supérieur                  |
| ARR     | Adjusted Relative Risk   |
| AVEC    | Association Villageoise d'Epargne et de Crédit                     |
| BDOM    | Bureau Diocésain des Œuvres Médicales                              |
| CHW     | Community Health Workers   |
| CI      | Confidence Interval  |
| COR     | Crude odds ratio;  |
| CRR     | Crude Relative Risk  |
| DRC     | Democratic Republic of Congo                                       |
| ERSP    | Ecole Régionale de Santé Publique                                  |
| FOREAMI | Fonds Reine Elisabeth pour l'Assistance Médicale Indigène          |
| GEE     | Generalized Estimating Equations                                   |
| HA      | Health Area  |
| HFU     | Health Facility Utilization  |
| HIV     | Human Immunodefiency Virus   |
| HT      | Hypertension   |
| HZ      | Health Zone  |
| ICC     | Intra-class correlation  |
| ICF     | International Classification of Functioning, disability and health |
| IQR     | Interquartile range  |
| LC      | Louvain Coopération  |
| LMIC    | Low- and Middle-Income Countries                                   |
| MCA     | Multiple Correspondance Analysis                                   |
| MPS     | Medico-psychosocial conditions                                     |
| MUAC    | Mid-Upper Arm Circumference  |
| NGO     | Non-Governmental Organization                                      |
| PR      | Prevalence Ratio   |
| PRD     | Projet de Recherche pour le Développement                          |
| RCD     | Rassemblement Congolais pour la Démocratie-Goma                    |
| RR      | Relative risk  |
| SD      | Standard deviation   |
| SDG     | Sustainable Development Goals                                      |
| SEP     | Socio-economic Position  |

| SES    | Socio-Economic Status                                    |
|--------|--|
| UCB    | Université Catholique de Bukavu                          |
| UHC    | Universal Health Coverage                                |
| VIF    | Variance inflation factor                                |
| WHO    | World Health Organisation                                |
| WHODAS | World Health Organisation Disability Assessment Schedule |
|        |  |

**Chapter 1. INTRODUCTION** 

# 1.1. How should individual and community health be viewed in the 21<sup>st</sup> century?

For over 71 years, health has been widely defined by the World Health Organisation (WHO) as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"<sup>1,2</sup>. Originally formulated to integrate the biological aspects with psychological and social dimensions of human life, this definition has had its share of heated debates in the recent past. Since the WHO definition of health, the global health landscape has been characterized by an unprecedented increase in the burden of aging and non-communicable diseases in high income countries on the one hand, and the concurrence of different hallmarks of the epidemiological transition across low-income and middle-income countries (LMIC), on the other<sup>3</sup>. This evolution has uncovered some of the areas where the WHO definition of health fell short of providing a solid basis for design and appraisal of strong health systems to deliver quality health rather than plain health services.

Of the common critics, one of the most consequential contend that the idea of health as a "complete" state of well-being furtively plunges the society into to medicalization and a superfluous slope towards the use medical technology and drug industries<sup>4</sup>. As result, health systems tend to mis-focus health programs and priorities on the disease rather than the quality of life, on the person in their unique situation<sup>5,6</sup>. The unintended risk is an overutilization of health care, potentially harmful to the physical, mental and social well-being of the people<sup>7</sup>. Additionally, the tendency to foolhardily pursue the absolute well-being is financially at odds with a sustainable health systems development because of unnecessarily increased costs, impoverishment of the population in settings where health financing relies on outof-pocket payment, dispelling trust into the health system and squandering of precious resources<sup>7-9</sup>. The consequences are particularly burdensome for resourceconstrained countries. But, how should health be viewed from the standpoint of quality life for all and sustainable development in LMIC is still open to debate.

Health encompasses and transcends the mere concept of medico-psychosocial morbidity and is increasingly seen as the ability to adapt and to self-manage<sup>4</sup>, an equilibrium between social and personal resources, physical capacity, demands of life and economic productivity<sup>10</sup>. The construct of health underlies a continuous spectrum that cannot be equated to a white-or-black reality<sup>5,11</sup>. Although a consensus on what should be the right definition of health is yet to be arrived at, there seems to be a common sense that how we perceive health shapes the way health policies are

formulated and programmes designed. With the steadily rising burden of chronic comorbidities in LMIC on top of poverty-compounded endemics, new health considerations such as functional dependence, cognitive functioning and social participation are becoming of greater importance.

One of the lessons we learn from the stormy debate about the right definition of health is the necessity for health systems to rethink the way priorities and objectives are set by shifting the focus from purely disease-based or bio-psychosocial indicators of health to a broader and person-centred perspective accounting for social and environmental factors, and for the uniqueness and wholeness of each person's life<sup>6,10-12</sup>. This change in mind-set underscores the need for person-centered and goal-oriented metrics that can help tailor care to what is most meaningful to the person; it also entails developing and testing relevant measures of overall health status<sup>5,13,14</sup>. However, health systems research has often fallen short of proposing operational approaches to measuring individual and community health in a way that allows to center health prioritization and programming to a personal history and experience of well-being.

Despite the recognition of the growing need of applying person-centered lenses to conceptualize health at individual and community level, sound and unequivocal methodological approaches have not yet been examined to understand how and under which circumstances change in health systems can improve a person's experience of healthy life<sup>15</sup>. The development such of approaches require a broader view of health in its complexity and multiple dimensions. It also requires more than the necessary but insufficient biomedical deductive reasoning that has admittedly contributed to the development of epidemiology, public health and medicine in general, but has often proved insufficient for complex public health problems solving<sup>16</sup>. A multidimensional and complex systems thinking approach may provide a strong framework for innovative research by harnessing the virtues of both positivism and critical realism paradigms<sup>15</sup>. But, how such a methodological combination can work in studies aiming to investigate the facilitators and barriers to the introduction person-centered models of care at the peripheral level of health systems in LMICs necessitates evidence.

The WHO, echoing the need for a holistic approach to assessing health status both at individual and community levels, developed appropriate tools that allow a better understanding and estimation of the impact of any health condition in term of functioning. The International Classification of Functioning, disability and health (ICF) published by the WHO in 2001 has proved to be a useful and valid framework integrating function and disability with the context of health conditions and contextual factors<sup>17</sup>. Additionally, the WHO Disability Assessment Schedule (WHODAS 2.0), drawing essentially on the ICF framework, provides a standardized approach to measuring health and disability across cultures<sup>18</sup>. It is not yet fully understood how health systems can leverage on these person-centered tools to identify the drivers of change that can be tapped by researchers, policymakers and healthcare workers to address complex health problems at individual and community level in low-income countries.

This thesis sought to describe the topology of population health status at community level in Eastern Democratic Republic of Congo, and its individual, social and contextual determinants, using person-centred tools. Our aim was to generate evidence that can inform system thinking approaches to understanding how community efforts and potentials can be leveraged to change the way primary healthcare services are organised and to help local communities in LMICs experience the momentum of the sustainable development goal target 3.8 advocating that no one is left behind.

#### **1.2.** Defining health complexity

Over the years, cumulative evidence has pointed to the reciprocal relationship between psychosocial factors and, for example, chronic diseases such as cardiovascular diseases and diabetes in high-income and low-income countries. Studies of malnutrition in mother-infant pairs in resource-constrained settings, as another illustration, consistently mentioned the key underlying role played by psychological, social and environmental determinants of health in both the occurrence and persistence of maternal and child undernutrition as well as its shortterm and long-term consequences <sup>19</sup>. In either situation, concerned people often face a complex set of problems spanning the medical, psychological and social spheres of life.

Health is increasingly seen as a continuum, as aforementioned, and social scientists contend that people's experiences are complex, subjective and embedded in specific social and historical contexts. But, whether at individual or community level, there is no single definition of health complexity and this concept can be understood from a number of perspectives including multi-morbidity, resource utilization, and psychosocial complexity <sup>20</sup>. From a rather restrictive and widespread clinical point

of view, complexity is sometimes referred to as a set of multiple attributes that, in the context of multi-morbidity, encompasses severity of illness, risk of dying, prognosis, treatment difficulty, need for intervention and resource intensity <sup>21</sup>. Although this dominant conception of health complexity may be useful in solving short-term health problems, it may not suffice to provide solid grounds for a sustained health and quality life from a longer-term point of view. There is thus a growing recognition of the need for a more comprehensive approach to conceptualizing health in its multiple dimensions, that is, a shift from biomedical and social models to more multi-dimensional medico-psycho-social models insisting on the dynamic and reciprocal relations between health conditions and contextual factors (personal, family, economic, societal and environmental factors) <sup>22,23</sup>. People in more complex medico-psychosocial situations may need particular attention in order to receive quality care responsive to their needs.

# **1.3.** Understanding the person-centred construct in public health and its meaning for low-income countries

The historical and philosophical origins of the person-centred or human-centred notion can be traced back to as far as the ancient Greece. This construct is echoed in virtually all the intellectual movements that have moulded the modern thinking<sup>24</sup>. This concept cross-cuts disciplines, from religions<sup>25</sup> to industrial and technological revolution<sup>26,27</sup>, computer sciences<sup>28</sup>, social sciences and health. The increasing scientific importance of the person-centred concept has even justified recent developments of distinct training and research disciplines around it<sup>29</sup>. Whatever the field, a person-centred approach aims at understanding human needs, resources and interests as solutions for human challenges are being engineered.

The first systematic use of a person-centred approach to health is credited to Carl Rodgers who coined the term client-centred approach that was later improved to human-centred <sup>30</sup>. Rogers insisted on the philosophical dimension of a person-centred care whereby, in the healthcare provision process, focus needs to be put on the necessity to create a 'growth-promoting climate' that renders healthcare sensitive to each individual's own experience and feeling, and taking into account each person' life goals and circumstances<sup>30</sup>.

When it comes to (public) health more broadly, one of the core premises of a personcentred approach is the role of each individual's judgement about their health, and the balance that needs to be found between a subjective perception of health and wellbeing on the one hand, and an objective health appraisal by healthcare providers on the other. While this concept has been widely used in mental health, nursing sciences and chronic care <sup>31,32</sup> over the last three decades, the design process of public health systems has lagged behind in getting permeated by the person-centred notion. Most health systems, particularly in low-income settings, remain largely diseasecentred, often oriented towards sole donors-dictated disease-based and mortality indicators for maternal and child health, infectious diseases, etc. An integration of the person-centred idea in public health practice necessitates adequate measurement methods and tools with potential to reconcile both individual perception of health and objective health metrics. One of the factors that might have delayed the wide adoption of the human-centred thinking in public health is likely the challenge associated with measuring health from the human-centred perspective at individual and community level.

Globally, the definition the people-centred concept in health sciences has fluctuated between authors, with several definitions proposed. The WHO considers the people-centred approach as a way of prioritising, funding, planning and offering healthcare services that openly take into account the individual, family and social contexts and considering people as stakeholders of a trusted health system, responsive to their preferences and holistic needs in human ways <sup>33</sup>. For healthcare to be people-centred, people need to have a certain level of health literacy and support in order to take action and participation in their own care.

The person-centred approach is central to the universal health coverage goal advocating that all the people should have access to quality and acceptable health services they need without suffering financial hardship when paying for them. In low-income countries, particularly in settings fragilised by protracted socio-political instability, access to health services is inequitable and limited to the elite and those with higher socio-economic position. The adoption of an integrated person-centred philosophy is more challenging in contexts where health financing heavily relies upon user's fees and, both individual and community health are largely viewed as a marketable resource.

One of the cornerstones of the strategies adopted by the 69<sup>th</sup> WHO assembly in 2016 in order to reorient health systems towards the people-centred vision is a renewed ambition of placing increased attention and resources on health promotion and primary healthcare. As rightly recognized by the WHO, such an ambition entails developing capacities for stratifying population health needs and risks, and monitoring population health status<sup>33</sup>. The public dividends associated this form of public health thinking r(evolution) are likely more important in sub-Saharan Africa and other resource-constrained regions. But, in many low-income countries, little is known in how best health and population healthcare needs (and resources) can be measured, stratified and monitored at population level using person-centred lenses.

#### 1.4. The public health context of the Democratic Republic of Congo

#### 1.4.1. General DRC context, demography and health system structure

The DRC is the second largest country in Africa and arguably one of the richest countries in the world in terms natural resources. However, the majority of its estimated 89,561,000 inhabitants<sup>34</sup> live in poor socio-economic conditions because of lack of governance, weak public leadership and protracted armed in the eastern provinces of the country. With a population growth rate of 3.19%, the DRC is expected to double its population by 2050<sup>35,36</sup>. An estimated 56.7% of the DRC population is aged below 20 years and only 3% of the population is aged 65 years and above<sup>34</sup>. About 57% of the DRC population live in rural areas<sup>37</sup> where access to public services and basic water, sanitation and hygiene facilities is problematic. Overall, nearly 15% of the 10-year old population have never gone to school; this proportion is remarkably higher in women (21%) and rural areas (19.4%) than in men (8 %) and urban areas (8%) respectively<sup>38</sup>. In urban areas, 35.3% of the population have access to electricity for lighting, against 0.3% in rural areas and a national average of 15.6%. As for drinkable water, up 74.6% of the households in DRC drink a water contaminated with fecal Escherichia coli; this proportion is expectedly higher in rural areas (82.1%) than in urban areas (65.9%). In addition, only 32.6% of the population use improved sanitary facilities (53.6% in urban areas and 16.3% in rural areas)<sup>39</sup>.

Administratively, there are 26 provinces in DRC organised in 192 territories. The health system follows a different subdivision: provinces are organised into health zones, and these in health areas (there are 8 territories and 34 health zones in South Kivu, for instance). There are on average 3-4 health zones by territory.

Healthcare services in health zones are staggered at two levels in DRC. The primary healthcare services are organised around health centres providing the minimum service package. Health centres catchment areas, referred to as 'health areas', theoretically cover 10,000 inhabitants, but some health areas actually have double that programmatic figure <sup>40</sup>. According to a 2016 report from the DRC ministry of

health, 79% of the health areas had health centres in 2009, of which 15% were built in permanent structures. Only 6% of the health centres provided an adequate minimum package of services<sup>41</sup>. The second level is centered around health zones hospitals offering hospitalisation and reference services, in addition to technical support to health centres through integrated supervision. In 2012, 24% of the 516 health zones/districts had no hospitals and only 16% of the hospitals were capable of providing adequate complementary package of services<sup>41</sup>.

# 1.4.2. Historical view of the impact of socio-political turmoil on the DRC health system

#### 1.4.2.1. The DRC health system from the colonial time to the early 1990s

Historically, the DRC had one of the best health systems in the francophone sub-Saharan Africa. In 1885 when the Congo Free State was founded, the medical task force was only comprised of civilian doctors working with the military administration, joined by protestant, then catholic missionaries (the first presence of a medical doctor was documented in1885)<sup>42</sup>. When the fist Direction of Health Services was created in 1909 (one year after the creation of the Belgian Congo), the number of medical doctors amounted to 30 in response to the propagation of sleeping sickness outbreaks. The DRC health system was in great part funded by the Queen Elizabeth fund for indigenous medical assistance [(in French, Fonds Reine Elisabeth pour l'Assistance Médicale Indigène (FOREAMI)] created by a royal decree in 1930 and operating in in some regions (Lower-Congo, Kwango, Northern Uele)<sup>42,43</sup>. The State and actors such as religious missions, philanthropic organizations, and mining and other industrial organizations were also involved in provision of health services<sup>42</sup>.

In 1945, a health system restructuration plan known as the "Van Hoof-Duren plan" came into force and led to creation of a medico-surgical centre in every territory with at least two full-time physicians appointed, managing a network of satellite dispensaries and mobile medical teams actively involved in search of cases, prevention and treatment of endemic diseases, immunization and general sanitation. In addition to health services, the Welfare Fund for the Indigenous Population (Fonds du Bien Etre Indigène, FOBEI) was created in 1947, aiming at providing better sanitation and housing in rural areas<sup>44,45</sup>.

In the aftermath of the 1960 DRC independence, the then government strove to maintain access to health services, but the increasing sociopolitical turmoil along

with massive flight of key European staff and financial constraints that followed led to the slump of the health system<sup>46</sup>. The vertical international humanitarian assistance supporting specific infectious diseases programs did not succeed to rebuild a strong health system because of both low capacity for (financial) resources mobilization by the local government and the selective nature of vertical programs leaving unaddressed questions about healthcare services access and equity<sup>47</sup>.

In the late 1970s, the DRC started implementing new community health policies that culminated in the institution of the primary health care systems following the 1978 Alma Ata declaration<sup>47</sup>. The South-Kivu province was one of the leading provinces to promote community health programs, first implemented in the Katana zone<sup>48</sup>. The internal debt crisis brought about in the 1980s by 'structural adjustment programs' dictated by the so-called Bretton Woods institutions, namely the International Monetary Funds and the World Bank caused drastic budget restrictions and shrinking funding of public services in sector deemed non-productive such as health or education in DRC<sup>49</sup> and other low-income countries<sup>50-52</sup>. Because of growing financial asphyxia, the DRC government declared many of the public institutions autonomous in 1982, abandoning nearly all the financial burden of public services to international actors, lucrative and faith organizations and users<sup>47</sup>. The financial crisis in the health system deepened to the extent that revenues from the health service users' fees were used to fund higher administrative levels. In fact, health centers and hospitals were requested to give 5-10% of their revenues from user's fees to central health zones offices which in turn had to give part of the amount to the provincial and national levels. Individual and community health became a marketable resource and an important funding source for health institutions in an informal tax payment system maintained by individuals and institutions for their survival<sup>47</sup>. The generalized socio-economic instability culminated in riots and plundering in 1991 and 1993, causing the shutdown of many enterprises and the explosion of unemployment<sup>53</sup>.

## 1.4.2.2. The DRC health system challenged by a spiral of armed conflicts

The war that erupted in eastern DRC in 1996, following the humanitarian crisis subsequent to massive arrival of Rwandan refugees fleeing the 1994 genocide accentuated the gloomy and protracted socio-economic and political landscape of crisis in DRC<sup>54</sup>.

The eastern DRC has remained plagued by decades-long sociopolitical instability and insecurity, despite the official end of war proclaimed in December 2002 when the Pretoria political power-sharing agreement was reached as an outcome of the socalled inter-Congolese dialogue<sup>55</sup>. Fourteen years after first DRC presidential elections organized in 2006<sup>56</sup>, at least 140 armed groups are still operating in eastern Kivu provinces<sup>57</sup>, many of them fighting for control over natural resources sold largely to the international community<sup>58</sup>. Recent exacerbation of endemic interethnic tensions driven by inequitable distribution of land and power, alongside the perpetual search for ethnic identity and repeated attacks by armed groups<sup>59,60</sup> have claimed each month an average of 84 brutal killings of civilians, 50 armed clashes and 122 abductions and kidnappings in the Kivu, between October 2017-December 2019<sup>61</sup>. In the sole month of June 2019, armed conflict has caused over 161 deaths and more than 300 000 people to flee their homes in a shorter than three-week time span in eastern DRC<sup>62</sup>. This new eruption of ethnic violence added a new dimension to the already dire crisis in a country that had over 4.5 millions internally displaced persons, the second highest number after Syria, at the end of 2017<sup>63</sup>. Previous bursts of killings of civilians in Beni (North Kivu) have been associated with Islamist claims by the Ugandan Allied Democratic Forces-NALU (ADF-NALU)<sup>64</sup>, further complicating the conflict puzzle in this region additionally torn by the most stubborn and deadliest Ebola virus disease outbreak ever seen in DRC<sup>65-67</sup>.

The consequences of decades-long destruction of the DRC health and socioeconomic structures are dire. Up to 64% of the population in DRC live under the poverty threshold. The DRC's human development index in 2019 was 0.459 (low), ranking 179 out of 189 countries according to United Nations Development Program<sup>68</sup>. The life expectancy at birth in DRC was 59 years and 62 years for men and women in 2016 respectively, and the total health expenditure per capita was 32 US Dollars, corresponding to 4.3 % of the GBP in 2014<sup>69</sup>. The health financing heavily relies on out-of-pocket payments and external aid in the form of humanitarian assistance, and the health sector regulation has been eroded substantially due to both a marked decline in public funding and insufficient leadership <sup>40</sup>. The UHC index was 40%, far below the global median (65%) in the WHO members states <sup>70</sup>. The distribution of services utilisation is likely to be skewed towards the elite echelons in urban areas, the rest of the population being left without adequate health care or simply marginalised<sup>71 40</sup>. This situation perpetuates inverse healthcare law-like patterns <sup>72,73</sup> whereby the health services utilisation balance is deteriorated against those most in need, leaving behind individuals in complex medico-psychosocial situations.

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# Chapter 2. PROBLEM STATEMENT, JUSTIFICATION, CONCEPTUAL FRAMEWORK AND OBJECTIVES

#### 2.1. Statement of the problem

In the DRC, healthy or unhealthily life at individual and population level is largely regarded from the angle of morbidity and mortality, rather than from that of the ability for each person to cope and adapt to their work and living environments. This reductionist conception of health hinders a proper assessment of population health complexity and needs in terms of the extent to which people are able to self-manage and pursue their life goals, given the contextual barriers and resources, and regardless of any particular disease label. Without embracing a person-centered thinking in public health, it is hard to appreciate the real burden of varying levels of complex medico-psychosocial situations at population level in LMICs and their impact on people's performance on daily activities that give sense to their personal and societal lives.

Although the WHO constitution recognizes the "enjoyment of the highest attainable health" as one of the fundamental human rights<sup>1</sup>, little effort has been made to adequately develop operational measures of health in a way that guides personcentered healthcare planning and prioritization in resource-constrained settings. Health is increasingly viewed as a continuum rather than a 'static' state of complete wellbeing or not, but there is a dearth of information on how to adequately assess the typology of possible health status patterns observable at the primary health care level in DR Congo and other LMICs. The few studies attempting to characterize health status and its complexity come from developed countries with emphasis either on aging-related disability or on disease severity in specific groups of hospitalized patients. In sub-Saharan countries, there is scanty evidence about the appropriate way of describing the health status of the people at community level from a personcentered stand-point. So far, efforts have been mostly centered to the identification of psychosocial disorders in relation with HIV, malnutrition and other acute health problems compounded by poverty, without sufficient attention to each person's own situation and experience of healthy life. The lack of adequate measurement strategies for individual and population health, that are oriented to each person's experience, needs and potentials makes it elusive to meaningfully prioritize and provide quality health to those most in need. It also brings about the medicalization of the society, intrusive interventions and dehumanization of healthcare services, inadequate health resources utilization irresponsive to people's real need, loss of trust in the health system, bio-psychosocial harms to the people, and financial wastes for individuals and the health systems.

Analytical data on the evolution of the typology of health status patterns at primary health care level is lacking. It is not well known whether and under which circumstances applying systems thinking lenses can help explain the dynamic or statics of change in the way individuals' health evolve at primary health care level in eastern DRC. Such data are necessary for shaping responsive health and social programs able to address the dynamic and continuous nature of an individual's health spectrum.

This research project set out to explore the typology of various health statuses, their link with health service utilization and evolution patterns at the first level of health care in a post-conflict region, the South-Kivu province. Such information is relevant to the shaping of evidence-based health care and/or promotion interventions that ensure people most in need receive appropriate healthcare.

## 2.2. Study rationale

LMICs hardly have rigorous data on health status at community level, yet it is recognized that integrated person-centred management of health problems can help improve quality of life of individuals and populations, reduce functional dependence and disability, and at least partly avert loss of human capital. In the momentum of the sustainable development goal 3 pledging healthy lives and well-being for all at all ages, data on how to meaningfully measure health in resource-limited settings are of paramount importance. Without these data, the SDG 3.8 target advocating equitable access to quality health for all is at high risk of remaining an empty rhetoric. Such information will contribute to rendering the health systems more responsive to people's health expectations and personal needs in terms of autonomy, self-management and functional independence.

As the objectives of health systems are being consistently advocated to move from merely providing plain services to providing quality healthcare, there is urgent need for evidence-based approaches to understanding potential interactions and mechanisms of change within the health system at primary level in LMIC from a person-centered angle. This information is essential to the designing and evaluation of health systems programs, decision making and implementation in order to deliver (quality) health. In DRC, particularly, such evidence is urgently needed by the ministry of health and its partners in order to start or step up the move from the disease-centred packages of the past to the reforms of the future considering individual and community health in all its dimensions.

## 2.3. Conceptual framework



**Figure 1**. Framework of complex interplay between medical (and biological), psychosocial and environmental factors characterizing the complex medicopsychosocial situations in rural and semi-urban South-Kivu, drawing both on the ICF framework<sup>2</sup> and the conceptual framework for action on the social determinants of health (WHO, 2002).

#### Narrative of the conceptual framework

Socio-economic, cultural and political contexts are underlying factors nurturing both personal and environmental predictors of an individual's health capital, including socio-demographics, socio-behavioral, nutritional and health system factors, among others. Both personal and environmental factors steadily influence each other, and

jointly impact on the body function and structure, a person's level of activity and participation in social life, labour, and interpersonal interaction and relationship. A person's health capital or health status is a result of the complex interplay between the latter factors.

## 2.4. Objectives

## 2.4.1. General objective

This study aimed to suggest a person-centred way of describing the typology of varying population health statuses observable at community level, its association with health service utilisation and its evolution patterns among rural and semi-rural residents in South Kivu province, from the perspective of cognitive, functional and social (dis)abilities. Our ultimate goal is to inform the design, monitoring and evaluation, and the prioritisation process of healthcare programs in LMICs.

## 2.4.2. Specific objectives

- 1. To describe the typology of health status patterns, based on the WHODAS, among mother-infant history of malnutrition, adults with chronic diseases, their informal caregivers and neighbors in South Kivu province, eastern DR Congo (*Study 1*)
- 2. Analyze the distribution of the community members in different health capital clusters identified at community level in South Kivu *(Study 1)*
- 3. To examine the link between WHODAS-derived health status clustering and health facility utilization in a rural eastern DR Congo population *(Study 2)*
- 4. To examine the natural evolution patterns of different health clusters (or health capital levels) derived from WHODAS at primary health care level over a two years follow-up period in rural South-Kivu *(Study 3)*

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 WHO. International classification of functioning, disability and health: ICF: Geneva: World Health Organization; 2001. Chapter 3. METHODOLOGY
### 1.1. Introduction and general methodological considerations

In this chapter, we provide an overview of the key methodological aspects cutting across all the three studies making up this thesis. More detailed descriptions of the methods are presented separately in each paper.

It is worth recalling that this thesis is nested within a broad research project for development (Projet de Recherche pour Développement, herein referred as PRD) funded by the Belgian cooperation through the Académie de Recherche et d'Enseignement Supérieur (ARES)<sup>1</sup>. The PRD's overall aim is to study how a person-centered model of management of medico-psychosocial situations can be effectively implemented at primary healthcare level (health center) in South Kivu. In the PRD, we capitalize on a combination of both deductive and inductive methodological approaches. Deductive strategies include cross-sectional and longitudinal quantitative study designs for descriptive and analytical assessment of health status patterns observable at primary health care level in South Kivu. Inductive methods consist in applying systems thinking methods to test a bunch of theories that may explain how and under which circumstances it is feasible to initiate change in the way healthcare is provided at the health center such that health services can be people-centered. Qualitative methods have been used and agent based modelling (ABM) will be considered for this purpose.

The use of a mixed methodological approach is premised on the idea that interactions between health systems agents are rarely linear. And when one considers the community around a health center as a health system, it quickly appears that unidirectional reasoning typically from one or two premises to a single conclusion does not always suffice to explain potential mechanisms of change (or absence of chance) within the system. In daily life, health systems agents tend to reason and behave based on premises which have the nature of presumptions, using inferences which are basically non-linear and bidirectional<sup>2</sup>. Therefore, circular and loop reasoning becomes useful and complementary to deductive approaches that are prominent in investigation of epidemiological problems.

This thesis focuses on the methods and results from the deductive and epidemiological component of the PRD. We will also be referring, in the discussion of the results, to results of qualitative studies conducted as part of a second thesis within this PRD<sup>3</sup> and shall outline our basic assumptions for future agent-based modelling studies.

### **1.2.** Rationale for the selection of the study sites

South-Kivu province is as 65,103 km<sup>2</sup>, lying in the Great Lakes region of Africa. This province shares borders with Burundi and Rwanda and borders the provinces of North-Kivu, Maniema, and Katanga. The Kivu region has experienced a long civil unrest over the last three decades, resulting in socio-economic instability and to some extent a dysfunction of the health system. With an estimated population of 7.1 million inhabitants in 2018 according to figures from the web-based District Health Information System, South-Kivu is a predominantly rural province akin to the rest of the DRC where about 60% of the population is believed to live in rural areas. The estimated maternal and under-five mortality rates in DR Congo were 473 per 100,000 in 2017 and 88 per 1,000 live births in 2018 respectively, against the SDGs targets of 70 per 100,000 and 25 live births<sup>4,5</sup>, The prevalence of chronic malnutrition in South-Kivu in one of the highest in the world with half (49.6%) of children younger than 5 years stunted<sup>6</sup>.

This study was conducted in six health areas spanning three health zones, purposively selected because of their large catchment areas, geographical accessibility, and the local health system governance. Two semi-urban health areas were selected in the Bagira health zone located on the outskirts of Bukavu, the capital city of Bukavu. One of these health areas is served by a public health centre (Nyamuhinga) and receives organisational and financial support from a non-governmental organisation, the Louvain cooperation (LC). Health staff at health centres where the LC operates were trained for the management of psychosocial problems. LC also supports the establishment of the function of social assistant at the health facility. The second health area is mainly organised around a health centre (Lumu) that is part of a Catholic network of health facilities managed by the Diocesan Office of Medical Works (Bureau Diocésain des Œuvres Médicales, BDOM).

The third health area (Lwiro) was selected from Miti-Murhesa health zone. Lwiro health centre was created in 2015 and is public-owned. It has limited infrastructures and little support from external donors. Some villages of the Lwiro health area are hard to reach and sprawl along the side of the Kahuzi Biega Park, with very poor populations. In the neighbouring Katana health zone, Kabushwa health area was selected. It is also organised around a public health facility with high standard infrastructures and receives support from LC.

Lastly, two health areas were included from Walungu health zone. Walungu is one of the health zones most severely affected by direct effects of armed conflicts during the relatively recent dark period of war, particularly due to recurrent armed clashes between the Interahamwe (Rwandan Hutu rebels), a local militia composed of local youngsters (Mudundu 40) and the Rwanda-backed rebel group (the Rally for Congolese Democracy-Goma known as RCD-G). The particular context of instability in Walungu accentuated the population poverty, caused the collapse of local markets and slackened the rural production to almost a disappearance of livestock in rural areas <sup>7</sup>, thus creating the conditions for a vicious circle of perpetual socio-political instability and conflict over land and power<sup>8</sup>. In Walungu, two health areas were selected. Bideka health area is easily accessible and located at one driving hour away from Bukavu. The main health centre in Bideka is owned but the Protestant church and its staff team is credited with a strong sense of leadership. Bideka health centre is also technically and financially supported by LC for the management of medico-psychosocial conditions and chronic diseases. The second health area selected in Walungu is Burhale, a large health area whose main health centre is owned and managed by religious nuns. The staff at the Burhale health centre did not receive any specific training nor technical support for the management of psychosocial problems. For instance, the function of social assistant is inexistent at Burhale health centre and home visits a rarely conducted.

A strong network of 158 community health workers (CHWs) operate in these health areas covering an estimated population of over 100,000 inhabitants.

As mentioned, three of the six study health areas are being supported by the Louvain cooperation, an international NGO associated with the Catholic University of Louvain and key partner of the broader PRD in which this work is embedded. Within these health areas, a multidisciplinary person-centered approach of healthcare service provision has started to be implemented since 2014, initially with a focus on frailty associated with aging and chronic conditions. Louvain coopération's strategy comprised the following pillars:

Enhancing health center's capacity of health information management through: 1) development of a structured medical file conducive to data collection on physical, mental and social aspects of each patients and 2) provision of openfronted compartments in form of "pigeonholes" for the keeping medical records. A medical notebook was also designed and first proposed for follow-up of the elderly, but later extended to all the people with chronic conditions;

- Training of healthcare workers to perform a rigorous and comprehensive geriatric evaluation;
- Bi-monthly visits of doctors from the referral hospital in the health zone to support the local team at the health center for the management of complex medico-psychosocial situations through case discussion and formative supervision. This dimension also aimed at reinforcing referral and counterreferral mechanisms between the health center and referral health facilities within the health zone;
- Home visits for a deep psychosocial investigation of complex situations and provision of home supports when necessary;
- Instilling a culture of multidisciplinary evaluation at the health center level and fostering the documentation and reporting of multidisciplinary case discussions;
- Elicit the intervention of a psychologist and creation the role of the social assistant. A staff member from the health center is equipped and trained to play the role of social assistant and coordinates home visits activities in collaboration with his fellows;
- Provision of socio-economic support to the elderly by encouraging community members to enroll into local saving cooperatives and social networks. Louvain cooperation supported the creation of local clubs for the elderly or patients with diabetes.

In addition to the three health areas where Louvain cooperation is operating, we selected three more health areas to serve as "controls" and to help gain in variability of study sites as described in the sections below.

### 1.3. Sampling procedure, selection and follow-up

A multi-stage sampling approach was used. Six health areas were conveniently selected as previously described. Within each health area, villages nearest to the health facility were selected because of logistical constraints. Given that in the PRD under which this thesis is conducted we were interested in assessing how change at health centre can translate into people's health and wellbeing, we deemed that the likelihood of using health services provided at the centre was higher among people living nearer to health facilities compared to those living in villages far afield. At village level, community health workers (CHW) were recruited, trained and assigned to identify households in which mother-infant dyads with history of child malnutrition or people with diabetes and hypertension were living (categories herein referred to as 'tracer groups'). Rosters of people in the tracer group were thus

established. Data collectors were then introduced to the head of household by the recruiters (CHW) and study questionnaires were administered either to the mother with history of malnutrition in the offspring or the adult person with chronic diseases. Within a household where a trace group member has been identified, informal caregivers (of participants with diabetes and hypertension) and helpers of mothers of children acutely malnourished were identified and selected. Lastly, a self-reported health neighbour (with regard to diabetes or hypertension) was selected, to help gain in variability of potential health statuses patterns expected at primary healthcare level in the six study health areas. Study participants were followed up as per scheduled 9-months home visits through a two years period.

### **1.4.** Data collection

A structured and pre-tested paper-based questionnaire was used at enrolment of participants to capture socio-demographic characteristics, medical history and anthropometric data. To assess the disability related to health condition, we used the WHO Disability Assessment Schedule (WHODAS 2.0). WHODAS 2.0 is a multidimensional and cross-cultural questionnaire with 36 items assessing an individual's cognition, mobility, self-care, getting along with people, life activities and participation in society. It is short to administer (5 to 20 minutes) both at clinical and community levels and across all diseases. WHODAS 2.0 has been validated and frequently used in LMICS with a high internal consistency (Cronbach's alpha) ranging from 0.77 in South-African women <sup>9</sup> to between 0.82 and 0.98 in people with severe mental disorders and their caregivers in rural Ethiopia, in addition to its ability to detect small changes over time <sup>10</sup>. In addition, the WHODAS-child adapted from the adult WHODAS-II has shown an 84% internal consistency with high test-retest and inter-rater reliability (r=0.83 and ICC=0.88) in Rwandan children <sup>11</sup>.

The data collection tools WHODAS 2.0 were translated to Kiswahili (national language spoken in eastern DR Congo) according to a rigorous translation protocol to ensure cross-cultural and conceptual equivalence. One French-speaking translator from the school of languages of the Université Catholique de Bukavu and whose mother tongue is Kiswahili carried out the translation. A bilingual panel comprised of the principal investigator, key health professionals working in the health areas of study and com- munity health workers leaders reviewed the translated version in order to address its potential cross-cultural inadequacies in terms of incomprehensibility or lack of clarity.

### 1.5. Brief overview of the statistical analysis

In Study I, aiming to define health status patterns at community level, we first used a principal component analysis of the WHODAS domains scores, then a cluster analysis to generate a hierarchical health status variable or healthcare need levels. An alternative approach to defining health status clusters could have consisted in creating a variable containing quantile categories from WHODAS scores. Although generating quantiles would lead to more balanced health status categories, we perceived this approach more arbitrary and likely less indicative of the true distribution of health status gradients in the community. We also used mixed-effects ordinal logistic regression models to identify the factors associated being in a certain healthcare need cluster. In our analysis, we did not rely on proportional odds assumptions tests as they can be misleading by prompting the rejection of a true null hypothesis when in fact the parallel slopes assumption holds<sup>12</sup>.

In Study II, a subsample of the study population was used, including those who reported having fallen sick in the prior 30 days. The study outcome was a binary variable, indicating whether a person has used a formal health facility during a recent illness or not. A logistic regression is intuitively a first choice to model the association between a binary outcome and its predictor variables. However, when the outcome of interest is common, odds ratios obtained from logistic regression models tend to overestimate the association and alternative models such as a modified Poisson regression with robust or "sandwich" variance estimator are recommended<sup>13</sup>. This was the case in our Study II.

In Study III, we assessed the risk of decline in health capital over time and associated factors using generalized estimating equations<sup>14</sup>. Detailed discussions about the analyses performed are laid out in separate studies.

### **1.6.** Ethical considerations

Respondents provided singed informed consent for participation in the study, either by written signature or by fingerprints, depending on literacy. Child assent was obtained for respondents below 18 years of age, after a parent or guardian's consent. Ethical approval for the study was obtained from the Université Catholique de Bukavu Ethics Committee (UCB/CIE/NC/06/2017) and the Hospital-Faculty Ethics Committee of UC Louvain (2017/110CT/476-B403201734111).

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Chapter 4. RESULTS

### 4.1. Study 1

In this section, we present the published results of the Study 1. Supplementary analyses and an erratum are presented in the addendum.

### A new look at population health through the lenses of cognitive, functional and social disability clustering in eastern DR Congo: a community-based cross-sectional study

### Background

The importance of viewing health from the standpoint of functional, cognitive and social disability dimensions is critical at primary health care level. It is no longer debatable that health is a dimension inextricably interwoven with all other aspects of life, daily life, working life, family life, and community life<sup>1</sup>. Health is increasingly considered as a human capital resource and a whole, personal, situation-specific phenomenon<sup>2</sup>, rather than the absence of disease<sup>3-5</sup>. Despite such a consensus, primary care activities are still largely structured around diseases control and mortality of sub-populations rather than promoting comprehensive person-centered care<sup>6</sup>.

When one addresses a person's health or community health, the life situation as a whole must be put into perspective and strategies for improving health needs must be grounded on factors conducive to good quality of life. Therefore, prioritising (community) care through population stratification based on functional, cognitive and social disability dimensions may be useful for comprehensiveness and quality of service provision. This has not yet been sufficiently explored in low- and middle-income countries (LMICs). Few studies from both high-income countries and LMICs examined these health dimensions of sub-populations, but mostly in the elderly or had a limited focus on hospital- and disease-based outcomes<sup>7</sup>.

The literature is insistently advocating the necessity to broaden the perspective of 'health measurement' by looking at functional and social status as part of individual and community health <sup>8,9</sup>. With recognition that health complexity encompasses and transcends the mere concept of physical morbidity, good health can be viewed as the ability to adapt and to self-manage, with emphasis put on social and personal resources as well as physical capacity <sup>10</sup>. In the era of steadily rising high burden of chronic comorbidities, new health considerations such as functional dependence,

cognitive functioning, disability and frailty are becoming of greater importance. But little is known on how these innovating insights into individuals and community health can be leveraged so that to ensure appropriate health services to people most in need and pave the way to universal health coverage and progress towards the health sustainable development goals (SDGs).

The World Health Organization (WHO), echoing the need for a holistic approach to assessing health both at individual and community levels, developed appropriate tools that allow a better understanding and estimation of the impact of any health condition in term of functioning. The International Classification of Functioning, Disability and Health (ICF) published by the WHO in 2001 has proved to be a useful and valid framework integrating function and disability with health conditions and contextual factors <sup>11</sup>. Besides, the WHO Disability Assessment Schedule 2.0 (WHODAS), drawing essentially on the ICF framework, provides a standardized approach to measuring health and disability across cultures <sup>12</sup>.

Primary health care services in sub-Saharan Africa and other low- and middleincome, particularly in post-war settings, are often considerably configured to donors-dictated disease-based indicators <sup>13</sup>. To some extent, this furtively leads to denaturalisation of the fundamental goal of primary health care. In such situations, individual and community health are confined to the narrow physical or biological aspects of health, ignoring the broader dimensions of health that are useful for a person's life. There is dearth of context-specific data on how to identify vulnerability-based sub-populations of complex patients who may benefit from targeted care management strategies in resources-constrained settings.

The aim of this study was twofold. First, we propose a new stratification of population health in a sample of adults with diabetes or hypertension, mothers of children with acute malnutrition as well as their respective informal caregivers and neighbours from the standpoint of functional, cognitive and social disabilities. Second, we identified covariates of population health in rural and semi-urban eastern DR Congo settings. Our overall goal is to better inform healthcare strategies and improve health services organization in rural and/or post-war settings.

### Methods

We conducted a community-based cross-sectional survey in adults with self-reported diabetes and/or hypertension, mother-infant pairs with severe acute malnutrition, and their informal caregivers and neighbours between December 2017 and March 2018.

These sub-population categories were deliberately selected to help gain a better insight into diverse perspectives of health status patterns observable at primary healthcare level in South Kivu. In addition, we deemed high the likelihood of complex medico-psychosocial conditions among individuals presenting with these three 'tracer' conditions <sup>14,15</sup>. Finally, these health problems are prevailing in South Kivu and are relatively easy to identify even at primary care level in resources-constrained settings. Indeed, the prevalence of acute malnutrition in South-Kivu is one of the highest in the world with up to 8% of children younger than 5 years being wasted <sup>16</sup>. In 2011, the estimated prevalence of diabetes in this region was 4.9% in urban areas and 3.2% in rural areas while hypertension was found in 41.4% and 38.1% of urban and rural residents respectively <sup>17</sup>.

### Study settings

South-Kivu is an Eastern DR Congo province as large as 65,103 km<sup>2</sup>, lying in the Great Lakes region of Africa. This province shares land borders with Burundi and Rwanda and borders the provinces of North-Kivu, Maniema and Katanga. The Kivu region has been a theatre of civil and political unrest over the last two decades, resulting in socio-economic instability, destruction of societal structures and, to a significant extent, dysfunction of the health system. With an estimated population of 6,932,107 inhabitants in 2012<sup>18</sup>, South-Kivu is a predominantly rural province with nearly 70% of the population living in rural areas. The operational unit and primary care level of the health system in DR Congo is the health center with the health area as catchment unit.

### Sampling procedure and selection of participants

A multi-stage sampling approach was used. Six health areas (Bideka, Burhale, Kabushwa, Lumu, Lwiro and Nyamuhinga) spanning four health zones (Bagira-Kasha, Katana, Miti-Murhesa and Walungu) were selected because of their large catchment area, geographical accessibility, experience and quality of records keeping. A strong network of over 240 community health workers (CHWs) operated in these health areas covering over 100,000 inhabitants. Given the logistic, geographical, time and-to a lesser extent-security constraints, we purposively confined the sampling to villages nearest to the health centre. This was also partly because this study was part of a broader and longer-term research for development project that set to find out whether changes in the way health services are provided (by focusing on psycho-medico-social status additionally to the disease) at health

centres in rural and post-war African contexts would change the health status of a population.

We initially aimed to recruit at least 90 patients (with any of the three conditions aforementioned) and an equal number of informal caregivers and neighbours in each of the six selected health areas. Within each health area, villages nearest to the health centre were selected. At village level, CHWs were recruited. Studies have shown that, with a minimum training, CHWs can effectively participate in screening, health promotion interventions and management of malnutrition <sup>19</sup>, diabetes or hypertension <sup>20,21</sup>. They benefited from a half-day refreshment training on the community diagnosis of severe acute malnutrition based on mid-upper arm circumference measurement (MUAC) equal or below ( $\leq$ ) 11.5 cm and/or presence of nutritional oedema. The refreshment training was deemed necessary to ensure a correct identification of mother-infant pairs with child acute malnutrition given that untrained mothers or caretakers are unlikely to properly detect and self-report acute malnutrition in their children<sup>22</sup>. CHWs were also assigned to identify households in which adults with self-reported diabetes or hypertension lived. During the data collection phase, the data collection team was introduced to each household in which a person of interest was identified. The purpose of the study was explained to the head of the household and permission to carry out the interview was asked. People with diabetes and hypertension were selected if being diagnosed for at least 6 months. Mothers were selected if being a mother of a child presenting with severe acute malnutrition. If the targeted person was absent, the data collectors could proceed to the next targeted household on the list and come back the following day until the person was found. A written and signed consent to participate in the study was sought before the interview started in the same household, an informal caregiver was identified and asked to consent to the study. For caregivers below 18 years of age, the consent was required from a parent or guardian. For every household in which a patient was recruited, a community member in the nearest neighbourhood was randomly selected by spinning a pen and following the direction in which it pointed. At this stage, an adult with the closest age and ideally (but not always) with the same sex as the neighbour patient was approached and asked to participate in the study, after providing a written consent. If in the selected neighbouring household there was no consenting adult, interviewers could move to a next household chosen through the same random process until they found a consenting adult. At the end, all participants had to be residents of the health area for at least 6 months and at least 15 years of age. People who refused to provide an informed consent or were severely ill, physically or mentally unable to withstand an interview were excluded.

### Data collection and instruments

A simple identification form was used by the CHWs during the phase of identifying households in which patients with known morbidity lived, within the entire health area. This helped us generate a sampling frame with information on age, sex, village of residence and type of morbidity. A structured and pre-tested paper-based questionnaire designed to capture socio-demographic and health characteristics data was administered to a convenience sample all identified individuals living in villages nearest to health centres, their informal caregivers and randomly selected neighbours by trained research assistants who were all nurses.

To assess the functional and social disability related to health condition, we used the WHO Disability Assessment Schedule 2.0 (WHODAS). WHODAS is a multidimensional and cross-cultural questionnaire with 36 items assessing an individual's cognition, mobility, self-care, getting along with people, life activities and participation in society. It is short to administer (about 20 minutes) both at clinical and community levels and across all diseases. WHODAS has been validated and frequently used in LMICS <sup>23,24</sup>, with a high internal consistency (Cronbach's alpha) ranging from 0.77 in South-African women <sup>25</sup> to between 0.82 and 0.98 in people with severe mental disorders and their caregivers in rural Ethiopia. It also is able to detect small changes over time <sup>26</sup>. In addition, the WHODAS-child adapted from the adult WHODAS 2.0 has shown an 84% internal consistency with high test-retest and inter-rater reliability (r=0.83 and intraclass correlation coefficient =0.88) in Rwandan children <sup>27</sup>.

The WHODAS was translated to Kiswahili (national language spoken in eastern DR Congo) according to a rigorous translation protocol to ensure cross-cultural and conceptual equivalence. One French-speaking translator from the school of languages of the Université Catholique de Bukavu and whose mother tongue is Kiswahili carried out the translation. A bilingual panel comprised of the principal investigator, key health professionals working in the health areas of study and community health workers leaders reviewed the translated version in order to address its potential cross-cultural inadequacies in terms of incomprehensibility or lack of clarity.

### Study variables

WHO developed a conceptual framework for action on the social determinants of health<sup>28</sup>, which we found complementary to that developed earlier on by Berkman, Glass<sup>29</sup>. Drawing on both frameworks, we examined social (including social cohesion), demographic and economic status as possible explanatory parameters. Socio-demographic characteristics included among other variables age (measured on a continuous scale in completed years), gender (male or female), education (continuous variable measured as complete years of schooling) or household size (number of people sleeping in the same house and eating from the same cooking pot) or health zone of residence. Some categorical variables needed to be recoded to obtain sufficient numbers in strata for ease of the comparisons. This was, for example, the case for marital status, tribe or occupation. Social cohesion and networking were approximated by regularly attending church activities and being member of a local socio-economic or savings network. To define the socio-economic status, we ran a Multiple Correspondence Analysis on household assets and housing characteristics to create wealth indices <sup>30</sup> based on ownership of a television, a radio, a computer, a manufactured bed, small animals, cattle, land, a bicycle, a motorcycle and on housing characteristics including pavement and permanent, semi-permanent or temporary structure. We then derived five socio-economic quintiles from wealth indices. The two lowest (poorest 40%) and the two middle (40%) quintiles were respectively merged following an approach suggested by Filmer and Pritchett<sup>31</sup>. We ended up with three socio-economic classes (least poor, middle poor, poorest).

The main dependant variable under study was functional and social disability defined as a three-level ordinal variable resulting from a Principal Component Analysis (PCA) with clustering performed on the six WHODAS domains scores (see explanation here below).

### Data management and analyses

Data were entered in EpiInfo7 and exported to Stata 15 for exploratory analyses. We used a three-stage WHODAS scoring strategy based on the complex and Item Response Theory (IRT) scoring algorithm. We first added up the recoded item scores within each domain. All six domains scores were totaled prior to converting the summary score into a metric ranging from 0 to 100 (where 0 = no disability; 100 = full disability) (Üstün et al., 2010). This algorithm was implemented in Stata 15.

The distribution of continuous variables was assessed graphically and statistically using the Shapiro-Wilk test. Extreme and implausible outlying values were checked for and set to missing. Qualitative variables were summarized in frequencies and proportions while continuous variables were described in terms of mean with standard deviation (SD) or median with interquartile range (IQR) depending on the shape of the distribution.

To define medico-psychosocial clusters, we first ran a principal component analysis on seven summary scores of the WHODAS domains. We then performed a hierarchical clustering of the principal components based on Ward's method and using the FactoMineR software package in R<sup>32</sup>. Three ordered clusters were created and termed cluster 1, cluster 2 and cluster 3. We used chi-squared and Kruskal-Wallis tests to compare the characteristics of the study participants by enrolment status or clustering.

To establish the factors associated with functional and social disability clustering, we did the inter-cluster comparison using a mixed-effects ordinal (proportional odds) logit regression model with health area as a random effect. This strategy enabled us to take into account the inherent non-independence of socio-demographic factors at health area level, thus ensuring more accurate standards errors for the measures of association between within-health area characteristics and disability clusters. The proportional odds model was favoured over the other ordinal models since the former is most suited to studies under which the outcome is obtained from categorizing a certain underlying continuum. In addition to its greater statistical power to detect differences in a relatively smaller sample<sup>33</sup>, this model often generates much simpler interpretable coefficients, even when the order of the outcome is reversed (in which case only the sign of the coefficient is changed)<sup>34</sup>. We used a backward elimination strategy to build the regression model, guided by Wald's tests and the principle of parsimony. Variables were hierarchically selected into the multivariable model in three stages, based either on a p-value equal to or below 0.2 or on public health plausibility as suggested by Victora, Huttly <sup>35</sup>. Socio-demographic factors were selected first. We then included household attributes before adding proximate factors reflecting physical health impairment. Multicollinearity between explanatory variables was assessed using the Variance Inflation Factor (VIF). A VIF greater than 4 was suspected of collinearity. We reported Crude Odds Ratios (COR) and adjusted odds ratios (AOR) with their 95% confidence intervals and p values. We regarded a type one error ( $\alpha$ ) < 5% as statistically significant. We used R 3.3.5 and Stata 15 software for the analyses.

### Ethical considerations

Respondents provided singed informed consent for participation in the study, either by written signature or by fingerprints, depending on literacy. Child assent was obtained for respondents below 18 years of age, after a parent or guardian's consent. Ethical approval for the study was obtained from the Université catholique de Bukavu Ethics Committee and the *Hospital*-Faculty *Ethics Committee* of UC Louvain.

### Results

### Background characteristics of the study population

Of the 1609 participants approached by data collectors in the field, 1266 provided valid information on functional and social disability. The general background characteristics of the study sample are presented in Table 1. The majority of the participants were female (63.6%), belonging to the indigenous Shi tribe (91.1%) and married (68.8%). The mean (SD) age was 48.3 (18.7) years. Participants lived in bigger size households [median (IQR): 6.5 (5–9)] compared to the national median of 5.3. Farming or petty trading were the main occupation for over half of the heads of households (55.8%). While 62.5% of the respondents claimed to be catholic, about one quarter (27.2%) reported to be members of any church organization with over half (52.4%) of all respondents attending church at least once a week. The median (IQR) duration of schooling was 6 (3–10) years. Nearly six in ten respondents (57%) did not listen to radio even once a week and less than 19.3% reported being members of local saving cooperatives.

| Variable                 | Descriptive statistics    |
|--------------------------|---------------------------|
| Health zone              |                           |
| Bagira                   | 523 (34.1)                |
| Katana and Miti-Murhesa  | 502 (32.7)                |
| Walungu                  | 509 (33.2)                |
| Gender<br>Female<br>Male | 1003 (63.6)<br>573 (36.4) |
| Age                      | 48.3 (18.7)               |

Table 1. General characteristics of the study population

| Socio-economic status           | 225 (20.2)  |
|---------------------------------|-------------|
| Least poor                      | 325 (20.3)  |
| Poor                            | 615 (38 5)  |
| 1 001                           | 015 (58.5)  |
| Occupation of head of household |             |
| Formal worker                   | 155 (10.7)  |
| Informal worker                 | 189 (13.0)  |
| Farmer or petty trading         | 810 (55.8)  |
| No profession                   | 298 (20.5)  |
| Participant                     |             |
| Patient                         | 450 (32)    |
| Informal caregiver              | 492 (35)    |
| Neighbor                        | 463 (33)    |
| Tribe                           |             |
| Shi                             | 1446 (91.1) |
| Others                          | 142 (8.9)   |
| Marital status                  |             |
| Never married                   | 168 (10.8)  |
| Married                         | 1072 (68.8) |
| Divorced/widowed/separated      | 322 (20.4)  |
| Religion                        |             |
| Catholic                        | 986 (62.5)  |
| Protestant                      | 531 (33.6)  |
| Muslim and others               | 62 (3.9)    |
| Church membership               |             |
| Yes                             | 415 (27.2)  |
| No                              | 1113 (72.8) |
| Church attendance frequency     |             |
| <= Once a week                  | 792 (52.4)  |
| 2-3 times a week                | 462 (30.5)  |
| >= 4 times a week               | 259 (17.1)  |
| Education (years)               | 6 (3–10)    |
| Household size                  | 6.5 (5-9)   |
|                                 |             |

| Preschool aged children in household (n=1011) | 1 (0–2)     |  |  |  |
|---|-------------|--|--|--|
| School-aged children in household             | 2 (1-3)     |  |  |  |
| Adults in household                           | 3 (2-4)     |  |  |  |
| Saving organization membership                |             |  |  |  |
| Yes   | 306 (19.3)  |  |  |  |
| No  | 1275 (80.7) |  |  |  |
| Frequency of listening to radio               |             |  |  |  |
| Less than once a week                         | 584 (57)    |  |  |  |
| At least once a week                          | 440 (43)    |  |  |  |
| Data are n (%), mean (SD) and median (IQR).   |             |  |  |  |

# Proposed clustering of the study population from the perspective of functional and social disability

The hierarchical clustering of the principal components of seven WHODAS domains scores resulted in three ordered categories of functional, cognitive and social disabilities termed cluster 1, cluster 2 and cluster 3 (Figure 1).



Figure 1. Health status of the study population from a functional and social disability perspective

The characteristics of the study population by cluster are displayed in Table 2. Of the 1226 respondents with valid WHODAS data, over two-thirds (69.7%) were found in cluster 1, with a median (IQR) WHODAS score [5.2 (0–10.9)] below that of the whole study population. Cluster 2 had 21.1% of the respondents with a median (IQR) WHODAS score of 31.7 (24.7–39.7). Respondents in cluster 3 (9.2%) had the poorest health status from the functional, cognitive and social disability standpoint with median (IQR) WHODAS score of 62.1 (53.2–75.7) (Table 3). The trend was consistent among all the WHODAS domains; the higher the cluster order, the more worrying the health status of the individuals. Half of the study population had a summary WHODAS score below 10.2 (Supplementary file).

The age of the respondents and the proportion of women increased with cluster ordering. The majority of respondents in cluster 3 were female (71.3%) and on average 63.0 (18.0 SD) years old and likely to be older than those in lower clusters

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(p<0.001). The clustering was independent on the socio-economic status (p=0.107) but dependent on the place of residence (p<0.001). In fact, it was more likely to find participants in cluster 3 in rural areas (Miti-Murhesa, Katana and Walungu health zones) than in semi-urban areas (p<0.001).

Clustering depended on the marital status of the respondents (p<0.001). Only 1.8% of the respondents in cluster 3 never married, 57% were married and 41.1% either were divorced, separated or widowed. Clustering was also dependent on hypertension status, diabetes status and history of acute illness in the 30 days prior to the interview. Over two-thirds of the respondents in cluster 1 (68%) had a normal blood pressure, against 44.6% in cluster 2 and 27.8% in cluster 3 which had 62.6% of its constituents presenting with self-reported hypertension (Table 3). Diabetes was more common in cluster 3 (18.7%) than in other clusters (p<0.001). Four in five people in cluster 3 reported an acute illness in the 30 days prior to the interview against 32.1% in cluster 1. Clustering was independent of acute malnutrition status of the child, tribe, religion and church attendance, but dependent on occupation. It was more likely to find individuals without profession in cluster 3 compared to cluster 2 and cluster 1 (p=0.004) and respondents in 3 were more likely to be members of local saving or development cooperatives than those in cluster 2 and cluster 1 (p=0.013). Listening to radio at least once a week, a proxy for access to information, was likely to be more frequent in cluster 3 relative to cluster 2 and cluster 1 (p<0.001).

| problems                        |              |                  |                  |       |
|---------------------------------|--------------|------------------|------------------|-------|
| Variable                        | Cluster 1    | Cluster 2        | Cluster 3        | P     |
| WHODAS and morbidity factors    |              |                  |                  | value |
| Overall WHODAS                  | 5.2 (0-10.9) | 31.7 (24.7–39.7) | 62.1 (53.2–75.7) | 0.001 |
| Communication and understanding | 0 (0–12.5)   | 41.7 (25–54.2)   | 70.8 (54.2–91.7] | 0.001 |
| Mobility                        | 0 (0-5.0)    | 30.0 (20.0-45.0) | 65.0 (50.0-80.0) | 0.001 |

Table 2. Distribution of the study population by clusters of functional and social disability representing the levels of complex medico-psychosocial problems

| Self-care                         | 0 (0-0)    | 0 (0–12.5)       | 50.0 (31.2-75.0) | 0.001   |
|-----------------------------------|------------|------------------|------------------|---------|
| Getting along with people         | 0 (0–15.0) | 25.0 (15.0–35.0) | 55.0 (30.070.0)  | 0.001   |
| Household activities              | 0 (0–12.5) | 43.7 (25.0–56.2) | 75.0 (62.5–93.7) | 0.001   |
| Work or school activities         | 0 (0–12.5) | 43.7 (31.2–56.2) | 81.2 (68.7–93.7) | 0.001   |
| Social participation              | 0 (0–16.6) | 40.6 (28.1–53.1) | 71.9 (59.4–84.4) | 0.001   |
| Enrolment status of the           |            |                  |                  | < 0.001 |
| Patient                           | 148 (18.7) | 133 (58.3)       | 78 (76.5)        |         |
| Caregiver                         | 333 (42.2) | 44 (19.3)        | 13 (12.8)        |         |
| Neighbor                          | 309 (39.1) | 51 (22.4)        | 11 (10.8)        |         |
| Acute illness/30 days             |            |                  |                  | < 0.001 |
| No                                | 599 (67.9) | 113 (43.3)       | 21 (18)          |         |
| Yes                               | 283 (32.1) | 154 (57.7)       | 96 (82)          |         |
| Child malnutrition                |            |                  |                  | 0.417   |
| No                                | 843 (95.6) | 259 (97)         | 114 (94.4)       |         |
| Yes                               | 39 (4.4)   | 8 (3)            | 3 (2.6)          |         |
| Blood pressure                    |            |                  |                  | < 0.001 |
| Normal                            | 543 (68.6) | 115 (44.6)       | 32 (27.8)        |         |
| Self-reported HT                  | 147 (18.6) | 120 (46.5)       | 72 (62.6)        |         |
| Fortuitous HT discovery           | 101 (12.8) | 23 (8.9)         | 11 (9.6)         |         |
| Diabetes                          |            |                  |                  | < 0.001 |
| No                                | 758 (94.7) | 192 (80.3)       | 87 (81.3)        |         |
| Yes                               | 42 (5.3)   | 47 (16.7)        | 20 (18.7)        |         |
| Socio-demographic characteristics |            |                  |                  |         |

| Place of residence      |                   |             |             | < 0.00 |
|-------------------------|-------------------|-------------|-------------|--------|
| Urban                   | 329 (39)          | 67 (26.2)   | 28 (24.6)   |        |
| Rural                   | 514 (61)          | 189 (73.8)  | 86 (75.4)   |        |
| Age                     | 42.9 (16.4)       | 58.2 (15.3) | 63.0 (18.0) | <0.00  |
| Sex                     |                   |             |             | 0.001  |
| Female                  | 519 (59.9)        | 187 (70.6)  | 82 (71.3)   |        |
| Male                    | 348 (40.1)        | 78 (29.4)   | 33 (28.7)   |        |
| SES                     |                   |             |             | 0.107  |
| Least poor              | 199 (22.6)        | 49 (18.5)   | 19 (16.2)   |        |
| Middle                  | 361 (40.9)        | 102 (38.5)  | 44 (37.6)   |        |
| Poorest                 | 322 (36.5)        | 114 (43)    | 54 (46.2)   |        |
| Health zone             |                   |             |             | <0.00  |
| Bagira                  | 329 (39.0)        | 67 (26.2)   | 28 (24.6)   |        |
| Miti-Katana             | 324 (38.4)        | 67 (26.2)   | 48 (42.1)   |        |
| Walungu                 | 190 (22.6)        | 122 (47.6)  | 38 (33.3)   |        |
| Marital status          |                   |             |             | < 0.00 |
| Never married           | 116 (13.4)        | 3 (1.2)     | 2 (1.8)     |        |
| Married                 | 628 (72.4)        | 192 (73.8)  | 64 (57.1)   |        |
| Divorced/widowed/separa | 123 (14.2)<br>ted | 65 (25)     | 46 (41.1)   |        |
| Tribe                   |                   |             |             | 0.073  |
| Shi                     | 782 (89.4)        | 249 (93.6)  | 108 (93.10) |        |
| Others                  | 93 (10.6)         | 17 (6.4)    | 8 (6.9)     |        |
| Religion                |                   |             |             | 0.254  |
| Catholic                | 524 (59.4)        | 96 (36)     | 41 (35)     |        |
| Others                  | 358 (40.6)        | 171 (64)    | 76 (65)     |        |

| Listening to radio     |            |            |           | < 0.001 |
|------------------------|------------|------------|-----------|---------|
| No                     | 346 (39.2) | 80 (30)    | 32 (27.4) |         |
| At least once a week   | 536 (60.8) | 187 (70)   | 85 (72.7) |         |
|                        |            |            |           |         |
| Occupation             |            |            |           | 0.004   |
| Formal salaried        | 85 (10.4)  | 19 (7.8)   | 15 (14.4) |         |
| Informal               | 213 (25.9) | 26 (10.7)) | 13 (12.5) |         |
| Farmer/petty trading   | 359 (43.7) | 147 (60.2) | 42 (40.4) |         |
| No profession          | 164 (20)   | 52 (21.3)  | 34 (32.7) |         |
| Saving organization    |            |            |           | 0.013   |
| membership             | (00, (20)) | 225(952)   | (77.4)    |         |
| INO                    | 699 (80)   | 225 (85.2) | 84 (72.4) |         |
| Yes                    | 175 (20)   | 39 (14.8)  | 32 (27.6) |         |
|                        |            |            |           |         |
| Church attendance/week |            |            |           | 0.170   |
| <= 1 time              | 452 (54.1) | 125 (48.6) | 56 (51.4) |         |
| 2–3 times              | 235(28.2)  | 93 (36.2)  | 32 (29.6) |         |
| >=times                | 148 (17.7) | 39 (15.2)  | 21 (19.3) |         |

SES: socio-economic status, HT: hypertension.

### Covariates of disability-based health status clustering

The crude and adjusted odds ratios of health status clustering based on functional, cognitive and social disability are presented in Table 3. The factors associated with clustering were being a patient compared to a neighbor (AOR: 4.67; 95% CI: 2.07–10.58), being a resident of rural Walungu health zone to semi-urban Bagira (AOR: 4.67; 95% CI: 2.07–10.58), being female (AOR: 2.1; 95% CI: 1.25–2.94), aging (AOR: 1.05; 95% CI: 1.04–1.07), doing informal work compared with being employed (AOR: 0.36; 95% CI: 0.17–0.78), being petty trader or farmer relative to being employed (AOR: 0.45; 95% CI: 0.22–0.85), being poorest compared to being least poor (AOR: 2.60; 95% CI: 1.24–3.58), and presenting with either diabetes or high blood pressure (AOR: 2.73; 95% CI:1.64–4.53) or both (AOR: 6.37; 95% CI: 2.67–15.17) to not presenting with either condition.

| Variable                           | COR (95% CI)                          | P value         | AOR (95% CI)                          | P value         |
|------------------------------------|---------------------------------------|-----------------|---------------------------------------|-----------------|
| Status of the participant          |                                       |                 |                                       |                 |
| Neighbors<br>Caregivers            | 1 (reference)<br>0.68 (0.58–1.31)     | 0.497           | 1(reference)<br>0.63 (0.37–1.09)      | 0.098           |
| Patients                           | 9.56 (6.62–12.86)                     | < 0.001         | 3.44 (1.92-6.15)                      | < 0.001         |
| Health zone                        |                                       |                 |                                       |                 |
| Bagira                             | 1 (reference)                         |                 | 1 (reference)                         |                 |
| Miti-Murhesa and Katana<br>Walungu | 1.20 (0.579–2.50)<br>2.79 (1.35–5.76) | 0.114<br><0.006 | 1.90 (0.82–4.41)<br>4.67 (2.07–10.58) | 0.134<br><0.001 |
| Sex                                |                                       |                 |                                       |                 |
| Male                               | 1 (reference)                         |                 | 1 (reference)                         |                 |
| Female                             | 1.91 (1.33–2.30)                      | < 0.001         | 2.1 (1.25–2.94)                       | 0.003           |
| Age                                | 1.07 (1.06–1.08)                      | < 0.001         | 1.05 (1.04–1.07)                      | < 0.001         |
| Household size                     | 0.94 (0.9–0.98)                       | 0.005           | 1.01 (0.95–1.08)                      | 0.760           |
| Living in conjugal union           |                                       |                 |                                       |                 |
| Yes                                | 1 (reference)                         |                 | 1 (reference)                         |                 |
| No                                 | 0.63 (0.48–0.84)                      | 0.001           | 1.37 (0.80–2.35)                      | 0.760           |
| Education of head of household     | 0.91 (0.88–0.94)                      | <0.001          | 0.97 (0.92–1.02)                      | 0.213           |
| Occupation head                    |                                       |                 |                                       |                 |
| Employed                           | 1 (reference)                         |                 | 1 (reference)                         |                 |
| Informal work                      | 0.48 (0.27-0.84)                      | 0.010           | 0.36 (0.17-0.78)                      | 0.010           |
| Petty trading/farming              | 1.01 (0.63–1.61)                      | 0.974           | 0.45 (0.22-0.85)                      | 0.016           |
| No occupation                      | 1.91 (1.12–3.28)                      | 0.018           | 1.01 (0.45-2.29)                      | 0.975           |
| SES                                |                                       |                 |                                       |                 |
| Least poor                         | 1 (reference)                         |                 |                                       |                 |

Table 3. Unadjusted and multivariable analysis of the determinants of clustering with regard to social and functional disability

| Middle                       | 0.87 (0.60–1.26)  | 0.455   | 1.67 (0.93-3.02)  | 0.088   |
|------------------------------|-------------------|---------|-------------------|---------|
| Poorest                      | 1.28 (0.88–1.86)  | 0.200   | 2.60 (1.22-5.56)  | 0.014   |
|                              |                   |         |                   |         |
| Listening to radio           |                   |         |                   |         |
| No                           | 1 (reference)     |         | 1 (reference)     |         |
| Yes                          | 0.88 (0.68–1.42)  | 0.342   | 1.49 (0.91–2.45)  | 0.113   |
|                              |                   |         |                   |         |
| Acute illness during past 30 |                   |         |                   |         |
| days                         | 1 (reference)     |         | 1 (reference)     |         |
| Vec                          | 5 08 (3 81 6 78)  | <0.001  | 2 11 (1 24 3 58)  | 0.006   |
| 103                          | 5.08 (5.81-0.78)  | \$0.001 | 2.11 (1.24-5.56)  | 0.000   |
| Child severe acute           |                   |         |                   |         |
| malnutrition                 |                   |         |                   |         |
| No                           | 1 (reference)     |         | 1 (reference)     |         |
| Yes                          | 0.81 (0.40-1.62)  | 0.549   | 0.84 (0.30-2.37)  | 0.739   |
|                              |                   |         |                   |         |
| Chronic morbidity            |                   |         |                   |         |
| Absent                       | 1 (reference)     |         | 1 (reference)     |         |
| Diabetes or hypertension     | 7.66 (5.58–10.52) | < 0.001 | 2.73 (1.64-4.53)  | < 0.001 |
| Diabetes and hypertension    | 15.09 (7.85–      | < 0.001 | 6.37 (2.67–15.17) | < 0.001 |
|                              | 29.02J            |         |                   |         |

COR: crude odds ratio; AOR: adjusted odds ratio.

### Discussion

This community-based study proposes a new way of stratifying population health in function of dependency or disability and social context rather than in function of specific diseases. Similar approaches have been quite frequently studied in high-income countries but scantily tested in LMICs. The implied hypothesis is that this way of stratifying population health may be a powerful lever for change in healthcare prioritization processes.

## A three-layered stratification strategy focusing on functionalities and leading to new strategies

The pyramidal distribution of the study population in three clusters with 9.2% participants with higher disability scores (cluster 3) is different from the few

available studies using similar grouping approaches, which nearly all come from high-income countries. Vuik, Mayer <sup>36</sup> classified patients based on healthcare utilization in England and identified 22% of the participants as patients with high health needs. A household-based survey conducted in France by Lefevre, Rondet <sup>37</sup> found that 30% of the study participants were in the cluster of largest primary care users, which may correspond to cluster 3 in our analyses. The observed differences in the proportion of individuals in high healthcare needs clusters between our findings and those from high-income settings can partly be due to the heterogeneity in study design and outcome measurements; therefore, the comparison with our study can only be indirect. Both studies based their outcome measurements on health service utilization. Moreover, the former study used hospital data that may represent people with lower access to healthcare services or with tacit non-disease based healthcare needs, such as social support of social participation. Additionally, a higher life expectancy and aging of the population in high-income countries could explain the higher proportion of individuals with more healthcare needs in these studies compared to our study.

In our study sample, the participants in cluster 3 (117 or 9.2%) would need particular healthcare attention compared to those with middle health and disability concerns in cluster 2 (267 or 21.1%) or those with minor health and disability concerns in cluster 1 (882 or 69.7%). Furthermore, by changing the prioritization process, not all diseased people need the same level of support. For example, 18.7% (148) of the participants in cluster 1 were living with diabetes or hypertension, or were mothers with an acutely malnourished child, while 23.5% (24) of the respondents in cluster 3 had no tracer condition. We also found that individuals in this high dependency cluster had a higher likelihood of presenting with both acute and chronic morbidities. They were sustaining complex medico-psychosocial problems that would require targeted healthcare interventions, such as systematic home visits and care, multidisciplinary case discussion and management, involving psychologist and social assistants. Individuals in the middle disability cluster may benefit more from health coaching strategies aiming to empower people to self-manage their health conditions, in addition to primary prevention of acute and chronic conditions. These strategies have proven useful and cost-effective in the management of chronic conditions and in averting or delaying disability <sup>38-40</sup>. Our findings also suggest people with health morbidities can still enjoy better cognitive, functional and social life through the transformation of their health conditions into 'life conditions'. This may be achieved through development of Kaiser-like integrated healthcare models and health promotion programmes enabling clients to take charge of their own health to lead an acceptable and good quality life <sup>41-44</sup>.

### Vulnerability factors associated with the population health strata

Our study also identified socio-economic risk factors of cognitive, functional and social dependency. Indeed, the odds of being in higher disability clusters were significantly higher for individuals with poor socio-economic background and empowerment, such as being a woman, elderly, rural resident and with acute or chronic morbidity. We observed that vulnerability factors such as lower socioeconomic status, older age, being a female or rural resident were significantly associated with higher odds of being in higher disability clusters than cluster 1. These findings are substantiated by results from studies from both high- and LMICs<sup>45-49</sup>. However, education had a significant effect on disability in the bi-variable analysis but was no longer significant after adjustment for potential confounders. A multicountry study on disability-measured by WHODAS in adults aged 50 and abovefound no association between education and disability in Ghana whereas a protective effect of education was reported in Russia, China, India and South Africa <sup>46</sup>. Posthoc analysis in individuals aged 50 and above did not change the pattern of association in our study. This difference may be related to the heterogeneity in socioeconomic structure between low-income countries like DR Congo and Ghana and middle- or high-income countries. Health status approached through disability dimensions is more common among the poorer. Thus, in low-income countries like DR Congo and Ghana, confounding by socioeconomic background may underestimate the beneficial effects of education on cognitive, functional and social disability because individuals with higher disability scores will tend to be poorer.

Though the likelihood of being in higher disability clusters was higher in rural areas in general compared to urban areas, there were clear disparities between health zones within rural areas. In fact, participants form Walungu health zone were worse off in terms of functional, cognitive and social disability compared to those living in Katana and Miti-Murhesa health zone. This difference is substantiated by the fact that Walungu zone had experienced longer and more direct effects of armed conflicts than Katana and Miti-Murhesa. It has been shown that the severity and gender dimensions of armed conflicts in Walungu has compromised family relationships and social interaction <sup>50-52</sup>, resulting in long-lasting effects of war including post-traumatic disorders, depression, destruction of the social structure and economy of the region <sup>53</sup>. This protracted fragile context explains the higher burden of complex

medico-psychosocial conditions observed in Walungu compared to other rural health zones and calls for rethinking healthcare programs in post-conflict regions in order to develop healthcare programs that are responsive to people's individual healthcare needs and context.

In this study, we found no significant association between the child's acute malnutrition status and the probability of a mother falling in higher disability clusters. We hypothesized that most severe cases of child malnutrition with a higher likelihood of impacting on the mother's functional, cognitive and social ability were more likely taken care of as inpatients in therapeutic feeding centers rather than in the community. Future studies involving mothers of inpatient children with severe acute malnutrition and by including qualitative approaches may clarify such a link.

### Strengths and limitations

This study had some limitations. First, these findings have limited generalizability to people living with other health conditions and which are difficult to reliably identify at community level in settings where patient's medical records are not available. Neither can our findings be generalizable to individuals severely physically or mentally impaired to the extent that they could not consent to the study or withstand the interview. However, we believe that by having extended the sampling to caregivers and randomly selected individuals in the neighborhood contributed to gaining insights in health status of individuals not presenting with the tracer conditions aforementioned and helped alleviating the effect of this potential bias. The sampling was also confined to villages close to the health center in each health area in order to be able to assess how change in the way healthcare services are being provided at the health center may have impacted on the health status of the population, in the framework of the research for development project on which this study draws. The sample selection was based on the assumption that people in villages far away from the health center were more likely to seek health services from health centers in neighboring health areas, therefore would have been hard to follow up with linkage to the research for development project on which this study is drawn. in the framework of the research for development project on which this study draws. This selection might have induced a selection bias whereby individuals living in remote villages relative to the health center may have limited access to health services, which in turn may impact on their health outcomes.

Sixty three percent of our respondents were female. This may partly be explained by the fact that the great majority of women in eastern DR Congo were housewives and more likely to be present at home when the interviewers passed by, with men moving around looking for occasional job opportunities in a region where the informal work sector or daily labour reigns. This may have resulted in a sampling bias, over representing women. We do acknowledge that such a bias might result in overestimating associations since women are more likely to score higher on WHODAS than men <sup>54,55</sup>. Our results should be interpreted accordingly. However, the replication of the associations observed across different settings with heterogeneous confounding structure suggests that this potential sampling bias likely has little effect on the pattern of associations we observed.

Akin to other observational studies, our analysis is subject to residual confounding. For example, we did not have data on psychosocial factors like anxiety and depression that are shown to be associated with higher disability scores <sup>56</sup>. In addition, we could not directly measure the effect of family and social interactions on health status clustering. A recent systematic review stressed the link between social relationship, mental health and wellbeing in physical disability <sup>56</sup>. Further studies are needed to explore the extent to which these factors may influence health status clustering.

Our study also has a number of strengths. It provides a unique insight into health status clustering of individuals at community level in a post-conflict setting. Based on modern and robust cluster analysis tools, this study proposes an innovative and programmatically useful approach to measuring health status and disability of individuals using the WHODAS. Our results can guide design and implementation of appropriate healthcare programs that fit people's needs and leverage the overall human health capital. This study also provides precise measures of associations estimates with narrow confidence intervals suggesting a sample size large enough, in a region relatively hard-to-reach and to some extent scientifically isolated.

### Conclusion

Population health stratification based on cognitive, functional social dependency at primary healthcare level may be a powerful lever for prioritization, design, implementation and scale-up of integrated care interventions with a great potential to improve quality of lives of people living in LMICs. The hierarchical health status clustering implies the necessity for a programmatic approach to the provision of healthcare services for individuals and communities in settings where resources are scarce. Our results suggest that health clustering derived from WHODAS domains scores has the potential to appropriately discriminate individuals based on the levels of health needs and increase the likelihood of appropriate healthcare service provision to all, included to those with vulnerabilities who could be easily overlooked by the usual disease-based classification of a population.

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### 4.2. Study 2

### Are people most in need utilizing health facilities in post-conflict settings? A cross-sectional study from South Kivu, eastern DR Congo

### **Paper context**

The disruptive effect of socio-political instability and conflict on the health systems is likely to exacerbate inequities in health in fragile settings. We examined the association between healthcare needs and health facility utilization in eastern DR Congo. Our study suggests that the vulnerable people are mostly using primary health facilities. Improving the availability and quality of the primary healthcare is critical to the achievement of universal health coverage in post-conflict settings.

### Abstract

### Background

The disruptive effect of protracted socio-political instability and conflict on the health systems is likely to exacerbate inequities in health services utilization in conflict-recovering contexts.

### **Objective**

To examine whether the level of healthcare need is associated with health facility utilization in post-conflict settings.

### Methods

We conducted a cross-sectional study among adults with diabetes, hypertension, mothers of infants with acute malnutrition, informal caregivers (of participants with diabetes and hypertension) and helpers of mothers of children acutely malnourished, and randomly selected neighbours in South Kivu province, eastern DR Congo. Healthcare need levels were derived from a combination, summary and categorisation of the World Health Organisation Disability Assessment Schedule 2.0. Health facility utilisation was defined as having utilised in the first resort a health post, a health centre or a hospital as opposed to self-medication, traditional herbs or

prayer homes during illness in the past 30 days. We used mixed-effects Poisson regression models with robust variance to identify the factors associated with health facility utilisation.

### Results

Overall, 82% (n=413) of the participants (N=504) utilised modern health facilities. Health facility utilisation likelihood was higher by 27% [adjusted prevalence ratio (aPR): 1.27; 95% CI: 1.13–1.43; p<0.001] and 18% (aPR: 1.18; 95% CI: 1.06–1.30; p=0.002) among participants with middle and higher health needs respectively compared to those with low healthcare needs. Using the lowest health need cluster as reference, participants in the middle healthcare need cluster tended to have a higher hospital utilisation level.

### Conclusion

Greater reported healthcare need was significantly associated with health facility utilization. Primary healthcare facilities were the first resort for a vast majority of respondents. Improving the availability and quality of health service packages at the primary healthcare level is necessary to ensure the universal health coverage goal advocating quality health for all can be achieved in post-conflict settings.
## Background

The sustainable development goals (SDG) target 3.8 advocates the principle of universal health coverage (UHC), stressing the importance of health services provision to all people in need in a way that ensures health and wellbeing of individuals and communities are improved at an affordable cost <sup>1</sup>. Inequitable utilisation of health facilities continues to pose a major threat to the progress towards UHC in resource-constrained settings, particularly in post-conflict contexts <sup>2,3</sup>. Reports from high and low middle-income countries (LMIC) suggest higher utilisation of healthcare services by people with higher socio-economic status <sup>4-6</sup> (vertical inequality). Although modern health facility utilisation (HFU) is not an end on its own, it indicates that people are seeking care and accessing facilities where services are likely to be available and of acceptable quality.

Globally, there is growing recognition of the need for health systems to shift from being diseases-centred to assuming a broader and person-centred perspective that accounts for social and environmental factors, as well as for the uniqueness and complexity of each person's life, needs and goals <sup>7-11</sup>. However, the definition of essential health services and the notion of equity in access to healthcare are not yet person-centred in many LMICs<sup>12,13</sup>, where disease control and mortality reduction for specific population groups are still at the centre. A recent study conducted in the Democratic Republic of Congo (DRC) province of South Kivu premised on a broader view of health and proposed a new way of defining health status and care needs at community level in LMIC by focusing on people's capacities and abilities to cope with day-to-day physical, social and emotional challenges<sup>14</sup>. By approaching individual health through measurement of performance in various life domains, including cognition, mobility, self-care, getting along with others, domestic and professional duties, social life and participation, the study revealed a clear needs gradient among community members which goes beyond the mere presence or absence of disease or disability.

Ensuring equitable utilization of healthcare according to needs remains a challenge in post-conflict, resource-constraint settings like the DRC. The health system has been destroyed by nearly three decades of socio-political turmoil in the eastern provinces. Because of decreasing public funding and insufficient leadership, health financing heavily relies on out-of-pocket payments and external aid (mainly humanitarian assistance)<sup>15</sup>. The distribution of health services utilization is likely to be skewed towards the richest in urban areas<sup>15</sup>, potentially perpetuating the inverse care law pattern <sup>16,17</sup> whereby the health services utilization balance is deteriorated against those most in need, leaving individuals in complex medico-psychosocial situations behind.

In the era of the SDG 3.8, assessing the link between health needs and health facility utilization is necessary for the development of health systems that are responsive to people's need for autonomy, self-management and coping with life's physical, emotional, and social challenges <sup>18</sup>. This is even more true in resource limited and post-conflict settings where horizontal inequalities can also contribute to instability. Given that protracted socio-political instability and conflict are likely to exacerbate inequities in health services utilization in post-conflict and fragile contexts, in this study we set to examine the association between healthcare needs and modern health facility utilization (HFU) in South Kivu.

## Methods

#### Study design, settings and population

This cross-sectional study was carried out in four health zones (HZ) of South Kivu Province in eastern DRC: one semi-urban (Bagira) and 3 rural (Miti-Murhesa, Katana and Walungu). Bagira HZ is located on the periphery of the province capital (Bukavu). Katana and Miti-Murhesa HZ span the national road connecting Bukavu and Goma, the two major cities of the Kivu. Walungu was one of the most conflictaffected HZ in the previous decades. The instability in the Kivu exacerbated population poverty, caused the collapse of local markets and diminished livestock production to almost its disappearance <sup>19</sup>, thus creating the conditions for a vicious cycle of socio-political instability<sup>20</sup>. From the health system point of view, each province in DRC is organized in health zones, and these in turn in health areas (HA). Within each HZ primary healthcare services are offered through health centers providing the minimum service package. This focuses on maternal and child preventive and curative care<sup>15</sup>. There are on average 15 HA per health zone in South Kivu. Secondary care is provided at HZ level hospitals offering inpatient and reference services, in addition to technical support to health centers through integrated supervision.

Six HA (estimated population of 105,047 inhabitants in 2017) were purposively selected for this study based on security constraints, geographical accessibility and availability and quality of data at the health centers. The study population is

comprised of three separate groups: 1) the tracer group: i.e. adults in one of the following conditions: either being a mother of a child with global acute malnutrition (defined as MUAC <=11.5 or nutritional oedema); or an individual with history of self-reported diabetes and/or hypertension; 2) their caregiver (or helper of mothers with a malnourished child), and 3) a randomly selected neighbor. Participants were aged at least 15 years. These sub-population categories were defined to gain better insight into different perspectives of health disability levels observable at primary healthcare facilities in eastern DRC. The likelihood of complex health situations spanning the medical, psychological and social spheres of an individual's life was deemed high in these sub-populations  $^{21,22}$ . The selected health conditions are prevailing in South Kivu  $^{23-25}$ , are relatively easy to identify and manageable even at primary care level when without complications.

### Sampling procedure and selection of participants

This study is nested in a broader research project that aims to investigate to what extent modifying how health services are provided at primary care level can influence the perceived health status of community members. For the current analysis, we used data from the baseline cross-sectional survey of the cohort that is enrolled in the main research project. The baseline study was conducted in villages around 6 health centres in the selected health areas. Within villages, households with individuals with self-reported diabetes, hypertension or child acute malnutrition were pre-identified by community-health workers. Subsequently, one caregiver living in the same household as the participant with the tracer condition and one random neighbour were selected by trained data collectors (locally recruited nurses). In each village, data collectors were guided by community health workers during the door-to-door visits. Further details on this methodology are provided elsewhere <sup>14</sup>.

Overall, 1266 participants who provided valid data on cognitive, functional and social disability were included in the main research study. Of these, we extracted a sub-sample of 553 participants who reported an acute illness during the 30 days preceding the interview for the current study. A set of questions were asked about the history of a possible acute illness in the past 30 days prior to the interview and if and where treatment was sought in the first resort. Questions covered a broad range of acute health conditions, either self-diagnosed or diagnosed by a health professional, such as fever, diarrheal, abdominal or generalized pain, difficulty in breathing, pneumonia, syncope, malaria, flu-like syndrome or any other acute

conditions (to be specified if possible). We used this inclusion criteria to reduce recall bias.

## Data collection and variables

A structured and pre-tested questionnaire was used to collect data on sociodemographics, social integration and health facility utilization between December 2017 and March 2018. The 36-item WHODAS 2.0 questionnaire was used to examine the cognitive, functional and social disability of the participants <sup>26</sup>. WHODAS 2.0 is a standard tool with cross-cultural validity extensively used across WHO regions to measure the impact of any health condition in terms of performance in a given life domain. WHODAS 2.0 covers following domains: cognition (understanding and communicating), mobility (moving and getting around), selfcare (ability to attend to personal hygiene and safety), getting along (interacting with other people), life activities (home responsibilities, leisure, work and school) and social participation (joining in community activities, social participation and engagement). The WHODAS 2.0 was translated to and back translated from Kiswahili (the national language widely spoken in eastern DRC), to ensure crosscultural and conceptual equivalence <sup>27</sup>. Details about the translation process are provided elsewhere <sup>14</sup>

WHODAS 2.0 measures decrement in performance in life domains making it a valuable instrument for health needs identification and monitoring; interventions design, and assessment of their outcomes and effectiveness; priority setting and resource allocation <sup>26</sup>. WHODAS 2.0 was used to define the main predictor variable under this study. A principal component analysis of the seven summary scores of the WHODAS 2.0 domains was performed with the use of the FactoMineR software package in R, prior to a hierarchical clustering of the principal components and guided by Ward's method <sup>28</sup>. Three health needs clusters were generated and used as a 3-levels ordinal variable reflecting the healthcare needs gradient corresponding to low, moderate and high disability levels.

#### Dependent variable

The primary outcome is modern health facility utilization, a binary variable referring to whether or not a person has utilized in the first resort a health post, a health center or a hospital as opposed to self-medication, traditional herbs or prayer homes during the illness episode in the 30 days preceding the survey.

As secondary outcomes, two additional binary variables were defined as follows: 1) utilization of primary health facilities (coded as 1 if a person reported having utilized as a first resort either a health post or centre during the 30 days prior to the interview; and as 0 if otherwise); 2) hospital utilisation coded as 1 if a person reported having utilised as a first resort a secondary level health facility during the 30 days prior to the interview; and as 0 if otherwise. Primary health facilities are officially run by nurses and offer the minimum package of activity. Secondary level health facilities are those, both public and private, with permanently appointed medical doctors, offering the complementary package of activity through hospitalisation and reference services.

## Independent variables

A wealth status variable was created in three steps. First, a Multiple Correspondence Analysis was run on housing characteristics (pavement and permanent, semipermanent or temporary structure) and ownership of a television, a radio, a computer, a manufactured bed, small animals, cattle, land, a bicycle, a motorcycle to create a socio-economic index. Five socio-economic quintiles were then derived from wealth indices, following an approach commonly used in Demographic and Health Surveys conducted in low- and middle-income countries. To create the three socio-economic classes (least poor, middle poor, poorest), the two lowest (poorest 40%) and the two middle (40%) quintiles were respectively merged as suggested by Filmer and Pritchett<sup>29</sup>.

Social cohesion and networking have been shown to be important social determinants of health and primary healthcare utilization<sup>30,31</sup>; they were approximated in this study by belonging to local social and saving cooperatives and attendance to religious activities.

Other independent variables included in the analyses were sociodemographic characteristics (sex and age of the respondent, occupation of the head of household), health zone of residence and the enrolment status of the participant (as described above, either an adult with self-reported chronic morbidity or a mother of child with acute malnutrition, a caregiver and a randomly selected neighbor).

#### Statistical analyses

Chi-squared and Student's t tests were used to compare the general characteristics of the study population by HFU. To examine the association between HFU and health needs clustering, we run bivariable and multivariable mixed-effects Poisson regression models with robust variance. In these models, health needs level was treated as fixed effect and health area as a random effect to account for the intrinsic non-independence of observations in the same health area. The choice of a modified Poisson regression over a logistic regression was justified by the fact that in presence of common outcomes (i.e. prevalence higher than 10%), odds ratios derived from logistic regression tend to bias the association away from the null. In such a scenario, alternative models directly estimating prevalence ratio (PR) are preferred to generate more accurate point and interval estimates <sup>32,33</sup>. All the study variables examined in the univariate regression models were maintained in multivariable models based on either a conservative p-value  $\leq 0.2$  or on public health plausibility. Multicollinearity between explanatory variables was suspected on the basis of a variance inflation factor greater than 10. We used Stata 15 for the analyses. The significance was set to p<0.05 (two-sided test).

## Ethical considerations

Ethical clearance was obtained from the Faculty of Medicine of Université Catholique de Bukavu and the Université Catholique de Louvain. Written informed consent was received from all participants, either by signature or fingerprint, depending on literacy. Child assent was obtained for respondents below 18 years of age, after a parent or guardian's consent. The research tools, including the consent forms, where translated to Kiswahili. Data collectors were trained on ethics and were requested to fully read out and explain the aim of the study to the respondents prior to enrolment in the study. Participants were clearly informed they were free to drop out of the interview at any time they would deem it necessary.

## Results

## Characteristics of the study participants

It was found that 59.5% of the study participants were enrolled in the tracer group; neighbours and informal caregivers were 20.9% and 19.6% respectively. Over half of the participants (52.2%) were in the lower health need level and 18.9% in the

highest health need level. The mean age was 53.2 (SD: 18.2), men were more represented in the study sample (67.1%) and 56.1% of the participants reported attending church at least twice a week. HFU was dependent on health needs level (p<0.001) and unrelated to wealth class (p=0.772) (Table 1).

| Characteristics           | Health facili | ty utilisation | Total       | P value |
|---------------------------|---------------|----------------|-------------|---------|
|                           | Yes           | No             |             |         |
| Enrolment status (N=445)  |               |                | -           | 0.195   |
| Neighbours                | 78 (83.9)     | 15 (16.1)      | 93 (20.9)   |         |
| Informal caregivers       | 66 (75.9)     | 21 (24.1)      | 87 (19.6)   |         |
| Tracer group              | 223 (84.2)    | 42 (15.8)      | 265 (59.5)  |         |
| Healthcare needs and      |               |                |             | < 0.001 |
| disability level (N=418)  |               |                |             |         |
| Low                       | 159 (72.9)    | 59 (27.1)      | 218 (52.2)  |         |
| Moderate                  | 111 (91.7)    | 10 (8.3)       | 121 (29.0)  |         |
| High                      | 63 (79.8)     | 16 (22.2)      | 79 (18.9)   |         |
| Zone (N=519)              |               |                |             | < 0.001 |
| Bagira                    | 127 (79.9)    | 32 (20.1)      | 159 (32.5)  |         |
| Miti-Murhesa and Katana*  | 172 (76.4)    | 53 (23.6)      | 255 (46.0)  |         |
| Walungu                   | 99 (94.3)     | 6 (5.7)        | 105 (21.5)  |         |
| Sex (N=499)               |               |                |             | 0.445   |
| Female                    | 131 (79.9)    | 33 (20.1)      | 164 (32.9)  |         |
| Male                      | 277 (82.7)    | 58 (17.3)      | 335 (67.1)  |         |
| Age (mean), (N=494)       | 54.8 (17.7)   | 52.1 (18.8)    | 53.2 (18.2) | 0.195   |
| Age group (N=494)         |               |                |             | 0.124   |
| < 40 years                | 89 (76.1)     | 28 (23.9)      | 117 (23.7)  |         |
| 40-59 years               | 132 (85.7)    | 22 (14.3)      | 154 (31.2)  |         |
| ≥60 years                 | 183 (82.1)    | 40 (17.9)      | 223 (54.1)  |         |
| Saving membership (N=504) |               |                |             | 0.277   |
| Yes                       | 315 (80.8)    | 75 (19.2)      | 390 (78.2)  |         |
| No                        | 93 (85.3)     | 16 (14.7)      | 109 (21.8)  |         |
|                           | ()            |                |             | 0.011   |
| Weekly church attendance  |               |                |             |         |
| (N=483)                   |               |                |             |         |
| $\leq 1$ time/week        | 163 (76.9)    | 49 (23.1)      | 212 (43.9)  |         |
| 2-3 times                 | 135 (83.9)    | 26 (16.1)      | 161 (33.3)  |         |

Table 1. Characteristics of the study participants by health facility utilization status

| $\geq$ 4 times                         | 99 (90)    | 11 (10)   | 110 (22.8) |       |
|--|------------|-----------|------------|-------|
| Chronic morbidity (N=467)              |            |           |            | 0.021 |
| Absent                                 | 139 (76.0) | 44 (24.0) | 183 (39.1) |       |
| Diabetes or hypertension               | 214 (84.9) | 38 (15.1) | 252 (53.9) |       |
| Diabetes and hypertension              | 30 (90.9)  | 3 (9.1)   | 33 (7.0)   |       |
| Wealth class (N=504)                   |            |           |            | 0.772 |
| Least poor                             | 86 (83.3)  | 16 (15.7) | 102 (20.2) |       |
| Middle poor                            | 175 (81)   | 41 (19)   | 216 (42.9) |       |
| Poorest                                | 152 (81.7) | 34 (18.3) | 186 (36.9) |       |
| Head of household's occupation (N=459) |            |           |            | 0.706 |
| Formal work                            | 54 (87.1)  | 8 (12.9)  | 62 (13.5)  |       |
| Informal work                          | 67 (81.7)  | 15 (18.3) | 82 (17.9)  |       |
| Petty trade/farming                    | 175 (80.7) | 42 (19.3) | 217 (47.3) |       |
| No occupation                          | 81 (82.7)  | 17 (17.3  | 98 (21.3)  |       |

Data are n (%), unless otherwise specified. \*: Miti-Murhesa and Katana health zones are grouped since they were formerly constituting the Katana health zone. They share the same characteristics in terms of health coverage, location and level of past exposure to conflict. Enrolment of the participants spanned villages across the border between the two health zones borders.

## Factors associated with health facility utilization

Among the study participants who reported being sick thirty days prior to being interviewed, 18.1% did not use any formal health facility, rather resorted to traditional healers, prayer homes or self-medication; 12.1% went to hospitals (Table 2).

 Table 2. Health facility utilization among study participants who reported being sick 30 days prior to the survey

| Health facility type                    | N (%)      |
|---|------------|
| Health post                             | 36 (7.1)   |
| Public health center in the health area | 248 (49.2) |
| Private health center                   | 68 (13.5)  |
| Hospital                                | 61 (12.1)  |
| Traditional healers                     | 16 (3.2)   |
| Prayer homes                            | 5 (1.0)    |
| Self-medication and other               | 70 (13.9)  |

Health needs level was significantly associated with high HFU. In fact, the level of HFU was higher by 27% [adjusted prevalence ratio (aPR): 1.27; 95% 1.13–1.43; p<0.001] and 18% (aPR: 1.18; 95% CI: 1.06–1.30; p=0.002) among participants with middle and higher health needs respectively, compared to those with lower health needs. Other factors independently and positively associated with HFU were attending church services at least four times a week compared to attending once or less (aPR: 1.17; 95% CI: 1.15–1.20; p<0.001), and being in the middle wealth group compared to being in the poorest group (aPR: 1.12; 95% CI: 1.06–1.19; p<0.001). Factors independently and negatively associated with HFU were the health status of the participant at enrolment, with caregivers (aPR: 0.77; 95% CI: 0.68–0.88; p<0.001) and participants in the tracer group (aPR: 0.73; 95% CI: 0.57–0.95; p=0.017) being less likely to utilise health facilities than neighbours; and younger age (aPR: 0.997 (95% CI: 0.995–0.999; p=0.017).

| Variable                              | Unadjusted PR (95% | P value | Adjusted PR      | P value |
|---------------------------------------|--------------------|---------|------------------|---------|
| Healthcare needs and disability level |                    |         | (5570 C1)        |         |
| Low                                   | Ref.               |         | Ref.             |         |
| Moderate                              | 1.27 (1.10–1.48)   | 0.002   | 1.27 (1.13–1.43) | < 0.001 |
| High                                  | 1.11 (1.01–1.20)   | 0.022   | 1.18 (1.06–1.30) | 0.002   |
| Enrolment status                      |                    |         |                  |         |
| Neighbours                            | Ref.               |         | Ref.             |         |
| Caregivers                            | 0.90 (0.86-0.95)   | < 0.001 | 0.77 (0.68–0.88) | < 0.001 |
| Tracer group                          | 1.00 (0.91–1.11)   | 0.939   | 0.73 (0.57–0.95) | 0.017   |
| Health zone                           |                    |         |                  |         |
| Bagira                                | Ref.               |         | Ref.             |         |
| Miti-Murhesa and katana               | 0.96 (0.92–0.99)   | 0.025   | 0.92 (0.74–1.14) | 0.462   |
| Walungu                               | 1.18 (1.13–1.23)   | < 0.001 | 1.18 (0.90–1.53) | 0.233   |
| Education (years)                     | 1.00 (0.99–1.02)   | 0.657   | 0.99 (0.97–1.02) | 0.688   |

#### Table 3. Factors associated with health facility utilization

| Sex   |                  |         |                  |         |
|---|------------------|---------|------------------|---------|
| Male  | Ref.             |         | Ref.             |         |
| Female  | 1.04 (0.98–1.11) | 0.206   | 1.06 (0.96–1.17) | 0.238   |
| Age   | 1.00 (1.00–1.00) | 0.162   | 1.00 (0.99–1.00) | 0.017   |
| Saving membership                                     |                  |         |                  |         |
| No  | Ref.             |         | Ref.             |         |
| Yes   | 1.05 (0.97–1.15) | 0.222   | 0.98 (0.88–1.10) | 0.773   |
| Church attendance                                     |                  |         |                  |         |
| $\leq$ 1 time/week                                    | Ref.             |         | Ref.             |         |
| 2-3 times   | 1.10 (1.03–1.17) | 0.003   | 0.98 (0.90-1.06) | 0.616   |
| $\geq$ 4 times  | 1.19 (1.02–1.39) | 0.029   | 1.17 (1.15–1.20) | < 0.001 |
| Occupation of head<br>of household<br>Formal salaried | Ref.             |         | Ref.             |         |
| Informal worker                                       | 0.94 (0.82–1.08) | 0.356   | 1 (0.71–1.40)    | 0.985   |
| Petty trade/farming                                   | 0.92(0.83-1.02)  | 0.129   | 0.89 (0.70–1.14) | 0.362   |
| No occupation   | 0.95 (0.87–1.05) | 0.302   | 0.87 (0.64–1.18) | 0.375   |
| Wealth class  |                  |         |                  |         |
| Poorest   | Ref.             |         | Ref.             |         |
| Middle poor   | 1.00 (0.89–1.11) | 0.940   | 1.12 (1.06–1.19) | < 0.001 |
| Least poor  | 1.03 (0.87–1.22) | 0.702   | 1.06 (0.87–1.31) | 0.548   |
| Chronic morbidity                                     |                  |         |                  |         |
| Absent  | Ref.             |         | Ref.             |         |
| Diabetes or   | 1.12 (1.05–1.19) | < 0.001 | 1.14 (0.92–1.41) | 0.234   |
| Diabetes and<br>hypertension                          | 1.20 (1.09–1.32) | < 0.001 | 1.24 (0.95–1.62) | 0.114   |

Ref.: reference category. The factors included in the multivariable regression analysis are: healthcare needs and disability level, enrolment status, health zone of residence, education (years of schooling), being member of a local saving organization, church attendance, occupation of the head of household, wealth class and history of chronic morbidity (diabetes and hypertension).

Analysis of secondary outcomes are reported in Tables 4 and 5. Compared to those with lower health needs, participants with middle health needs were less likely to use primary health facilities (PR: 0.93; 95% CI: 0.88–0.99; p=0.015) and much more likely to use hospitals (PR: 2.17; 95% CI: 1.44–3.29; p<0.001). Additionally, participants in the tracer group (PR: 3.75; 95% CI: 1.22–11.57; p=0.021) and their caregivers (PR: 6.55; 95% CI: 5.25–8.18; p<0.001) had significantly higher hospital utilization levels compared to neighbours.

| Variable                              | Unadjusted PR (95% CI) | P<br>value | Adjusted PR<br>(95% CI) | p value |
|---------------------------------------|------------------------|------------|-------------------------|---------|
| Healthcare needs and disability level |                        |            |                         |         |
| Low                                   | Ref.                   |            | Ref.                    |         |
| Moderate                              | 0.93 (0.85–1.03)       | 0.154      | 0.93 (0.88-0.99)        | 0.015   |
| High                                  | 0.84 (0.71–1.00)       | 0.050      | 1.00 (0.83–1.19)        | 0.970   |
| Enrolment status                      |                        |            |                         |         |
| Neighbours                            | Ref.                   |            | Ref.                    |         |
| Caregivers                            | 0.89 (0.80-0.99)       | 0.026      | 0.85 (0.76-0.94)        | 0.003   |
| Tracer group                          | 0.88 (0.75-1.04)       | 0.129      | 0.93 (0.80–1.07)        | 0.290   |
| Health zone                           |                        |            |                         |         |
| Bagira                                | Ref.                   |            | Ref.                    |         |
| Miti-Murhesa and                      | 1.01 (0.92–1.11)       | 0.813      | 0.78 (0.56–1.08)        | 0.133   |
| katana<br>Walungu                     | 1.20 (1.14–1.26)       | < 0.001    | 1.01 (0.80–1.28)        | 0.915   |
| Education (years)                     | 0.99 (0.97–1.00)       | 0.13       | 1.00 (0.98–1.02)        | 0.927   |
| Sex                                   |                        |            |                         |         |
| Male                                  | Ref.                   |            | Ref.                    |         |
| Female                                | 0.96 (0.90–1.02)       | 0.182      | 1.03 (0.94–1.11)        | 0.562   |

Table 4. Factors associated with utilization of primary healthcare facilities

| Age                             | 1.00 (1.00–1.00)  | 0.943 | 1.00 (1.00–1.00)   | 0.620   |
|---------------------------------|-------------------|-------|--------------------|---------|
| Saving membership               |                   |       |                    |         |
| No                              | Ref               |       | Ref                |         |
| Ves                             | 0.97(0.88-1.06)   | 0.45  | 0.91 (0.85 - 0.98) | 0.013   |
| 105                             | 0.57 (0.00 1.00)  | 0.15  | 0.91 (0.05 0.90)   | 0.015   |
| Church attendance               |                   |       |                    |         |
| $\leq 1$ time/week              | Ref.              |       | Ref.               |         |
| 2-3 times                       | 1.03 (0.93–1.14)  | 0.553 | 1.25 (1.18–1.32)   | < 0.001 |
| $\geq$ 4 times                  | 0.99 (0.94–1.05)  | 0.851 | 1.11 (1.03–1.18)   | 0.004   |
|                                 |                   |       |                    |         |
| Occupation of head of household |                   |       |                    |         |
| Formal salaried                 | Ref.              |       | Ref.               |         |
| Informal worker                 | 1.27 (1.08–1.49)  | 0.004 | 1.13 (0.92–1.39)   | 0.254   |
| Petty trade/farming             | 1.32 (1.03–1.70)  | 0.028 | 1.32 (1.15–1.52)   | < 0.001 |
| No occupation                   | 1.16 (0.99–1.35)  | 0.069 | 1.02 (0.75–1.39)   | 0.883   |
|                                 |                   |       |                    |         |
| Wealth class                    |                   |       |                    |         |
| Poorest                         | Ref.              |       | Ref.               |         |
| Middle                          | 0.99 (0.95–1.02)  | 0.407 | 1.09 (0.98–1.21)   | 0.094   |
| Least poor                      | 0.84 (0.71-0.98)  | 0.028 | 1.00 (0.86–1.17)   | 0.977   |
|                                 |                   |       |                    |         |
| Morbidity                       |                   |       |                    |         |
| Absent                          | Ref.              |       | Ref.               |         |
| Diabetes or                     | 0.93 (0.79–1.08)  | 0.348 | 0.79 (0.69–0.91)   | 0.001   |
| hypertension<br>Diabetes and    | 0.80 (0.64, 1.00) | 0.047 | 0.76 (0.57, 1.01)  | 0.06    |
| hypertension                    | 0.00 (0.04-1.00)  | 0.047 | 0.70 (0.37-1.01)   | 0.00    |

Ref.: reference category. Primary health facilities include health posts and health centres. The factors included in the multivariable regression analysis are: healthcare needs and disability level, enrolment status, health zone of residence, education (years of schooling), being member of a local saving organisation, church attendance, occupation of the head of household, wealth class and history of chronic morbidity (diabetes and hypertension).

| Variable                              | Unadjusted PR<br>(95% CI) | P value | Adjusted PR (95%<br>CI) | P value |
|---------------------------------------|---------------------------|---------|-------------------------|---------|
| Healthcare needs and disability level |                           |         | ,<br>,                  |         |
| Low                                   | Ref.                      |         | Ref.                    |         |
| Moderate                              | 2.38 (1.53-3.72)          | < 0.001 | 2.17 (1.44-3.29)        | < 0.001 |
| High                                  | 2.92 (2.43-3.51)          | < 0.001 | 1.30 (0.87–1.93)        | 0.194   |
| Enrolment status                      |                           |         |                         |         |
| Neighbours                            | Ref.                      |         | Ref.                    |         |
| Caregivers                            | 2.25 (0.92-5.49)          | 0.076   | 6.55 (5.25-8.18)        | < 0.001 |
| Tracer group                          | 3.72 (1.53–9.07)          | 0.004   | 3.75 (1.22–11.57)       | 0.021   |
| Health zone                           |                           |         |                         |         |
| Bagira                                | Ref.                      |         | Ref.                    |         |
| Miti-Murhesa and                      | 0.91 (0.60-1.40)          | 0.674   | 3.69 (0.42-32.85)       | 0.241   |
| katana                                |                           |         |                         |         |
| Walungu                               | 0.19 (0.04–1.096)         | 0.044   | 1.04 (0.24–4.42)        | 0.962   |
| Education (years)                     | 1.07 (0.98–1.17)          | 0.149   | 0.99 (0.88–1.11)        | 0.849   |
| Sex                                   |                           |         |                         |         |
| Male                                  | Ref.                      |         | Ref.                    |         |
| Female                                | 1.28 (0.87–1.90)          | 0.209   | 0.98 (0.45–2.10)        | 0.952   |
| Age                                   | 1.01 (1.00–1.02)          | 0.163   | 1.0 0 (0.98–1.02)       | 0.944   |
| Saving membership                     |                           |         |                         |         |
| No                                    | Ref.                      |         | Ref.                    |         |
| Yes                                   | 1.27 (0.89–1.83)          | 0.193   | 1.38 (0.59–3.22)        | 0.454   |
| Church attendance                     |                           |         |                         |         |

Table 5. Univariable and multiple regression analysis of the associationbetween health need level and hospital utilization

| $\leq 1$ time/week  | Ref.              |       | Ref.              |         |
|---------------------|-------------------|-------|-------------------|---------|
| 2-3 times           | 0.99 (0.50-1.96)  | 0.979 | 0.21 (0.07-0.63)  | 0.005   |
| $\geq$ 4 times      | 1.15 (0.74–1.79)  | 0.535 | 0.70 (0.55-0.89)  | 0.004   |
|                     |                   |       |                   |         |
| Occupation of head  |                   |       |                   |         |
| of household        |                   |       |                   |         |
| Formal salaried     | Ref.              |       | Ref.              |         |
| Informal worker     | 0.46 (0.28-0.75)  | 0.002 | 0.89 (0.08-9.40)  | 0.919   |
| Petty trade/farming | 0.29 (0.11-0.76)  | 0.011 | 0.27 (0.12-0.61)  | 0.001   |
| No occupation       | 0.78 (0.53-1.13)  | 0.188 | 1.06 (0.10-10.83) | 0.96    |
| -                   |                   |       |                   |         |
| Wealth class        |                   |       |                   |         |
| Poorest             | Ref.              |       | Ref.              |         |
| Middle              | 0.98 (0.72-1.33)  | 0.887 | 0.66 (0.22-1.95)  | 0.450   |
| Least poor          | 2.23 (1.21-4.10)  | 0.010 | 1.00 (0.33-3.05)  | 0.995   |
| _                   |                   |       |                   |         |
| Morbidity           |                   |       |                   |         |
| Absent              | Ref.              |       | Ref.              |         |
| Diabetes or         | 2.61 (1.16-5.87)  | 0.021 | 3.64 (1.82-7.27)  | < 0.001 |
| hypertension        | . ,               |       | . ,               |         |
| Diabetes and        | 4.72 (1.77–12.58) | 0.002 | 4.77 (1.52–14.95) | 0.007   |
| hypertension        |                   |       |                   |         |

Ref.: Reference category. The factors included in the multivariable regression analysis are: healthcare needs and disability level, enrolment status, health zone of residence, education (years of schooling), being member of a local saving organization, church attendance, occupation of the head of household, wealth class and history of chronic morbidity (diabetes and hypertension).

# Discussion

This community-based cross-sectional study is one of the first studies to apply a comprehensive approach to measuring healthcare needs and its association with health facility utilization at community level in post-conflict settings. We investigated HFU in a heterogeneous group composed of adults with diabetes, hypertension, mothers of children with acute malnutrition, their informal caregivers and randomly selected neighbours. The majority of them utilized health facilities as

a first resort in case of illness. Informal caregivers and participants in the tracer group were less likely to utilize modern health facilities compared to neighbours. Participants with moderate and higher level of health needs and disability were also more likely to utilize modern health facilities compared to those in with lower health need and disability level. They tended to seek care at hospital level rather than at primary health care facilities, possibly expecting a more comprehensive management of their condition.

The level of HFU observed in this study is slightly higher than the 76.7% reported in a Kenyan study <sup>34</sup>. This relatively high HFU could be an effect of a selective sample of people with known morbidities. However, data from a study conducted in another eastern DRC province showed a similarly high HFU <sup>35</sup>, suggesting additional explanations are plausible. For example, in post-conflict settings, a considerable number of humanitarian actors provide financial and capacity building support to health facilities, thus helping them remain functional. Despite (or thanks to) the ongoing conflict, the health system in South Kivu is the best funded in the country, if humanitarian aid is taken into account <sup>15</sup>. Other factors such as population resilience and adaptation capacity of health providers might also contribute to maintain this level of HFU in health zones of South Kivu that are progressively recovering from conflict. Further research to inform health service provision strategies in post-conflict settings is needed for cross-country learning.

Participants enrolled in the tracer group and their caregivers were unexpectedly less likely to utilize modern health facilities, but had higher hospital utilization level than their neighbours. This may reflect the traditional organization of healthcare services whereby chronic diseases are managed at hospital level in most LMICs settings <sup>36,37</sup>, including South Kivu. However, most vertical or selective donor-funded health programs are disproportionately focused on mortality reduction and disease indicators rather than on person-centered approaches of healthcare service organization. This may lead to a shrinking role of primary healthcare for chronic patients and an increased utilization of costly hospital-based curative services in post-conflict settings where the government leadership and health regulatory powers are weak. Further research is needed to understand how primary healthcare priorities for chronic conditions should be set in conflict-affected settings to overcome the potential competing visions between international donors' vertical approaches and local government ambitions of building strong and sustainable primary healthcare systems <sup>38-40</sup>.

Being part of a social network can influence health seeking behavior and health care service utilization. All studied health centers facilitate social initiatives to enhance the economic and social capital of vulnerable community members. These include for example the small-scale village saving and loan cooperative AVEC (from French 'Association Villageoise d'Epargne et de Credit') or social support clubs for the elderly. Although these initiatives make the health center pivotal to community dynamics and are expected to encourage their members to resort to modern health facility services <sup>41,42</sup>, we could not find such effect in our study. The lower HFU observed among members of local saving cooperatives could reflect a reverse causation whereby those joining saving cooperatives are more likely to be young and economically active, thus less prone to severe health problems that would require health care. It could also mirror positive effects of social integration and connectedness on self-esteem, sense of well-being, social competence, self-efficacy in management of chronic conditions, depression and stress responses <sup>30</sup>.

Questions about the link between religion and health have often raised stormy debates <sup>43</sup>. Attendance of religious services has been associated with modern HFU and positive health outcomes <sup>44-46</sup>. Our finding may reflect high religious service attendance among participants with higher perceived health needs and vulnerability. In South Kivu, many health facilities are owned by and located near churches. Religious services attendance may also be an opportunity for social interaction, integration, and positive attitudes sharing, which can in turn exert a positive influence on health seeking behaviors <sup>44,47,48</sup>.

The association between wealth status and modern HFU<sup>4,49</sup> is not clear in our study. While respondents in the middle wealth level seemed to have higher utilization than those in the poorest group, utilization of primary health care and hospitals was comparable across wealth levels, as it was also the case in as study from Kenya<sup>34</sup>. This may be due to little heterogeneity across the asset based wealth index in this predominantly rural population. Furthermore, in some post-conflict health zones of the Kivu, specific health services related to chronic diseases are subsidised by humanitarian organisations and are provided free of charge irrespectively of the patient's wealth status. This is the case for insulin and some oral antidiabetic drugs, treatment services for child malnutrition or management of pregnancy-related conditions, among other services.

With regard to household head's occupation, our results seem suggesting a differential health seeking behavior between households headed by petty trader or

farmer, and those headed by formal salaried. Farmers and petty traders are likely to have a lower socio-economic position and education level, and more limited access to specialized and often expensive health services offered at hospitals compared to formal salaried <sup>50</sup>. On the other hand, the quality of services offered at primary healthcare level may be deemed sub-optimal by richer and more educated individuals. This finding supports the claim that one of the most efficient ways of bringing quality care to the most vulnerable in poor and post-conflict fragile contexts is to invest in strong primary healthcare schemes <sup>51,52</sup>.

#### Study limitations

This is one of the first studies to apply a comprehensive approach to measuring healthcare needs and its association with health facility utilization at community level in post-conflict settings. Using a sample of people with self-reported diabetes, hypertension and mothers of infant with malnutrition selected from villages around the health centers limits the generalizability of our findings. Besides, this study may not reflect the situation of the most hard-to-reach and remote areas with active armed conflict in South Kivu and where the health needs and service utilization may be different. Therefore, additional investigations are needed to cover such contexts. That our sample size was not estimated for this study is less likely to introduce a bias given the high precision of point intervals reflected in narrow confidence intervals. We did not do post-hoc power calculations since this practice is increasingly seen as obsolete and discouraged <sup>53</sup>. Although we used a cross-sectional study design, the strength of the associations observed between explanatory factors and HFU despite multivariable adjustment for extensive confounders suggests the associations are real. Our findings may still be subject to residual confounding and unmeasured factors such as distance to health facilities or financial inaccessibility <sup>54</sup>. Furthermore, some of the study participants who reported illness might have not necessarily felt the need to attend a health facility, therefore caution needs to be exerted while interpreting findings about the level of HFU. Finally, the effect estimates might have been influenced by both social desirability bias and the interviewer effect as data collectors were nurses living in the study sites and the questionnaire could not be self-administered given the low literacy level in these predominantly rural settings. This may have led participants to conceal information about seeking care from informal sources, in which case modern HFU will end up over reported.

# Conclusion

In this post-conflict setting, healthcare need was significantly associated with health facility utilization whereby those with greater reported needs were more likely to utilize health facilities. Primary health- care facilities were the first resort for a vast majority of respondents. There is a need to rethink priorities regarding the provision of quality primary healthcare in post-conflict settings. This is critical to achieving the UHC goal of advocating quality health for all.

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# 4.3. Study 3

This study has not yet been published.

# A two-year longitudinal assessment of people's healthcare status and needs from a person-centred perspective at community level in South-Kivu, DR Congo: lessons learned

## Abstract

### Background

Despite the growing recognition of the relevance of a person-centred view of health to the universal health coverage goal, there is little evidence on whether and how people's health status or healthcare needs can be measured and followed-up in postconflict settings. We aimed to assess how and why people's perceived health has (not) evolved over a two-year period in South-Kivu, eastern DR Congo.

## **Methods**

We conducted cohort study among 1) a 'tracer group' of individuals with selfreported diabetes or hypertension and mothers whose children had an acute malnutrition; 2) informal caregivers of people with chronic conditions (diabetes and/or hypertension) and helpers of mothers of children acutely malnourished); and 3) randomly selected neighbours of people in the tracer group. Participants were followed-up at 10 and 21 months on average from the baseline. We used the World Health Organization Disability Assessment Schedule (WHODAS 2.0) to measure people's perceived health. A principal component analysis of the WHODAS domain scores, followed by a cluster analysis were used to define a three-level hierarchical health capital variable at baseline. The study outcome was the change in an individual's overall health capital, seen as improved if a participant's summary WHODAS score at a given follow-up visit was lower than that measured at baseline, or worse otherwise. To identify the factors associated with the risk of decline in health capital over time, we used generalized estimating equations models of Poisson family, with a log link and a robust standard error.

## Results

Of the 1120 participants with validated data on tracer group status and WHODAS at baseline; 725 (64.7%) were interviewed at both follow-up visits, corresponding to 1450 person-visits. The overall risk of decline in health capital was 45.7%. Participants in the high healthcare need cluster had a lower absolute risk (15.4) of decline in health capital than those in the middle (33.3%) and low healthcare care need clusters (53.8%). The decline in health capital was not significantly associated with the enrolment status (tracer group variable), but was strongly linked to the baseline health capital. In fact, the risk of decline in health capital was lower in participants in the middle (adjusted RR: 0.46; 95% CI: 0.37–0.57, p<0.001) and low (adjusted RR:0.21; 95% CI: 0.14–0.31; p<0.001) health capital cluster than in those in the high health capital cluster. We also found that each five-years increase in a participant's age was expected to increase the risk of decline in health capital by 4% (RR: 1.04, 95% CI: 1.02–1.06, p<0.001). The direction of the association between decline in health capital and rural location was unclear.

## Conclusion

That the risk of decline in health capital over time was higher among individuals with high health capital level at baseline, without being impacted by the enrolment status, underscores the necessity of using person-centred tools to identify people in need of close follow-up and specific care. Assessing each person's healthcare status with multidimensional person-centred tools, in additional to traditional assessments based on disease indicators, can help better fit healthcare services to each person's own needs and contexts.

#### Key words

Person-centered, health status, primary healthcare, cohort, post-conflict, DR Congo

# Background

Health, at individual and community level, is a naturally and continuously changing state of being[1]. Its definition has also evolved over time. Many scholars are increasingly calling for shifting away from the notion of equating health to the state of 'complete well-being' to new definitions viewing health as a personal continuum of physical, cognitive and social functioning [2], or as the ability for each individual to self-manage and adapt to their work or living environment[3]. This (r)evolution in the conceptualization of health is becoming central to the development of person-centered primary healthcare systems across the world[4]. Rendering health systems person-centered is recognized as a key step towards achieving the universal health coverage goal[5], by centering healthcare service prioritization strategies and provision to each person's own experience of illness and health, their environment, the circumstances of their daily life and their socio-cultural context [6, 7].

The International Classification of Functioning, Disability and Health (ICF) framework has been developed in a bid to foster the view of health through the lenses of physical, cognitive and social functioning rather than the sole prevention and management of diseases[8]. The WHO subsequently drew on the ICF to develop the World Health Organization Disability Assessment Schedule (WHODAS) tool. It has been recently shown that the WHODAS can effectively be used to measure health at population level in high-income and low-income settings, including in post-conflict contexts such as the eastern Democratic Republic of Congo[9]. In addition, we recently showed its utility in linking healthcare needs with health services utilization[10].

The individual and public health implications of considering health from the personcentered angle have started to be documented [11]. But, whether and how people's health status and healthcare needs, viewed form a person-centered angle, can be measured and followed-up at population level is still insufficiently addressed. Besides, individual and social determinants driving positive or negative evolution of people's health measured with person-centered friendly tools have not yet been fully examined. In this study, we aimed to assess how and why people's perceived health has evolved over a two-year period in a cohort of individuals recruited from the community in South-Kivu province in eastern DRC, using the WHODAS to measure people's perceived health and healthcare needs.

# Methods

#### Study context, settings and population

This study is embedded within a broader 5-year research project for development whose aim is to investigate the feasibility of moving from diseases-centred to peopleand community-centred healthcare at the primary level of the health system in South-Kivu, and how it is associated or not with changes in people and community health. The project is being implemented by public health research institutions in partnership with an implementing non-governmental organisation (NGO) based in DRC. The study methodology has been extensively detailed elsewhere [9, 10] and is summarized in the following sections.

We conducted this study in six health areas spreading over four post-conflict, rural and semi-urban health zones (Bagira, Katana, Miti-Murhesa and Walungu) in South-Kivu province. Three health centres form these health areas (Bideka, Kabushwa and Nyamuhinga) were selected because of their geographical accessibility and longterm collaboration with Louvain Cooperation (LC), a Belgium-funded NGO affiliated with the Catholic University of Louvain. LC has been supporting these health areas for over 6 years in terms of medical records keeping, community and home-based healthcare activities, management of chronic conditions (such as diabetes and hypertension), and medico-psychosocial support of the elderly [12]. The remaining three health areas (Burhale, Lumu and Lwiro) did not receive any support from Louvain cooperation and were selected from the neighbourhood, based on existing basic infrastructure and functioning capacity.

It is worth noting that from an administrative point of view, the DRC is organized in 26 provinces and 192 territories. The health system follows a different structure: provinces are divided into health zones, and these in health areas. In South-Kivu, there are 8 territories and 34 health zones. There are on average 3-4 health zones by territory, and approximately 15 health areas by health zone. The health areas selected for this study cover over 105000 population as of 2018, according to population projections from the South Kivu provincial health division.

The population enrolled in this cohort in 2017 comprises 1) individuals with selfreported diabetes or hypertension and mothers whose children had a global acute malnutrition (herein referred to as "tracer group"); 2) informal caregivers of people with chronic conditions (diabetes and/or hypertension) and helpers of mothers of children with acute malnutrition); and 3) randomly selected neighbors of people in the tracer group. Participants in the tracer group were initially identified thanks to networks of community health workers (CHW) in the study sites. It is worth emphasizing that in this study the attention is not fixated on diabetes and hypertension, or child malnutrition; we selected these conditions as tracers because of both their relative ease of diagnosis at community level, even in settings where resources are scarce, and the assumption that people affected by these conditions may experience complex healthcare needs involving the physical, psychological and social dimensions of life.

#### Summary of the sampling procedure

The baseline study sample was programmatically set to 270 people in each health area, that is, 90 people in each category (tracer group, informal caregivers, and neighbours), because of logistic constraints. We built up on existing networks of CHW to establish rosters of people in the tracer groups at village level. Trained data collectors who were locally recruited nurses were assigned to trace back households where people in the tracer groups were previously identified by CHW, starting from villages nearest to the health centres. Within each household, a verbal consent was sought from the head of household in order to survey the pre-identified household member. The target person in the household had in turn to provide a written informed consent for participation in the study and their caregivers or helpers were identified and surveyed (after they have consented to be included in the study). A neighbour without self-reported tracer conditions was randomly selected in the nearest household [9].

## Data collection and follow-up

Participants enrolled at baseline were followed up 10 months (first follow-up) and 21 months (second follow-up) after the baseline survey, and requested each time to provide an informed consent to participate in the follow-up interviews. Pre-tested paper-based and structured questionnaires were used to collect baseline data on socio-demographics, economic characteristics and medical history of the participants. We used the WHODAS 2.0 to measure the perceived physical, cognitive, functional and social performance of the participants at baseline and during follow-up visits. The WHODAS is a cross-culturally validated tool largely used across the world to measure health. It has six domains spanning a wide life spectrum: cognition(understanding and communicating capacity), mobility (moving

and getting around), self-care (attending to one's hygiene, dressing, eating and staying alone), getting along (interacting with other people), life activities (domestic tasks, leisure, work and school); and social participation (joining in community activities and participating in society)[13]. We separately assessed domestic tasks and leisure from work and school activities and ended up with seven domains.

## Study variables

We measured an individual's health capital by generating a summary WHODAS score from the recoded item scores within each domain. All domains scores were summed and rescaled into a metric ranging from 0 to 100[13], where zero expresses a low health capital and 100 an optimal or high health capital. For each WHODAS domain, a score was created on a 100-graded scale to measure performance or level of functioning. Each score varies from 0 (best performance or health status) to 100 (lower performance and highest level of disability and dependency, corresponding to the highest level of healthcare need).

The primary outcome was the change in an individual's overall health capital and was treated as a binary variable derived from the summary or composite WHODAS score. The health capital was seen as improved if a participant's summary WHODAS score at a given follow-up visit was lower than that measured at baseline, or worse otherwise. We calculated this difference at the first and second follow-ups. The secondary outcomes were changes in each of the seven WHODAS domain scores, defined following the same logical as for the primary outcome.

In our previous work[10], we identified three hierarchical health status clusters of the population, representing three health capital or healthcare need levels. In the current analysis, we examined whether the probability of decline in health capital over time was dependent on the health status clustering at baseline, or on the enrolment label of the participant (tracer group, informal caregivers or neighbours). The other independent variables included socio-demographics (age, sex, health zone and health area of residence, size of household), history of chronic conditions (diabetes and/or hypertension), level of education, occupation, socio-economic position, and social networking appraised though membership of local saving cooperatives and religious activities attendance. We also had a location variable allowing us to assess whether the probability of decline in one's health capital was dependent on rurality, or on living in a health area receiving support from Louvain cooperation. Age was treated as a five-years unit continuous variable. Socio-economic position was measured by first creating a wealth index at baseline as a proxy for socio-economic status of the household of the participant. We carried out a Multiple Correspondence Analysis (MCA) of items owned by the household such as a mobile phone, television, a radio, a computer, a manufactured bed, small animals, cattle, land, a bicycle, a motorcycle, and a housing feature (pavement in the house). The next step consisted in dividing the wealth index into quintiles, akin to the strategy being used in large population surveys in low-income countries such as the Demographic and Health Surveys[14] and the Multiple Indicator Cluster Survey [15]. We then created three socio-economic positions from the lowest quintile (20%), the mid two quintiles (40%) and the top two quintiles (40%), similar to what has been frequently done in other low-income contexts where expenditure data are not available for a better assessment of the socio-economic status[16].

#### Statistical analysis

We examined the distribution of quantitative variables graphically with the use of histograms and statistically using the Shapiro-Wilk test. Categorical data were summarized into frequencies and proportions, and continuous data into medians with interquartile ranges. Wilcoxson rank-sum test, Kruskal-Wallis rank test and chi squared test where used to compare the characteristics of the participants by health capital level at baseline. To identify the factors associated with change in health capital over time, we used generalized estimating equations (GEE) models of Poisson family, with a log link and a robust standard error. The choice of a GEE model was motivated by the repeated nature of the data within each study participant. We preferred GEE to mixed-effects models because the former were shown to provide better population average estimates than the latter[17]. We assumed that correlations between close repeated measured are stronger than between measures taken with long time intervals, and thus used a first-order autoregressive correlation matrix. The selection of variables in the multivariate models was based on a conservative p-value≤ 0.2 in bivariable analysis, using Wald's chi squared test, and/or on public health relevance. We report the relative risks of health capital decline with their 95% CI intervals. Statistical significance was set to type one error (alpha) below 5%. We used Stata 14 for all the analyses.

## Results

Of the 1266 participants enrolled in the baseline survey, 1120 (88.5%) had validated data on both the tracer group status and WHODAS, among which 725 (64.7%) were

followed up at both visits. The mean (SD) interval between the baseline survey and the first follow-up was 10.1 (1.0) months, and 11.0 (11.4) months between the first and second follow-ups. Figure 1 presents the flow chart of the study participants. Of the 1120 participants with validated data on the tracer group status and WHODAS at baseline, 725 (64.7%) were interviewed at both follow-up visits, corresponding to 1450 person-visits.

## Figure 1. Flow chart of the study participants with valid WHODAS data



The baseline characteristics of the study participants with complete WHODAS data at all the three data collection visits are summarized in Table 1, by health capital level. The median (IQR) age of the participants was 49 (33-62) years; participants with low health capital appeared older than those with middle or high health capital levels. The majority of the study participants were female (65.4%). The proportion of study participants who reported being members of local cooperatives for social solidarity, a proxy for social networking, was comparable by health capital levels and this membership (p=0.090). Over half of the study population (53.3%) reported attending religious activities (another proxy for social networking) at least once a week, and 19.0% of the participants were at least 4-times attendants of religious activities in a week. But, the health capital level seemed independent of membership of attendance of religious activities (p=0.949). However, subgroup analysis suggested a statistically significant association between attendance of religious activities and presence of chronic conditions (p<0.001). In fact, 25.8% (n=63) of participants with diabetes or hypertension and 23.5% (n=8) of those with both diabetes and hypertension reported attending religious activities at least four times a weekend compared to 13.1% (n=54) of those without any of these conditions. The proportion of participants who were poorest appeared higher in the lowest health capital level, though the difference did not reach a statistical significance. Higher health capital was significantly related to higher education level.

| Characteristics         | High health capital | Middle<br>health | Low health capital | Total      | P<br>value |
|-------------------------|---------------------|------------------|--------------------|------------|------------|
| Enrolment status        |                     | capital          |                    |            | < 0.001    |
| Neighbors               | 182 (36.0)          | 25 (18.1)        | 8 (9.9)            | 215 (29.7) |            |
| Caregivers              | 217 (42.9)          | 21 (15.2)        | 10 (12.3)          | 248 (34.2) |            |
| Tracer group            | 107 (21.1)          | 92 (66.7)        | 63 (77.8)          | 262 (36.1) |            |
| Age                     | 42 (29–57)          | 62 (53–69)       | 64 (54–75)         | 49 (33–62) | < 0.001    |
| Sex                     |                     |                  |                    |            | 0.005      |
| Female                  | 310 (61.7)          | 105 (76.1)       | 55 (69.6)          | 470 (65.4) |            |
| Male                    | 192 (38.3)          | 33 (23.9)        | 24 (30.4)          | 249 (34.6) |            |
| Health area             |                     |                  |                    |            | < 0.001    |
| Nyamuhinga, urban, LC+  | 128 (25.7)          | 37 (27.2)        | 13 (16.1)          | 178 (24.9) |            |
| Lumu, urban, LC-        | 122 (24.5)          | 19 (14.0)        | 9(11.1)            | 150 (21.0) |            |
| Bideka, rural, LC+      | 34 (6.8)            | 16 (11.8)        | 11 (13.6)          | 61 (8.5)   |            |
| Burhale, rural, LC-     | 34 (6.8)            | 29 (21.3)        | 12 (14.8)          | 75 (10.5)  |            |
| Lwiro, rural, LC-       | 107 (21.5)          | 30 (22.1))       | 31 (38.3)          | 168 (23.5) |            |
| Kabushwa, rural, LC+    | 73 (14.7)           | 5 (3.7)          | 5 (6.2)            | 83 (11.6)  |            |
| Saving membership       |                     |                  |                    |            | 0.090      |
| No                      | 408 (81.4)          | 117 (86.0)       | 60 (74.1)          | 585 (81.5) |            |
| Yes                     | 93 (18.6)           | 19 (14.0)        | 21 (25.9)          | 133 (18.5) |            |
| Church attendance       |                     |                  |                    |            | 0.949      |
| ≤1                      | 259 (53.9)          | 69 (51.1)        | 41 (53.3)          | 369 (53.3) |            |
| 2-3 times               | 129 (26.8)          | 41 (30.4)        | 22 (28.6)          | 192 (27.7) |            |
| $\geq$ 4 times          | 93 (19.3)           | 25 (18.5)        | 14 (18.8)          | 132 (19.0) |            |
| Socio-economic position |                     |                  |                    |            | 0.484      |
| Least poor              | 147 (29.0)          | 36 (26.1)        | 17 (21.0)          | 200 (27.6) |            |
| Middle                  | 198 (39.1)          | 52 (37.7)        | 32 (39.5)          | 282 (38.9) |            |

|  | Table 1. | Baseline | characteristic | of the | study pop | oulation | by health | capital level |
|--|----------|----------|----------------|--------|-----------|----------|-----------|---------------|
|--|----------|----------|----------------|--------|-----------|----------|-----------|---------------|

| Poorest             | 161 (31.8) | 50 (36.2) | 32 (39.5) | 243 (33.5) |         |
|---------------------|------------|-----------|-----------|------------|---------|
| Education           | 6 (1–10)   | 2 (0-6)   | 0(0–5)    | 5(0-10)    | < 0.001 |
| Occupation of HH    |            |           |           |            | < 0.001 |
| Formal salaried     | 54 (11.66) | 14 (11.1) | 14 (18.9) | 862(12.4)  |         |
| Informal worker     | 126 (27.2) | 16 (12.7) | 6 (8.1)   | 148 (22.3) |         |
| Farmer/petty trader | 173 (37.4) | 60 (47.6) | 27 (36.5) | 260 (39.2) |         |
| No occupation       | 110 (23.8) | 36 (28.6) | 27 (36.5) | 173 (26.1) |         |
|                     |            |           |           |            |         |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération.

Table 2 describes the change in health capital over time. The overall absolute risk of decline in health capital was 45.7%. Participants in the high healthcare need cluster had a lower absolute risk (15.4) of decline in health capital than those in the middle (33.3%) and low healthcare care need clusters (53.8%).

| Variable                | Improvement | Decline    | Total      |
|-------------------------|-------------|------------|------------|
| Overall (total)         | 788 (54.3)  | 662 (45.7) | 1450 (100) |
|                         |             |            |            |
| Healthcare need cluster |             |            |            |
| Low                     | 467 (46.2)  | 545 (53.8) | 1012(69.8) |
| Middle                  | 184 (66.7)  | 92 (33.3)  | 276(19.0)  |
| High                    | 137 (84.6)  | 25 (15.4)  | 162(11.2)  |
|                         |             |            |            |
| Enrolment status        |             |            |            |
| Neighbours              | 231 (53.7)  | 199 (46.3) | 430 (29.7) |
| Caregivers              | 243 (49.0)  | 253 (51.0) | 496 (34.2) |
| Patients                | 314 (59.9)  | 210 (40.1) | 524 (36.1) |
|                         |             |            |            |
| Health area             |             |            |            |
| Nyamuhinga, urban, LC+  | 177 (49.7)  | 179 (50.3) | 356 (24.9) |
| Bideka, rural, LC+      | 63 (51.6)   | 59 (48.4)  | 122 (8.5)  |
| Burhale, rural, LC-     | 74 (49.3)   | 76 (50.7)  | 150 (10.5) |
| Kabushwa, rural, LC+    | 91 (54.8)   | 75 (45.2)  | 166 (11.6) |
| Lumu, urban, LC-        | 160 (53.3)  | 140 (46.7) | 300 (21.0) |
| Lwiro, rural, LC-       | 213 (63.4)  | 123 (36.6) | 336 (23.5) |
|                         |             |            |            |

Table 2. Descriptive analysis of the absolute risk of decline in health capital

| Age in years                 | 48 (32–63) | 50 (33-61) | 49 (33-62) |
|------------------------------|------------|------------|------------|
| Sex                          |            |            |            |
| Male                         | 273 (54.8) | 225 (45.2) | 498 (34.6) |
| Female                       | 508 (54.0) | 432 (46.0) | 940 (65.4) |
| Saving membership            |            |            |            |
| No                           | 632 (54.0) | 538 (46.0) | 1170 (81.5 |
| Yes                          | 149 (56.0) | 117 (44.0) | 266 (18.5) |
| Religious service attendance |            |            |            |
| $\leq$ Once a week           | 396 (53.7) | 342 (46.3) | 738 (53.3) |
| 2-3 times per week           | 216 (56.3) | 168 (43.7) | 384 (27.7) |
| $\geq$ 4 times per week      | 139 (52.3) | 125 (47.7) | 264 (19.0) |
| Morbidity                    |            |            |            |
| None                         | 402 (52.8) | 360 (47.2) | 762 (57.1) |
| Diabetes or hypertension     | 287 (56.9) | 217 (43.0) | 502 (37.8) |
| Diabetes and hypertension    | 42 (61.8)  | 26 (38.2)  | 68 (5.1)   |
| Marital status               |            |            |            |
| Never married                | 75 (52.1)  | 69 (47.9)  | 144 (10.1) |
| Married                      | 543 (55.3) | 439 (44.7) | 982 (68.9) |
| Divorced/widowed/separated   | 158 (52.7) | 142 (47.3) | 300 (21.0) |
| SES                          |            |            |            |
| Least poor                   | 209 (52.3) | 191 (47.7) | 400 (27.6) |
| Middle poor                  | 302(53.6)  | 262 (46.4) | 464 (38.9) |
| Poorest                      | 277 (57.0) | 209 (43.0) | 486 (33.5) |
| Occupation                   |            |            |            |
| Formal salaried              | 99 (60.4)  | 65 (39.6)  | 164 (12.4) |
| Informal                     | 149(50.3)  | 147 (49.7) | 296 (22.3) |
| Farming/petty trading        | 282 (54.2) | 238 (47.8) | 520 (39.2) |
| None                         | 201 (58.1) | 145 (41.9) | 346 (26.1) |
| Education (years)            |            |            |            |
| 7+                           | 280 (52.2) | 256 (47.8) | 536 (40.5) |
| Between 1-6                  | 194 (51.3) | 184 (48.7) | 378 (28.6) |
| None                         | 220 (53.9) | 188 (46.1) | 408 (30.9) |

Data are the number and proportion (%) of observations (or person-visits) by change in health capital, considering all the three study visits, and median (interquartile range) for age (measured in years). The results of the crude and multivariable analysis of the change in health capital are presented in Table 3. The unadjusted analysis showed that the only factor significantly associated with the probability of decline in a participant's health capital was the baseline healthcare need clustering. Participants in the middle [Crude Relative Risk (cRR): 0.62, 956% CI: 0.52–0.75, p<0.001] and high (cRR: 0.29, 95% CI: 0.23–0.42, P<0.001) healthcare need clusters had a significantly lower risk of decline in health capital compared to those in the low healthcare need cluster. In multivariable regression analysis, apart from the baseline healthcare need clustering, the other variables significantly associated the risk of decline in health capital were the health area of residence and older age. Participants residing in rural Burhale health area, located in the post-conflict Walungu health zone (and not receiving any financial and technical support) from Louvain cooperation had a higher risk of health capital decline compared to those living in semi-urban Nyamuhinga health area. However, residents from the Lwiro health area, a rural health area created in 2015 and facing important financial and infrastructural resources, had a lower risk of decline in health capital compared to those in the semi-urban health area.

In our simple regression analysis (including 802 participants), aging was insignificantly associated with decline in health capital. Adding the healthcare need cluster variable in the model resulted in the change of the direction and significance of the association (the sample size remaining the same), indicating a negative confounding effect of healthcare need cluster on the relationship between age and change in health capital (as the unadjusted relative risk is lower than the unadjusted relative risk). We also found that each five-years increase in a participant's age was expected to increase the risk of decline in health capital by 4% (adjusted RR: 1.04, 95% CI: 1.02-1.06, p<0.001).

The analysis of secondary outcomes suggested that being in the lower healthcare need cluster and aging were consistently associated with decline in capacities related to the WHODAS domains scores considered separately (supplementary file, Tables S1-S7).

| Variable                     | Crude analysis     |         | Adjusted analysis  |         |
|------------------------------|--------------------|---------|--------------------|---------|
|                              | cRR (95% CI)       | P value | aRR (95% CI)       | P value |
| Haalthaara raad aluatar      |                    |         |                    |         |
| L ow                         | 1                  |         | 1                  |         |
| Middle                       | 0.62 (0.52 - 0.74) | <0.001  | 0.46(0.37-0.57)    | <0.001  |
| High                         | 0.29 (0.20–0.41)   | < 0.001 | 0.21 (0.14–0.31)   | < 0.001 |
| Enrolment status             |                    |         |                    |         |
| Neighbours                   | 1                  |         | 1                  |         |
| Caregivers                   | 1.10 (0.97–1.26)   | 0.148   | 1.11 (0.96–1.28)   | 0.156   |
| Patients                     | 0.87 (0.74–1.01)   | 0.063   | 1.09 (0.87–1.37)   | 0.433   |
| Health area                  |                    |         |                    |         |
| Nyamuhinga, urban, LC+       | 1                  |         | 1                  |         |
| Bideka, rural, LC+           | 0.96 (0.77–1.19)   | 0.724   | 1.27 (0.93–1.73)   | 0.136   |
| Burhale, rural, LC-          | 1.01 (0.83–1.23)   | 0.939   | 1.29 (1.05–1.58)   | 0.016   |
| Kabushwa, rural, LC+         | 0.90 (0.73–1.10)   | 0.300   | 0.84 (0.67–1.04)   | 0.100   |
| Lumu, urban, LC-             | 0.93 (0.79-1.09)   | 0.366   | 0.90 (0.75-1.07)   | 0.229   |
| Lwiro, rural, LC-            | 0.73 (0.61–0.87)   | 0.001   | 0.82 (0.67–1.00)   | 0.046   |
| Age (unit=5 years)           | 1.00 (0.98–1.01)   | 0.829   | 1.04 (1.02–1.06)   | < 0.001 |
| Sev                          |                    |         |                    |         |
| Male                         | 1                  |         | 1                  |         |
| Female                       | 1 02 (0.90 - 1.15) | 0.782   | 1 07 (0.94 - 1.21) | 0.290   |
| 1 cillulo                    | 1.02 (0.90 1.13)   | 0.762   | 1.07 (0.91 1.21)   | 0.290   |
| Saving membership            |                    |         |                    |         |
| No                           | 1                  |         | 1                  |         |
| Yes                          | 0.96 (0.81–1.13)   | 0.600   | 0.97 (0.82–1.14)   | 0.679   |
| Religious service attendance |                    |         |                    |         |
| $\leq$ Once a week           | 1                  |         | 1                  |         |
| 2-3 times per week           | 0.94 (0.82–1.09)   | 0.423   | 0.92 (0.79–1.06)   | 0.229   |
| $\geq$ 4 times per week      | 1.02 (0.87–1.20)   | 0.788   | 0.94 (0.80–1.10)   | 0.439   |
| Morbidity                    |                    |         |                    |         |
| None                         | 1                  |         | 1                  |         |
| Diabetes or hypertension     | 0.91 (0.80–1.04)   | 0.168   | 1.03 (0.84–1.26)   | 0.800   |
| Diabetes and hypertension    | 0.81 (0.58–1.13)   | 0.209   | 1.16 (0.80–1.65)   | 0.453   |
| Marital status               |                    |         |                    |         |
| Never married                | 1                  |         |                    |         |
| Married                      | 0.93 (0.78–1.12)   | 0.456   |                    |         |

Table 3. Factors associated with risk of decline in health capital over time

| Divorced/widowed/separate<br>d | 0.99 (0.80–1.22) | 0.909 |
|--------------------------------|------------------|-------|
| SES                            |                  |       |
| Least poor                     | 1                |       |
| Middle poor                    | 0.97 (0.85-1.12) | 0.701 |
| Poorest                        | 0.90 (0.78–1.04) | 0.166 |
| Occupation                     |                  |       |
| Formal salaried                | 1                |       |
| Informal                       | 1.25 (0.99-1.58) | 0.060 |
| Farming/petty trading          | 1.15 (0.92–1.44) | 0.208 |
| None                           | 1.06 (0.83–1.35) | 0.650 |
| Education (years)              |                  |       |
| 7+                             | 1                |       |
| Between 1-6                    | 1.02 (0.88-1.17) | 0.792 |
| None                           | 0.96 (0.84–1.11) | 0.620 |
|                                |                  |       |

Crude Relative Risk; aRR: Adjusted Relative Risk. LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The sample size for the final multivariable model was 611.

# Discussion

In this two-year longitudinal study conducted among a predominantly rural population in eastern DRC, we showed that the WHODAS can be effectively used to measure and monitor health at individual and community level in an innovative and person-centered manner. We found that the decline in an individual's overall health capital was not significantly associated with the enrolment label (individuals with self-reported diabetes or hypertension and mothers whose children had a global acute malnutrition, randomly selected neighbours or informal caregivers), but was strongly linked to the baseline health capital. In fact, participants with a low health capital at baseline were less likely to see their health capital decline compared to those with a middle or high health capital.

The absence of effect of enrolment status on change in health capital over the study course may appear counter-intuitive. There is a number of studies showing the medico-psychosocial impact of chronic conditions in low-income settings[18] where health promotion activities for non-communicable diseases are often overlooked in the prioritization process of primary healthcare, in favour of infectious diseases and other acute maternal and child health problems. Although the epidemiological

landscape in many LMICs is still predominantly overwhelmed by these health problems, the epidemiological transition happening in sub-Saran Africa is associated with an increasing burden of non-communicable diseases[19], including in the Kivu[20]. To be responsive to this double burden in a way that is cost-effective and meaningful to the dynamic of change in people's healthcare needs, the health system in resource-constrained settings in sub-Saharan Africa will need to reinvent itself. Indeed, the epidemiological transition in LMICs comes with the need for policy makers to become more sensitive to the fact that, as suggested by our findings, what matters to people is not necessarily the disease level, since it did not impact on the evolution of participants' health capital; but rather the extent to which each person, regardless of their disease-label, is able to cope with daily life challenges.

Our findings pointed to a mixed effect of rural residence on change in health capital. In two of the four rural health areas (those receiving support from Louvain Coopération), the decline in the overall health capital was statistically comparable to that of the urban health area used for comparison. Meanwhile, in the two other rural areas (not supported by LC), the probability of decline in health capital was ambivalent. Some contextual factors may account for observed differential effect of rurality on people's health capital. Lwiro health area where the probability of decline in health capital was lower compared to that in the urban area used for comparison is a relatively recently created health still struggling to attract non-governmental funders that would help solve the infrastructural and logistical challenges impeding its functioning. Health and development aids were shown to have a significant impact on the lives of the poor living in recipient settings[21, 22]. However, akin to the neighbouring Kabushwa health area, the majority of the participants recruited in Lwiro reside around the heath center located near the Katana commercial center, along the national road connecting Goma and Bukavu (the two major cities of the Kivu provinces). In both (Lwiro and Kabushwa) health areas, petty trading and agriculture is the main occupation given the good soil fertility, as opposed to the more remote Burhale health area located in post-conflict the Walungu territory.

The territory of Walungu was one of the most severely affected by direct effects of armed conflicts during the dark period of war in previous decades, particularly due to repeated armed clashes between the Interahamwe (Rwandan Hutu rebels), a local militia composed of local youngsters (Mudundu 40) and the Rwanda-backed rebel group (the Rally for Congolese Democracy–Goma known as RCD-G). This particular context of instability might have accentuated the population poverty, caused the collapse of local markets and severely slackened the rural production of
livestock in Walungu[23], thus perpetuating the conditions for a vicious circle of socio-political and economic instability[24]. Adding to this context the fact that rural health areas often have poorer public services, insufficient infrastructures, higher level of poverty and illiteracy, and least funded health programs compared to urban areas may explain, at least partly, the observed higher probability of health capital decline in Burhale (located Walungu territory and not supported by LC). Another likely explanation for ambiguous effect of health area of residence on decline in an individual's health capital may be that it possibly reflects a potential selective lost to follow-up creating an imbalance in the study population.

Lastly, through the regular supervision conducted as part of the PRD in all the six study health areas, Kabushwa appeared to embrace better all the components of the person-centred approach being implemented. That might have contributed to the efficacy of the health centre to respond to the needs of its clients and may have been instrumental to the building of confidence between the health centre and the population. Participants enrolled for this study had the opportunity to receive at their homes the data collectors who were all nurses, during field data collection. This was a form a free home-based consultation. Blood pressure was assessed for all the study participants and glycaemia was measured for those with self-reported diabetes, free of charge. Advices and health education were also provided to those found with high blood pressure or abnormal glycaemia. In health areas where the confidence in local health professionals is high, the health education offered at the end of each interview may have triggered a positive behaviour change and resulted in an improvement in the health capital dynamic among residents around a health area.

Socio-economic status and lack of education were not significantly associated with the change in the overall health capital, contrary to suggestions from studies conducted elswhere[18]. Poverty is one of the most studied and undisputable social determinant of health across countries and regions, whether you look at it from the narrow perspective of communicable and non-communicable disease, as it is being laid bare by the Covid-19 pandemic irrespective of the income levels of countries[25, 26], or whether you are examining it from a wider and more integrated person-centered standpoint[27, 28]. Additionally, the health system financing in DRC heavily relies on out-of-pocket payments, making it harder for the poorest to get access to (quality) health services. These factors could be expected to reduce the capacity of the health systems in rural areas to respond to population healthcare needs and result into a poor health status of the communities they are serving. The apparent lack of effect of socio-economic position on change in health capital may

be indicative of the absence of variability in socio-economic empowerment in this predominantly rural and impoverished population in a way that impacts change in health capital over a period as short as two years. Longer term studies are useful to further understand the link between socio-economic factors and change in health capital at population level in post-conflict settings.

Aging was consistently shown to be a significant contributor to the negative evolution of the health capital in the Kivu[9, 20]. The frailty related to aging has been a topic of great focus in many high-income countries[29], in contrast to LMICs where hardly there are studies and recognition of the specific, multidimensional and often complex health needs of old people. With the number individuals aged over 65 years expected to double in sub-Saharan Africa by 2050[30], investing in the development of comprehensive and integrated programs addressing the complex and multidimensional needs coming with aging appears an indispensable component of the universal health coverage goal in low-income countries. In most settings, the need for adopting a care model emphasizing the comprehensive view of older people's health rather than a disjointed approach to health services provision has been documented[31, 32]. But, a mind-set shift in the way healthcare services for older people are being designed and planned will not be possible unless personcentered strategies for measurement of health start to be taught, implemented and incentivized, particularly in settings where resources are too scarce to afford a fragmented and disintegrated approaches of care focusing on single clinical entities or diseases. A sustained health system development boasting a universal health coverage in LMIC will remain a void slogan if health systems remain insensible to the multidimensional health needs of those whose lives have been saved and prolonged by decades of global and national investments in the fight against premature deaths caused by infant and maternal mortality, and infectious diseases.

In this analysis and our previous studies[9, 10], being a regular attendant of religious activities or member of local solidarity and saving cooperatives did not seem to be associated with change in health capital level. Although these local solidarities and saving initiatives are intended to empower their members socio-economically, this goal may be hindered by the lack of heterogeneity within these organisations. The poorest and least poor members of the community are less likely to belong to the same cooperatives because of the minimum level of contribution required from each member. There are cooperatives known as "for the rich people" and others for the poor, depending on the level of contribution agreed on by their members. Thus, such initiatives may fail short of their purported goal of solidarity between different socio-

economic layers within the community, because they are constituted in a way that is unlikely to bring together the poor and the least poor.

Also, lack of a statistically significant association between regular attendance of religious activities, another proxy for social networking intended to enhance the social capital of participants[33], and the risk of decline in health capital can be explained by the fact that frequent attendants of religious services are likely to be old, poor or chronically ill. Some attendants of religious activities are often hoping for health and help from divine powers, and using the little resources they may possess as offerings, in expectation of reciprocal blessings in this life and the next[34, 35]. The effect of social networking through attendance of religious activity may therefore be balanced out by the fact that participants with chronic conditions or those perceiving themselves as frail are more likely to attend religious services[35]. Religiosity can been seen as a coping mechanisms for some people with particular complex medico-psychosocial problems[35], as supported by our findings showing higher frequency of attendance of religious services among participants with chronic conditions. That participants with high religiosity had a health capital dynamic comparable to that of non-(regular) attendants of religious activities may be seen as a positive effect of networking through religion on an individual's health capital.

#### Study limitations and strengths

To the best of our knowledge, this study is the first to use the WHODAS longitudinally in a post-conflict and rural setting in sub-Saharan Africa. Our sample size, though initially estimated on a convenience basis, turned out to be large enough, translating into a high precision around points estimates (narrow confidence intervals). The study limitations include a relatively important attrition rate, particularly in Burhale health zone (Supplementary file, Table S8). Only 64.7% of the with validated data at baseline could be traced at both follow-up visits. In fact, our research team in Burhale health area was stopped from carrying out the first follow-up survey by health areas responsible because they conditioned the continuation of the work on them selecting (new) enumerators for the study. Working with a new team of enumerators between surveys appeared had an important effect of the follow-up rate in this health area. Another explanation for the observed attrition rate is that some participants enrolled at baseline refused to participate in follow-up interviews claiming there was no point "wasting" their time while the data collectors were not providing medicines for their health problems.

The fact that we only had three data points covering a 2-year period did not allow a better assessment of the change in health capital over time. Change in an individual's health capital measured with person-centered metrics may occur at a slower pace than could our study be able to capture. Further assessments of the health capital dynamic with longer follow-up me be necessary to deepen our understanding of the individual and contextual factors that can be leveraged upon to improve the wellbeing of the population in LMICs. There is also a likelihood of an interviewer bias that could influence the WHODAs scoring between follow-ups. Selective survivor bias (also known as Neyman bias)[36] is also possible. Those with lower health capital level may have been more likely to get lost to follow-up; some were reported to have died and others moved to Bukavu (the major city of South Kivu province) to seek specialized healthcare services. Those who were followed-up through the 2-year period are therefore more likely to have a better health status than those lost to follow-up.

Our strategy of evaluating the change in the WHODAS score from its baseline for each patient was qualitative and may not allow to fully account for the magnitude of the variation in a participant's health capital. A person whose WHODAS score increased by one unit was considered to have declining health capital as much as another person whose WHODAS increased by 10 or more units, for instance. One way to avoid such a limitation would have been to keep the difference in WHODAS scores between consecutive visits in its quantitative form. Although such an approach may seem more precise from an analytical point of view, it is likely to lead to results that are less easily interpretable from a practical and operational perspective, particularly by end-users of our findings who are unlikely to have advanced statistical literacy. Lastly, the fact that we used a sample of people with self-reported diabetes, hypertension and mothers of infant with malnutrition selected from villages around the health centers limits the generalizability of our findings.

## Conclusion

Our study suggests that monitoring population health with person-centered is feasible at population level even in post-conflict settings. The fact that the risk of decline in health capital over time was higher among individuals with high health capital level at baseline, without being impacted by the enrolment status, underscores the necessity of using person-centered tools to identify people in need of close follow-up and comprehensive healthcare. Assessing each person's healthcare need level with multidimensional person-centered tools, in additional to traditional assessments based on disease indicators, can help better fit health care services to each person's specific needs, age, baseline health capital level and unique contexts. Longer term studies will be necessary to better understand the dynamic of individual and population over time and the cost-effectiveness of such an approach in the organisation and prioritization of health services at primary and higher levels of health systems in low-income countries.

## Supplementary analysis

In this section, we present the tables about the analyses of secondary outcomes (WHODAS domain scores) and the distribution of missing data by the main study outcome (change in the overall health capital).

## Analysis of secondary outcomes

The analysis of the decline in capacities related to WHODAS domains considered separately indicated that the high healthcare need cluster was associated with a lower probability of decline in all the WHODAS domains. Aging was a significant predictor of the decline in all the WHODAS domains.

The risk of decline in abilities to get along with others was 26% significantly higher among the participants with one to six years on education compared to those with a least 7 years of education [(aRR): 1.26, 95% CI: 1.03-1.55, p=0.028)] (Table S3). Women had 21% increased risk of decline in capacities to perform work-related tasks than men (aRR: 1.21, 95% CI: 1.04-1.40, p=0.012)] (Table S6).

Participants with multi-morbidity (diabetes and hypertension) had a 52% increased risk of decline in social participation compared to those without any of these conditions (aRR: 1.52, 95% CI: 1.06-2.18), p=0.023 (Table S7)

| Variable                | Unadjusted RR<br>(95% CI) | P<br>value | Adjusted RR (95%<br>CI) | P value |
|-------------------------|---------------------------|------------|-------------------------|---------|
| Healthcare need cluster |                           |            |                         |         |
| Low                     | 1                         |            | 1                       |         |
| Middle                  | 0.71 (0.57-0.86)          | 0.001      | 0.50 (0.39-0.64)        | < 0.001 |
| High                    | 0.37 (0.26–0.54)          | 0.001      | 0.22 (0.14–0.35)        | < 0.001 |
| Enrolment status        |                           |            |                         |         |
| Neighbours              | 1                         |            | 1                       |         |

#### Table S1. Factors associated with decline in cognitive abilities

| Caregivers                   | 1.21 (1.03–1.43)                      | 0.019 | 1.20(1.02 - 1.48)                    | 0.001   |
|------------------------------|---------------------------------------|-------|--------------------------------------|---------|
| Patients                     | 0.95 (0.79–1.14)                      | 0.578 | 1.27 (0.93–1.72)                     | 0.131   |
|                              | , ,                                   |       |                                      |         |
| Health area                  |                                       |       |                                      |         |
| Nyamuhinga urhan I C+        | 1                                     |       | 1                                    |         |
| Rideka rural I C+            | 1 34(102 175)                         | 0.036 | 1 74(125 243)                        | 0.001   |
| Burbala rural LC             | 1.34(1.02-1.73)<br>1.15(0.99, 1.51)   | 0.050 | 1.74(1.23-2.43)<br>1.27(0.04, 1.72)  | 0.001   |
| Kabuahana mural I.C.         | 1.13(0.00-1.31)                       | 0.295 | 1.27(0.94-1.72)<br>1.22(0.02, 1.(0)) | 0.110   |
| Kabushwa, rural, LC+         | 1.44 (1.14–1.83)                      | 0.002 | 1.22(0.93-1.60)                      | 0.160   |
| Lumu, urban, LC-             | 1.18 (0.94–1.47)                      | 0.151 | 1.19 (0.94–1.52)                     | 0.155   |
| Lwiro, rural, LC-            | 1.27 (1.04–1.55)                      | 0.021 | 1.38 (1.09–1.75)                     | 0.007   |
| Age (unit=5 years)           | 1.01 (1.00–1.03)                      | 0.143 | 1.06 (1.04–1.09)                     | < 0.001 |
| S                            |                                       |       |                                      |         |
| Mala                         | 1                                     |       | 1                                    |         |
| Male                         |                                       | 0.700 |                                      | 0 (22   |
| Female                       | 0.98 (0.85–1.12)                      | 0.728 | 1.04 (0.89–1.22)                     | 0.633   |
| Saving membership            |                                       |       |                                      |         |
| No                           | 1                                     |       | 1                                    |         |
| NO                           | 1                                     | 0.072 | 1 1 04 (0.97 1.24)                   | 0.602   |
| ies                          | 1.00 (0.84–1.19)                      | 0.975 | 1.04 (0.87–1.24)                     | 0.092   |
| Religious service attendance |                                       |       |                                      |         |
| < Once a week                | 1                                     |       | 1                                    |         |
| 2-3 times per week           | 0.99(0.84 - 1.17)                     | 0.934 | 0.99(0.83-1.17)                      | 0.898   |
| 2-5 times per week           | 0.99(0.04-1.17)                       | 0.954 | 0.99(0.03-1.17)<br>1.01(0.84, 1.22)  | 0.898   |
| ≥4 times per week            | 0.98 (0.81–1.18)                      | 0.803 | 1.01 (0.84–1.23)                     | 0.885   |
| Morbidity                    |                                       |       |                                      |         |
| None                         | 1                                     |       |                                      |         |
| Diabetes or hypertension     | 0.83(0.71-0.97)                       | 0.017 | 0.84(0.63 - 1.12)                    | 0.234   |
| Diabetes and hypertension    | 0.05(0.71-0.97)<br>0.70(0.53, 1.10)   | 0.017 | 1.00(0.62 + 1.62)                    | 0.254   |
| Diabetes and hypertension    | 0.79 (0.33-1.19)                      | 0.234 | 1.00 (0.02–1.02)                     | 0.337   |
| Education (years)            |                                       |       |                                      |         |
| 7+                           | 1                                     |       | 1                                    |         |
| Between 1-6                  | 1 16(0.97 - 1.38)                     | 0.100 | 1 17 (0.96 - 1.44)                   | 0.121   |
| None                         | 1.10(0.97 - 1.38)<br>1.18(1.00, 1.41) | 0.100 | 1.17(0.90-1.44)<br>1.18(0.08 1.42)   | 0.121   |
| none                         | 1.18 (1.00–1.41)                      | 0.048 | 1.18 (0.98–1.42)                     | 0.081   |
| Marital status               |                                       |       |                                      |         |
| Never married                | 1                                     |       |                                      |         |
| Married                      | 1 14(0.01 1.44)                       | 0.250 |                                      |         |
| Mained                       | 1.14(0.91-1.44)<br>1.22(0.04, 1.60)   | 0.239 |                                      |         |
| Divorced/widowed/separated   | 1.23 (0.94–1.00)                      | 0.127 |                                      |         |
| Socia aconomia accitica      |                                       |       |                                      |         |
| L sest we set                | 1                                     |       |                                      |         |
| Least poor                   |                                       | 0.540 |                                      |         |
| Middle poor                  | 1.06 (0.88–1.26)                      | 0.548 |                                      |         |
| Poorest                      | 1.09 (0.91–1.31)                      | 0.341 |                                      |         |
|                              |                                       |       |                                      |         |

| Occupation            |                  |       |
|-----------------------|------------------|-------|
| Formal salaried       | 1                |       |
| Informal              | 0.97 (0.74–1.28) | 0.839 |
| Farming/petty trading | 1.14 (0.89–1.45) | 0.293 |
| None                  | 0.91 (0.69–1.21) | 0.527 |

LC+: refers to health areas receiving support from Louvain coopération. The final sample size for the final multivariable model was 561.

| Variable                     | Unadjusted RR<br>(95% CI) | P value | Adjusted RR<br>(95% CI) | P value |
|------------------------------|---------------------------|---------|-------------------------|---------|
| Healthcare need cluster      |                           |         | · · · · ·               |         |
| Low                          | 1                         |         | 1                       |         |
| Middle                       | 0.80 (0.64-1.01)          | 0.065   | 0.57 (0.44–0.75)        | < 0.001 |
| High                         | 0.44 (0.30–0.65)          | < 0.001 | 0.28 (0.17–0.45)        | < 0.001 |
| Enrolment status             |                           |         |                         |         |
| Neighbours                   | 1                         |         | 1                       |         |
| Caregivers                   | 1.27 (1.04–1.55)          | 0.020   | 1.23 (0.98–1.56)        | 0.075   |
| Patients                     | 1.09 (0.88–1.35)          | 0.420   | 1.17 (0.84–1.64)        | 0.360   |
| Health area                  |                           |         |                         |         |
| Nyamuhinga, urban, LC+       | 1                         |         | 1                       |         |
| Bideka, rural, LC+           | 1.41 (1.04–1.92)          | 0.028   | 1.50 (0.92-2.43)        | 0.101   |
| Burhale, rural, LC-          | 1.60 (1.21-2.12)          | 0.001   | 1.84 (1.31-2.58)        | < 0.001 |
| Kabushwa, rural, LC+         | 1.45 (1.10–1.90)          | 0.009   | 1.32 (0.95–1.83)        | 0.095   |
| Lumu, urban, LC-             | 0.97 (0.74–1.28)          | 0.846   | 1.16 (0.86–1.58)        | 0.332   |
| Lwiro, rural, LC-            | 1.24 (0.96–1.59)          | 0.094   | 1.44 (1.05–1.96)        | 0.023   |
| Age (unit= 5 years)          | 1.02 (1.00–1.04)          | 0.044   | 1.06 (1.02–1.09)        | 0.001   |
| Sex                          |                           |         |                         |         |
| Male                         | 1                         |         | 1                       |         |
| Female                       | 0.99 (0.84–1.17)          | 0.901   | 1.06 (0.87–1.27)        | 0.575   |
| Saving membership            |                           |         |                         |         |
| No                           | 1                         |         | 1                       |         |
| Yes                          | 1.03 (0.83–1.28)          | 0.763   | 1.10 (0.88–1.37)        | 0.399   |
| Religious service attendance |                           |         |                         |         |
| $\leq$ Once a week           | 1                         |         | 1                       |         |
| 2-3 times per week           | 1.02 (0.84–1.23)          | 0.869   | 0.93 (0.75-1.14)        | 0.479   |
| ≥4 times per week            | 0.91 (0.72–1.15)          | 0.412   | 0.94 (0.73–1.21)        | 0.630   |
| Morbidity                    |                           |         |                         |         |

## Table S2. Factors associated with decline in mobility

| None                       | 1                                   |       | 1                 |       |
|----------------------------|-------------------------------------|-------|-------------------|-------|
| Diabetes or hypertension   | 1.02 (0.85-1.22)                    | 0.819 | 1.09 (0.78–1.51)  | 0.617 |
| Diabetes and hypertension  | 0.80 (0.48-1.33)                    | 0.382 | 0.95 (0.52-1.76)  | 0.882 |
|                            |                                     |       |                   |       |
| Education (unit= 5 years)  |                                     |       |                   |       |
| 7+                         | 1                                   |       | 1                 |       |
| Between 1-6                | 1.37 (1.11–1.68)                    | 0.004 | 1.20 (0.93-1.54)  | 0.154 |
| None                       | 1.40 (1.15–1.71)                    | 0.001 | 1.23 (0.97–1.56)  | 0.081 |
|                            | · · · · ·                           |       | · · · · ·         |       |
| Socio-economic position    |                                     |       |                   |       |
| Least poor                 | 1                                   |       | 1                 |       |
| Middle poor                | 1.21 (0.97–1.51)                    | 0.089 | 1.09(0.83 - 1.42) | 0.537 |
| Poorest                    | 1.29 (1.03–1.61)                    | 0.025 | 1.05 (0.79–1.40)  | 0.725 |
|                            |                                     |       |                   |       |
| Marital status             |                                     |       |                   |       |
| Never married              | 1                                   |       |                   |       |
| Married                    | 1.31 (0.98–1.74)                    | 0.069 |                   |       |
|                            | 1.24 (0.90–1.72)                    | 0.187 |                   |       |
| Divorced/widowed/separated | · · · · ·                           |       |                   |       |
| *                          |                                     |       |                   |       |
| Occupation                 |                                     |       |                   |       |
| Formal salaried            | 1                                   |       |                   |       |
| Informal                   | - 0.07 (0.60, 1.25)                 | 0.856 |                   |       |
| Earming/patty trading      | 0.97(0.09-1.55)<br>1.20(1.04, 1.96) | 0.030 |                   |       |
| Faming/peuy traung         | 1.39(1.04-1.80)                     | 0.027 |                   |       |
| INUIIC                     | 0.54(0.00-1.30)                     | 0.090 |                   |       |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The final sample size for the final multivariable model was 561.

Table S3. Factors associated with decline in ability in getting along with people

| Variable                | Unadjusted RR    | Р     | Adjusted RR      | P value |
|-------------------------|------------------|-------|------------------|---------|
|                         | (95% CI)         | value | (95% CI)         |         |
| Healthcare need cluster |                  |       |                  |         |
| Low                     | 1                |       | 1                |         |
| Middle                  | 0.78 (0.64-0.94) | 0.011 | 0.58 (0.46-0.74) | < 0.001 |
| High                    | 0.69 (0.53–89)   | 0.005 | 0.51 (0.37–0.69) | < 0.001 |
| Enrolment status        |                  |       |                  |         |
| Neighbours              | 1                |       | 1                |         |
| Caregivers              | 1.05 (0.89–1.24) | 0.564 | 1.07 (0.89–1.29) | 0.847   |
| Patients                | 1.05 (0.89–1.24) | 0.588 | 1.07 (0.81–1.41) | 0.635   |
| Health area             |                  |       |                  |         |

| Nyamuhinga, urban, LC+       | 1                                   |       | 1                                   |         |
|------------------------------|-------------------------------------|-------|-------------------------------------|---------|
| Bideka, rural, LC+           | 0.89 (0.67-1.18)                    | 0.410 | 0.73 (0.44-1.20)                    | 0.210   |
| Burhale, rural, LC-          | 1.08 (0.83–1.39)                    | 0.581 | 1.29 (0.96–1.74)                    | 0.093   |
| Kabushwa rural LC+           | 1 02 (0 80-1 31)                    | 0.865 | 1.06(0.80-1.40)                     | 0 693   |
| Lumu urban I C-              | 1 10 (0.91 - 1.33)                  | 0.310 | 1.00(0.00-1.10)<br>1.16(0.93-1.45)  | 0 177   |
| Luniu, urban, LC-            | 1.10(0.71-1.55)                     | 0.510 | 1.10(0.93-1.43)<br>1.18(0.02, 1.40) | 0.171   |
| Lwito, tutai, LC-            | 0.90 (0.79–1.10)                    | 0.078 | 1.18 (0.93–1.49)                    | 0.171   |
| Age (unit= 5 years)          | 1.02 (1.00–1.04)                    | 0.019 | 1.05 (1.02-1.08)                    | < 0.001 |
| Sex                          |                                     |       |                                     |         |
| Male                         | 1                                   |       | 1                                   |         |
| Female                       | 1.07 (0.93–1.23)                    | 0.377 | 1.11 (0.94–1.31)                    | 0.201   |
| Saving membership            |                                     |       |                                     |         |
| No                           | 1                                   |       | 1                                   |         |
| Yes                          | 0.98 (0.81–1.19)                    | 0.850 | 1.00 (0.82–1.22)                    | 0.999   |
| Religious service attendance |                                     |       |                                     |         |
| < Once a week                | 1                                   |       | 1                                   |         |
| 2-3 times per week           | 1 00 (0.85 1 19)                    | 0.963 | 1 01 (0.84 - 1.20)                  | 0.955   |
| 2-5 times per week           | 1.00(0.85-1.19)<br>1.06(0.80, 1.27) | 0.905 | 1.01(0.04-1.20)<br>1.00(0.92, 1.21) | 0.955   |
| ≥4 times per week            | 1.00 (0.89–1.27)                    | 0.489 | 1.00 (0.83–1.21)                    | 0.989   |
| Morbidity                    |                                     |       |                                     |         |
| None                         | 1                                   |       | 1                                   |         |
| Diabetes or hypertension     | 1.05 (0.90-1.22)                    | 0.528 | 1.01 (0.77-1.33)                    | 0.955   |
| Diabetes and hypertension    | 1.03 (0.74–1.44)                    | 0.845 | 1.05 (0.68–1.62)                    | 0.822   |
| Education (vears)            |                                     |       |                                     |         |
| 7+                           | 1                                   |       | 1                                   |         |
| Between 1-6                  | 1 19(101 - 141)                     | 0.042 | 126(103-155)                        | 0.028   |
| None                         | 1.19(1.01-1.41)<br>1.12(0.05, 1.31) | 0.042 | 1.20(1.03-1.33)<br>1.18(0.04, 1.48) | 0.020   |
| None                         | 1.12 (0.95–1.51)                    | 0.190 | 1.18 (0.94–1.48)                    | 0.144   |
| Socio-economic position      |                                     |       |                                     |         |
| Least poor                   | 1                                   |       | 1                                   |         |
| Middle poor                  | 0.93 (0.79 1.10)                    | 0 381 | 0.94 (0.77 - 1.16)                  | 0 572   |
| Decreat                      | 0.95(0.79-1.10)<br>0.86(0.73-1.02)  | 0.381 | 0.94(0.77-1.10)                     | 0.572   |
| Poolest                      | 0.80 (0.75-1.02)                    | 0.080 | 0.80 (0.04–1.00)                    | 0.033   |
| Marital status               |                                     |       |                                     |         |
| Never married                | 1                                   |       |                                     |         |
| Married                      | 1.14 (0.90-1.45)                    | 0.260 |                                     |         |
|                              | 1.21 (0.93–1.57)                    | 0.149 |                                     |         |
| Divorced/widowed/separated   | (1111)                              |       |                                     |         |
| Occupation                   |                                     |       |                                     |         |
| Formal salaried              | 1                                   |       |                                     |         |
|                              |                                     | 0.252 |                                     |         |
| Informal                     | 0.14 (0.86–1.50)                    | 0.353 |                                     |         |
| Farming/petty trading        | 1.15 (0.89–1.48)                    | 0.285 |                                     |         |

| None |   |  |  | 1.16 | 5 ( | 0.8 | 89–1.51) | 0.2 | 264 |  |  |  | <br> |
|------|---|--|--|------|-----|-----|----------|-----|-----|--|--|--|------|
|      | • |  |  |      |     |     | œ        |     |     |  |  |  |      |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The final sample size for the final multivariable model was 561.

| Variable                     | Unadjusted RR<br>(95% CI) | P<br>value | Adjusted RR<br>(95% CI) | P value |
|------------------------------|---------------------------|------------|-------------------------|---------|
| Healthcare need cluster      |                           |            | \$ <i>č</i>             |         |
| Low                          | 1                         |            | 1                       |         |
| Middle                       | 1.32 (1.06–1.64)          | 0.012      | 0.71 (0.55–0.93)        | 0.014   |
| High                         | 0.80 (0.56–1.15)          | 0.232      | 0.38 (0.24–0.59)        | < 0.001 |
| Enrolment status             |                           |            |                         |         |
| Neighbours                   | 1                         |            | 1                       |         |
| Caregivers                   | 1.05 (0.82–1.34)          | 0.696      | 0.99 (0.75-1.30)        | 0.918   |
| Patients                     | 1.35 (1.07–1.71)          | 0.012      | 1.37 (0.94–1.99)        | 0.105   |
| Health area                  |                           |            |                         |         |
| Nyamuhinga, urban, LC+       | 1                         |            | 1                       |         |
| Bideka, rural, LC+           | 1.91 (1.37-2.67)          | < 0.001    | 3.03 (2.01-4.59)        | < 0.001 |
| Burhale, rural, LC-          | 2.22 (1.65-2.98)          | < 0.001    | 2.40 (1.61-3.67)        | < 0.001 |
| Kabushwa, rural, LC+         | 1.62 (1.16-2.25)          | 0.004      | 1.51 (1.01–2.25)        | 0.042   |
| Lumu, urban, LC-             | 1.11 (0.80–1.54)          | 0.533      | 1.26 (0.87–1.81)        | 0.220   |
| Lwiro, rural, LC-            | 1.37 (1.01–1.86)          | 0.040      | 1.56 (1.07–2.28)        | 0.022   |
| Age (unit=5 years)           | 1.06 (1.04–1.09)          | < 0.001    | 1.07 (1.02–1.12)        | 0.002   |
| Sex                          |                           |            |                         |         |
| Male                         | 1                         |            | 1                       |         |
| Female                       | 1.20 (0.97–1.47)          | 0.091      | 1.23 (0.96–1.57)        | 0.109   |
| Saving membership            |                           |            |                         |         |
| No                           | 1                         |            | 1                       |         |
| Yes                          | 1.01 (0.80–1.28)          | 0.915      | 0.95 (0.73–1.22)        | 0.683   |
| Religious service attendance |                           |            |                         |         |
| $\leq$ Once a week           | 1                         |            | 1                       |         |
| 2-3 times per week           | 0.94 (0.76–1.17)          | 0.579      | 0.84 (0.66-1.06)        | 0.138   |
| $\geq$ 4 times per week      | 0.77 (0.58–1.03)          | 0.080      | 0.76 (0.55–1.03)        | 0.077   |
| Morbidity                    |                           |            |                         |         |
| None                         | 1                         |            | 1                       |         |
| Diabetes or hypertension     | 1.19 (0.97–1.45)          | 0.094      | 0.86 (0.58-1.28)        | 0.456   |
| Diabetes and hypertension    | 1.11 (0.70–1.75)          | 0.662      | 0.90 (0.51-1.58)        | 0.708   |

Table S4. Factors associated with decline in capacity for self-care

| Marital status<br>Never married<br>Married<br>Divorced/widowed/separated | 1<br>1.82 (1.19–2.79)<br>2.17 (1.38–3.41) | 0.006<br>0.001  | 1<br>1.19 (0.71–1.99)<br>1.29 (0.73–2.28) | 0.516<br>0.376 |
|--|---|-----------------|---|----------------|
| SES  |   |                 |   |                |
| Least poor<br>Middle poor<br>Poorest                                     | 1<br>1.16 (0.91–1.49)<br>1.15 (0.90–1.47) | 0.229<br>0.275  | 1<br>1.08 (0.80–1.46)<br>0.82 (0.60–1.14) | 0.597<br>0.236 |
| Education (years)<br>7+  | 1   |                 | 1   |                |
| Between 1-6<br>None  | 1.74 (1.39–2.18)<br>1.32 (1.04–1.69)      | <0.001<br>0.025 | 1.13 (0.85–1.52)<br>1.25 (0.93–1.68)      | 0.387<br>0.143 |
| Occupation   | 1   |                 |   |                |
| Formal salaried  | 1 0.77 (0.54, 1.09)                       | 0.142           |   |                |
| Farming/petty trading  | 1.02 (0.76–1.39)                          | 0.873           |   |                |
| None   | 0.80 (0.57-1.11)                          | 0.184           |   |                |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The final sample size for the final multivariable model was 552.

| Variable                | Unadjusted RR<br>(95% CI) | P<br>value | Adjusted RR<br>(95% CI) | P value |
|-------------------------|---------------------------|------------|-------------------------|---------|
| Healthcare need cluster |                           |            |                         |         |
| Low                     | 1                         |            | 1                       |         |
| Middle                  | 0.70 (0.58-0.86)          | 0.001      | 0.47 (0.37-0.60)        | < 0.001 |
| High                    | 0.38 (0.27–0.52)          | < 0.001    | 0.26 (0.19–0.37)        | < 0.001 |
| Enrolment status        |                           |            |                         |         |
| Neighbours              | 1                         |            | 1                       |         |
| Caregivers              | 1.05 (0.90-1.23)          | 0.543      | 1.03 (0.86–1.23)        | 0.758   |
| Patients                | 0.97 (0.82–1.15)          | 0.708      | 1.23 (0.95–1.60)        | 0.116   |
| Health area             |                           |            |                         |         |
| Nyamuhinga, urban, LC+  | 1                         |            | 1                       |         |
| Bideka, rural, LC+      | 1.35 (1.09–1.68)          | 0.006      | 1.77 (1.29–2.44)        | < 0.001 |
| Burhale, rural, LC-     | 1.17 (0.93–1.47)          | 0.180      | 1.45 (1.13–1.86)        | 0.004   |
| Kabushwa, rural, LC+    | 0.93 (0.73–1.19)          | 0.579      | 0.85 (0.65-1.10)        | 0.218   |

| Table S5 | . Factors | associated | with | decline in | capacities | for | household | tasks |
|----------|-----------|------------|------|------------|------------|-----|-----------|-------|
|          |           |            |      |            |            |     |           |       |

| Lumu, urban, LC-                    | 1.09(0.91 - 1.31)   | 0.343 | 1.10(0.91-1.34)   | 0.329 |
|-------------------------------------|---|-------|-------------------|-------|
| Lwiro rural IC-                     | 0.84 (0.69 - 1.03)  | 0.094 | 0.94(0.75-1.17)   | 0.591 |
| Lwite, futal, LC-                   | 0.04 (0.0)-1.03)  | 0.074 | 0.74 (0.75-1.17)  | 0.571 |
| $\Lambda a_{\alpha}$ (unit 5 years) | 1.01(0.00, 1.02)  | 0 501 | 1.04 (1.01, 1.06) | 0.002 |
| Age (unit- 5 years)                 | 1.01 (0.99–1.02)  | 0.391 | 1.04 (1.01–1.00)  | 0.002 |
| Sex                                 |   |       |                   |       |
| Male                                | 1   |       | 1                 |       |
| Female                              | 1.00 (0.87–1.14)  | 0.953 | 1.04 (0.91–1.20)  | 0.572 |
| Saving membershin                   |   |       |                   |       |
| No                                  | 1   |       | 1                 |       |
| Var                                 | 1 00 (0.94, 1.10)   | 0.000 | 0.00(0.02, 1.10)  | 0.970 |
| Yes                                 | 1.00 (0.84–1.19)  | 0.966 | 0.98 (0.82–1.18)  | 0.860 |
| Religious service attendance        |   |       |                   |       |
| $\leq$ Once a week                  | 1   |       | 1                 |       |
| 2-3 times per week                  | 0.95 (0.82-1.11)  | 0.555 | 0.94 (0.80-1.11)  | 0.469 |
| ≥4 times per week                   | 0.95 (0.79–1.14)  | 0.565 | 0.89 (0.74–1.08)  | 0.250 |
| 1                                   | × /   |       | × /               |       |
| Morbidity                           |   |       |                   |       |
| None                                | 1   |       | 1                 |       |
| Diabetes or hypertension            | 1.00 (0.87-1.16)  | 0.951 | 1.07 (0.83-1.39)  | 0.602 |
| Diabetes and hypertension           | 0.90 (0.66–1.23)  | 0.514 | 1.04 (0.71–1.52)  | 0.836 |
| Marital status                      |   |       |                   |       |
| Name warded                         | 1   |       |                   |       |
| Never married                       | $\begin{bmatrix} 1 \\ 0 & 02 & (0 & 77 & 1 & 12) \end{bmatrix}$ | 0 476 |                   |       |
| Married                             | 0.93(0.77-1.13)   | 0.4/0 |                   |       |
| Diversed/widewed/compreted          | 0.94 (0.75–1.17)  | 0.563 |                   |       |
| Divorced/widowed/separated          |   |       |                   |       |
| SES                                 |   |       |                   |       |
| Least poor                          | 1   |       |                   |       |
| Middle poor                         | 1.03 (0.88–1.21)  | 0.682 |                   |       |
| Poorest                             | 0.92 (0.78–1.09)  | 0.354 |                   |       |
| Education (years)                   |   |       |                   |       |
| 7+                                  | 1   |       |                   |       |
| Between 1-6                         | 1 11 (0 94_1 30)  | 0.220 |                   |       |
| None                                | 1.11(0.94-1.30)<br>1.04(0.80, 1.21)                             | 0.220 |                   |       |
|                                     | 1.04 (0.09–1.21)  | 0.038 |                   |       |
| Occupation                          |   |       |                   |       |
| Formal salaried                     | 1   |       |                   |       |
| Informal                            |   |       |                   |       |
|                                     | 0.15(0.90-1.47)   | 0.254 |                   |       |
| Farming/netty trading               | 0.15 (0.90–1.47)  | 0.254 |                   |       |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The final sample size for the final multivariable model was 611.

| Variable                     | Unadjusted RR<br>(95% CI) | P<br>value | Adjusted RR<br>(95% CI)               | P value |
|------------------------------|---------------------------|------------|---------------------------------------|---------|
| Healthcare need cluster      |                           |            | · · · · · · · · · · · · · · · · · · · |         |
| Low                          | 1                         |            | 1                                     |         |
| Middle                       | 0.74 (0.62-0.89)          | 0.002      | 0.54 (0.43-0.68)                      | < 0.001 |
| High                         | 0.36 (0.25–0.52)          | < 0.001    | 0.28 (0.19–0.41)                      | < 0.001 |
| Enrolment status             |                           |            |                                       |         |
| Neighbours                   | 1                         |            | 1                                     |         |
| Caregivers                   | 1.08 (0.92-1.26)          | 0.352      | 1.09 (0.91-1.30)                      | 0.348   |
| Patients                     | 0.94 (0.80–1.11)          | 0.482      | 1.24 (0.96–1.60)                      | 0.100   |
| Health area                  |                           |            |                                       |         |
| Nyamuhinga, urban, LC+       | 1                         |            | 1                                     |         |
| Bideka, rural, LC+           | 1.31 (1.05–1.63)          | 0.017      | 1.44 (0.97–2.14)                      | 0.069   |
| Burhale, rural, LC-          | 1.31 (1.06–1.61)          | 0.011      | 1.60 (1.27-2.02)                      | < 0.001 |
| Kabushwa, rural, LC+         | 0.96 (0.75-1.24)          | 0.766      | 0.89 (0.68-1.17)                      | 0.413   |
| Lumu, urban, LC-             | 1.12 (0.93–1.34)          | 0.229      | 1.07 (0.88-1.30)                      | 0.518   |
| Lwiro, rural, LC-            | 0.91 (0.74–1.12)          | 0.371      | 1.02 (0.82–1.27)                      | 0.866   |
| Age (unit= 5 years)          | 1.00 (0.99–1.02)          | 0.792      | 1.04 (1.02–1.07)                      | 0.001   |
| Sex                          |                           |            |                                       |         |
| Male                         | 1                         |            | 1                                     |         |
| Female                       | 1.13 (0.99–1.30)          | 0.076      | 1.21 (1.04–1.40)                      | 0.012   |
| Saving membership            |                           |            |                                       |         |
| No                           | 1                         |            | 1                                     |         |
| Yes                          | 1.05 (0.88–1.24)          | 0.601      | 1.02 (0.84–1.23)                      | 0.857   |
| Religious service attendance |                           |            |                                       |         |
| < Once a week                | 1                         |            | 1                                     |         |
| 2-3 times per week           | 0.93 (0.79–1.10)          | 0.395      | 0.88 (0.74–1.04)                      | 0.135   |
| $\geq$ 4 times per week      | 1.08 (0.91–1.28)          | 0.390      | 1.00 (0.83–1.20)                      | 0.984   |
| Morbidity                    |                           |            |                                       |         |
| None                         | 1                         |            | 1                                     |         |
| Diabetes or hypertension     | 0.95 (0.82-1.10)          | 0.460      | 0.94 (0.73–1.21)                      | 0.630   |
| Diabetes and hypertension    | 0.83(0.62 - 1.13)         | 0.230      | 0.92 (0.64–1.33)                      | 0.666   |

 Table S6. Factors associated with decline abilities to conduct work-related tasks

| Marital status<br>Never married<br>Married<br>Divorced/widowed/separated | 1<br>0.96 (0.78–1.19)<br>1.07 (0.85–1.34) | 0.730<br>0.590 |
|--|---|----------------|
| SES  |   |                |
| Least poor<br>Middle poor<br>Poorest                                     | 1<br>1.00 (0.86–1.17)<br>0.91 (0.77–1.07) | 0.995<br>0.233 |
| Education (years)  |   |                |
| 7+<br>Between 1-6  | 1<br>1 06 (0 90–1 25)                     | 0.457          |
| None   | 1.11 (0.95–1.29)                          | 0.193          |
| Occupation   |   |                |
| Formal salaried  | 1   |                |
| Informal   | 1.23 (0.95–1.58)                          | 0.117          |
| Farming/petty trading  | 1.09 (0.85–1.40)                          | 0.492          |
| None   | 0.94 (0.72–1.23)                          | 0.650          |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The final sample size in the multivariable model was 611 participants.

| Variable                | Unadjusted RR<br>(95% CI) | P<br>value | Adjusted RR<br>(95% CI) | P value |
|-------------------------|---------------------------|------------|-------------------------|---------|
| Healthcare need cluster | · · · · ·                 |            |                         |         |
| Low                     | 1                         |            | 1                       |         |
| Middle                  | 0.72 (0.60-0.88)          | 0.001      | 0.50 (0.40-0.62)        | < 0.001 |
| High                    | 0.47 (0.35–0.63)          | < 0.001    | 0.30 (0.21–0.42)        | < 0.001 |
| Enrolment status        |                           |            |                         |         |
| Neighbours              | 1                         |            | 1                       |         |
| Caregivers              | 1.06 (0.90-1.25)          | 0.515      | 1.06 (0.88-1.28)        | 0.510   |
| Patients                | 1.08 (0.92–1.28)          | 0.334      | 1.16 (0.90–1.49)        | 0.251   |
| Health area             |                           |            |                         |         |
| Nyamuhinga, urban, LC+  | 1                         |            | 1                       |         |
| Bideka, rural, LC+      | 1.10 (0.88–1.38)          | 0.407      | 1.56 (1.14-2.13)        | 0.005   |
| Burhale, rural, LC-     | 0.97 (0.77–1.23)          | 0.830      | 1.29 (0.99–1.67)        | 0.058   |
| Kabushwa, rural, LC+    | 0.92 (0.73–1.17)          | 0.503      | 0.92 (0.71–1.17)        | 0.486   |

| Table S7. Factors associated | with decline in | social participation |
|------------------------------|-----------------|----------------------|
|------------------------------|-----------------|----------------------|

| Lumu, urban, LC-             | 0.89 (0.73–1.08) | 0.230 | 0.91 (0.73–1.12) | 0.377 |
|------------------------------|------------------|-------|------------------|-------|
| Lwiro, rural, LC-            | 0.82 (0.68–0.99) | 0.038 | 1.00 (0.81–1.25) | 0.986 |
| Age (unit= 5 years)          | 1.02 (1.00–1.03) | 0.089 | 1.03 (1.01–1.06) | 0.005 |
| Sex                          |                  |       |                  |       |
| Male                         | 1                |       | 1                |       |
| Female                       | 1.06 (0.92–1.21) | 0.407 | 1.09 (0.95–1.26) | 0.221 |
| Saving membership            |                  |       |                  |       |
| No                           | 1                |       | 1                |       |
| Yes                          | 1.02 (0.86–1.22) | 0.797 | 0.99 (0.82–1.19) | 0.913 |
| Religious service attendance |                  |       |                  |       |
| $\leq$ Once a week           | 1                |       | 1                |       |
| 2-3 times per week           | 1.00 (0.85–1.18) | 0.988 | 0.94 (0.80–1.11) | 0.490 |
| $\geq$ 4 times per week      | 1.13 (0.96–1.34) | 0.144 | 1.05 (0.88–1.26) | 0.584 |
| Morbidity                    |                  |       |                  |       |
| None                         | 1                |       | 1                |       |
| Diabetes or hypertension     | 1.14 (0.99–1.31) | 0.069 | 1.22 (0.95–1.56) | 0.112 |
| Diabetes and hypertension    | 1.14 (0.86–1.53) | 0.360 | 1.52 (1.06–2.18) | 0.023 |
| Occupation                   |                  |       |                  |       |
| Formal salaried              | 1                |       |                  |       |
| Informal                     | 1.27 (0.97–1.65) | 0.080 |                  |       |
| Farming/petty trading        | 1.20 (0.94–1.54) | 0.152 |                  |       |
| None                         | 0.99 (0.75–1.30) | 0.944 |                  |       |
| Marital status               |                  |       |                  |       |
| Never married                | 1                |       |                  |       |
| Married                      | 0.91 (0.74–1.11) | 0.383 |                  |       |
| Divorced/widowed/separated   | 1.11 (0.89–1.38) | 0.374 |                  |       |
| CEC                          |                  |       |                  |       |
| olo                          |                  |       |                  |       |
| Least poor                   | 1                |       |                  |       |
| Middle poor                  | 1.06 (0.90–1.24) | 0.504 |                  |       |
| Poorest                      | 1.00 (0.84–1.19) | 0.984 |                  |       |
| Education (years)            |                  |       |                  |       |
| 7+                           | 1                |       |                  |       |
| Between 1-6                  | 1.07 (0.92–1.25) | 0.381 |                  |       |
| None                         | 1.07 (0.91–1.26) | 0.418 |                  |       |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération. The final sample size in the multivariable model was 611 participants.

### Distribution of missing data by the main study outcome

Table S8 shows the distribution of the missing data by change in health capital. It should be noted the high attrition rate in Burhale health area where majority (54.7%) of the study participants enrolled at baseline were missing at one or both follow-up visits.

The lost to follow-up rate was lower in individuals in the high healthcare need cluster compared to those in the middle and low healthcare need clusters (P=0.011). This might have contributed to participants in the high healthcare need level being less likely to see their health capital decline than those in higher healthcare levels. However, the effect of such a selective loss to follow-up is less likely to be the sole explanation for the observation association between healthcare need cluster and decline in health capital given the strength of this association both in crude and adjusted analyses. Participants in the tracer group were less likely to get lost to follow-up compared to neighbours and informal caregivers. Similarly, individuals with diabetes and/or hypertension were less likely to be lost to follow-up compared to those without any of these conditions.

Male participants were significantly more likely to be lost to follow-up compared to women, consistently with the fact that in these rural and semi-urban settings where the informal job market is predominant, men are very mobile in search of job opportunities compared to women who are in majority housewives or farmers. In our previous analysis, women were shown to have poorer health capital (or higher healthcare need) compared to men<sup>9</sup>. As the probability of decline in one's health capital is lower among those with lower health capital level at baseline, a higher attrition rate in men than women might have accounted for part of the apparent lack of effect of sex on the probability of decline in health capital.

| <b>S8</b> . | Characteristics | of | missing | data | bv | change | in | health | capit | al |
|-------------|-----------------|----|---------|------|----|--------|----|--------|-------|----|
|             |                 |    |         |      | •  |        |    |        |       |    |

| Variable                | Followed   | Lost to follow-up | Total      | P value |
|-------------------------|------------|-------------------|------------|---------|
|                         | up         |                   |            |         |
| Healthcare need cluster |            |                   |            | 0.011   |
| Low                     | 562 (63.7) | 320 (36.3)        | 882 (69.7) |         |
| Middle                  | 161 (60.3) | 106 (39.7)        | 267 (21.1) |         |

| High                         | 89 (76.1)  | 28 (23.9)   | 117 (9.2)   |         |
|------------------------------|------------|-------------|-------------|---------|
| Status                       |            |             |             | < 0.001 |
| Neighbours                   | 215 (58.0) | 156 (42.0)  | 371 (33.1)  |         |
| Caregivers                   | 248 (63.6) | 142 (36.4)  | 390 (34.8)  |         |
| Tracer group                 | 262 (73.0) | 97 (27.0)   | 459 (32.0)  |         |
| Health area                  |            |             |             | < 0.001 |
| Nyamuhinga, urban, LC+       | 189 (87.5) | 27 (12.5)   | 216 (17.8)  |         |
| Bideka, rural, LC+           | 83 (52.5)  | 75 (47.5)   | 158 (13.0)  |         |
| Burhale, rural, LC-          | 87 (45.3)  | 105 (54.7)  | 192 (15.8)  |         |
| Kabushwa, rural, LC+         | 100 (53.2) | 88 (46.8)   | 188 (15.5)  |         |
| Lumu, urban, LC-             | 163 (77.9) | 46 (22.1)   | 208 (17.2)  |         |
| Lwiro, rural, LC-            | 181 (72.1) | 70 (27.9)   | 251 (20.7)  |         |
| Age (years)                  | 48 (32–62) | 49 (32–61)  | 48 (32–62)  | 0.950   |
| Sex                          |            |             |             | 0.007   |
| Male                         | 274 (56.7) | 185 (40.3)  | 459 (36.8)  |         |
| Female                       | 530 (67.3) | 258 (32.7)  | 788 (63.2)  |         |
| Saving membership            |            |             |             | 0.141   |
| No                           | 657 (65.2) | 351 (34.8)  | 1008 (80.4) |         |
| Yes                          | 148 (60.2) | 98 (39.8)   | 246 (19.6)  |         |
| Religious service attendance |            |             |             | 0.170   |
| $\leq$ Once a week           | 419 (66.2) | 214 (33.8)  | 633 (52.7)  |         |
| 2-3 times per week           | 218 (60.6) | 142 (39.4)  | 360 (30.0)  |         |
| $\geq$ 4 times per week      | 138 (66.4) | 70 (33.6)   | 208 (17.3)  |         |
| Morbidity                    |            |             |             | < 0.001 |
| None                         | 439 (60.5) | 287 (39.5)  | 726 (65.5)  |         |
| Diabetes or hypertension     | 252 (73.9) | 89 (26.1)   | 341 30.8)   |         |
| Diabetes and hypertension    | 34 (82.9)  | 7 (18.1)    | 41 (3.7)    |         |
| Occupation                   |            |             |             | < 0.001 |
| Formal salaried              | 86 (72.3)  | 33 (27.7)   | 119 (10.2)  |         |
| Informal                     | 169 (67.1) | 83 (32.9)   | 252 (21.6)  |         |
| Farming/petty trading        | 303 (55.3) | 245 (44.7)  | 548 (46.9)  |         |
| None                         | 188 (75.2) | 62 (24.8)   | 250 (21.4)  |         |
| Marital status               |            |             |             | 0.170   |
| Never married                | 80 (66.1)  | 41 (33.9)   | 121 (9.8)   |         |
| Married                      | 555 (62.8) | 329 (37.2)  | 884 (71.4)  |         |
|                              | 162 (69.2) | 72 (30.8)   | 234 (18.9)  |         |
|                              | . /        | · · · · · · |             |         |

| SES               |            |            |            | < 0.001 |
|-------------------|------------|------------|------------|---------|
| Least poor        | 211 (79.0) | 56 (21.0)  | 267 (21.1) |         |
| Middle poor       | 317 (63.3) | 184 (36.7) | 501 (39.6) |         |
| Poorest           | 284 (57.3) | 212 (42.7) | 496 (39.2) |         |
| Education (years) |            |            |            | 0.643   |
| 7+                | 294 (93.3) | 21 (6.7)   | 253 (31.6) |         |
| Between 1-6       | 213 (91.4) | 20 (8.6)   | 233 (29.1) |         |
| None              | 236 (92.3) | 17 (6.7)   | 253 (31.6) |         |

LC+: refers to health areas receiving financial and organizational support from Louvain coopération.

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**Chapter 5. GENERAL DISCUSSION** 

## 5.1. Summary of the results

In this thesis, we conducted a series of population-based observational studies in semi-urban and conflict-recovering rural settings of South Kivu province in eastern DRC. We explored a new way of measuring and monitoring individual and community health from a person-centred standpoint. The purpose of this thesis was to examine how health practitioners at the primary care level, policy makers and health programs implementing organisations can embrace the challenge of regarding health beyond the necessary but insufficient disease or mortality perspective. Our discussion is framed around three studies conducted among 1) individuals in the study tracer groups (those with self-reported diabetes or hypertension and mothers whose children had acute malnutrition); 2) informal caregivers of people with chronic conditions (diabetes and/or hypertension) and helpers of mothers of children with acute malnutrition; and (3) randomly selected neighbours of people in the tracer group.

In the baseline study, we began by exploring a new approach to stratifying population health with person-centred measures. We used the WHODAS 2.0, a WHO questionnaire measuring individual performance in six overarching life domains, without focus on any singular disease. The WHODAS domains comprise cognition (understanding and communication ability), mobility, self-care, setting along with people, life activities, work or school activities and social participation (impact of one's health problems on themselves and their family). The WHODAS domains scores were combined in a principal component analysis followed by a cluster analysis leading to three hierarchical levels denoting a health capital level or healthcare needs gradient. We found that 9.2% of the study population fell in the cluster of high healthcare needs (high disability level or low health capital), of which 23.5% were not in the tracer group (i.e. diseased). On the other extreme, 69.7% of the study population had minor healthcare needs (minor dependency or high health capital), among which 18.7% from the tracer group. The factors significantly determining belonging to higher healthcare needs clusters where social vulnerability indicators such as aging, being female, chronic morbidities, and living in rural areas.

In the second study, we set to examine whether the health clusters (defined in study 1) were associated with modern health facility utilization. We drew a sub-sample of study participants who reported having fallen sick in the 30 days prior to the baseline survey and asked them where they sought healthcare in first resource when needed in the past month. The majority of the study participants (82%) utilized modern

health facilities (health post, health centers or hospitals, as opposed to traditional healers, prayer homes or self-medication) in the first resort. Informal caregivers and participants in the tracer group were less likely to utilize modern health facilities compared to neighbors. Participants with moderate and higher level of health needs and disability were also more likely to utilize modern health facilities compared to those with lower health needs and disability level; they tended to seek care at hospital level rather than at primary healthcare facilities, possibly expecting a more effective management of their condition.

We subsequently embarked on studying the health dynamic of the study participants and examine how the person-centered approach to classifying health can help monitor population health over time. The study participants were followed-up as per two 9-months visits. Follow-up data were concentrated on the WHODAS score and health facility utilization. we showed that the WHODAS can be effectively used to measure and monitor health at individual and community level in an innovative and person-centered manner. The overall risk of decline in health capital was 45.7%. Participants in the high healthcare need cluster had a lower absolute risk (15.4) of decline in health capital than those in the middle (33.3%) and low healthcare care need clusters (53.8%). We found that the decline in an individual's overall health capital was not significantly associated with the enrolment label (tracer group variable), but was strongly linked to the baseline health capital. In fact, participants in the middle (adjusted RR: 0.46; 95% CI: 0.37-0.57, p<<0.001) and high (adjusted RR:0.21; 95% CI: 0.14–0.31; p<0.001) healthcare need clusters at baseline were less likely to see their health capital decline compared to those in the healthcare need cluster. We also found that each five-years increase in a participant's age was expected to increase the risk of decline in health capital by 4% (RR: 1.04, 95% CI: 1.02-1.06, p<0.001). The direction of the association between decline in health capital and rural location was unclear.

## 5.2. Study strengths and limitations

In each of the study papers, we thoroughly discussed key methodological limitations and strengths of this thesis. In the next sections, we briefly synthesize salient methodological reflections that cross-cut all the three studies.

In this thesis, the 36-items WHODAS has been used in an innovative way to (re)centre health measuring to the person rather than the disease at population level in post-conflict settings. This thesis provides a unique insight into how a population

health can be followed-up with person-centred lenses even in settings where resources are scare. The sample size was large and the overall attrition rate was relatively small.

We conducted this thesis study in six health areas spreading four of the 34 health zones of the South Kivu province. Because of logistic and security reasons, the selection of the study sites was based on a priori criteria: geo-security accessibility, a minimum functioning level of the health centre of the area and partnership with the Louvain cooperation NGO. There are over 643 health areas (each centred around a health centre) with varying geography, security level, infrastructures, human resources, financing and functional levels in South Kivu. Our study findings may therefore not be generalizable to the entire South-Kivu province, nor the whole (eastern) DRC. Future studies will be necessary to investigate the extent to which our reasoning may apply to contexts plagued by dire socio-political and humanitarian crisis, in DRC and other low-income countries. In some South Kivu health zones such as Mulungu or Fizi, the health system is challenged by frequent armed clashes, massive population displacement or presence of refugees, attacks of health facilities, etc. Other eastern DRC provinces are facing chronic inter-ethnic conflicts over land and ethnic identify<sup>1</sup>. Health systems funding and functioning in such contexts rely quasi-exclusively on a few humanitarian donors such as Médecins Sans Frontières<sup>2</sup> and other humanitarian actors<sup>3</sup>. Implementing a person-centred approach in such settings may be more challenging than in settings relatively more stable. This is an unchartered health system research field open to future investigations.

It is worth stressing that the studies forming this thesis were not primarily meant for the establishment of certain "disease" prevalence, but rather aimed to explore the feasibility and usefulness of a new approach to measuring health. Our sample size estimation was not mathematically computed based on a specific disease outcome, but estimated based on resources available. The good precision (narrow confidence intervals) around point estimates of different outcomes in all the three studies boosted our confidence that the sample size was large enough.

We limited the selection of the study participants to individuals with self-reported diabetes, hypertension, and mothers who had a child acutely malnutrition at the time of the baseline survey (our trace group). Our initial aim was to include in the study individuals with long-term health problems with the potential to span the physical, mental and social life spheres. The likelihood of such complex medico-psychosocial problems was deemed high in individuals with chronic conditions. However, given

the wide range of chronic health conditions and the challenges associated with identifying them at community level in low-income settings, we confined the primary targeted study population to individuals with self-reported diabetes and hypertension, and mothers of children suffering from acute malnutrition. Our study population is therefore not representative of all the array of chronic conditions observable at population level. But, to minimize this selection bias, we extended the enrolment of the study population to informal caregivers and randomly selected neighbours without a self-reported history of diabetes, hypertension or malnutrition in the offspring. Additionally, the fact that mothers of infant with acute malnutrition were explicitly selected might have contributed to the overrepresentation of women in our study.

There was a likelihood of observer/interviewer bias in these studies because the WHODAS questionnaire used to measure health was interviewer-administered. In fact, interviewers were all nurses and the fact that they knew the enrolment status of the respondent prior to the administration of the WHODAS questionnaire might have influenced the scoring on different WHODAS domains. The low level of literacy in these settings precluded the use of self-administered or proxy-administered versions of the WHODAS to minimize such a bias.

The WHODAS is an objective measure of a person's performance in the six comprehensive life domains; it is not designed to measure the subjective quality of life in terms of how an individual feels satisfied about their performance in a given life domain<sup>4</sup>. The WHO Quality of Life (WHOQOL) tool has been developed for that purpose and is a very useful complement to the WHODAS. However, given the time constraints and length of the data collection tools we already had, we decided not to add the WHOQOL to our study. The low literacy level in our study settings would have required us to use the interviewer-administered version of the WHOQOL which necessitates up to 40-90 minutes for each respondent<sup>5</sup>.

Lastly, our study tools were only translated to Kiswahili, the national language largely spoken in eastern DRC. A few people in rural health areas may not be fully fluent in Kiswahili. This might have impacted both the face and content validity of the questionnaires<sup>6</sup>. To minimize the likelihood of such a distortion, we locally recruited data collectors who were nurses, fluent in French, Kiswahili and local dialects spoken by the study participants.

## 5.3. Policy, programmatic and research implications

We discussed the public health implications of our findings in each of the papers making up this thesis. The following paragraphs highlight the overarching themes and aspects that are not sufficiently discussed in the separate articles to avoid redundancy.

#### 5.3.1. What did go wrong with the DRC health system?

The DRC has had a historically good primary healthcare system dating back to the colonial period and centered around health district<sup>7</sup>. The focus of the DRC primary health system, akin to many other sub-Saharan countries, has long been placed on prevention of communicable diseases, particularly among children; pregnancy monitoring and health promotion activities. The health system landscape in DRC has however been significantly impacted by the steady collapse of the public leadership and shrinking of the funding of public services in the late 1980s. The socio-political decay culminated in decades-long armed conflicts that followed the humanitarian crisis associated with thousands of Rwandan refugees crossing the borders to escape the genocide in 1994<sup>8</sup>. As a consequence, the DRC health system had also to selfadapt in order to survive. Primary healthcare services became prominently focused on lucrative at the expense of health promotion activities. Health services planning, prioritization and provision became more and more disease- or indicators-centered. Vertical funding schemes imposed or proposed by some humanitarian donors also contributed to this shift of the health system goal from promoting and improving health to providing plain health services. In DRC and other low-income countries, the health system financing became prominently shaped by selective diseases or population groups programs that have undoubtedly played a critical role in the mobilizing of resources and tackling specific health problems, but have often fallen short of fostering a comprehensive or holistic approach to healthcare service organization and provision<sup>9</sup>.

# 5.3.2. How could a person-centered approach help fix at least part of the problem?

The idea of funding health zones or health areas in terms of how many people have a certain health condition (diabetes, HIV, hypertension, etc.) and the "commercialization" of individual and community health may fail to account for the real healthcare needs of the population at health zone or health area level. We found in this thesis that not all the people with the same underlying conditions have the same healthcare needs. The existence of a hierarchical healthcare need gradient at population level in South Kivu implies that health programs designers and implementing actors should also integrate a person-centered perspective into their programmatic thinking. They should acknowledge the need to consider viewing health not only in terms of the number of people diseased or dead because of a certain health condition, but also and above all in terms of how many people, with or without any underlying health conditions, are able to cope with cognitive, mobility, self-care, social participation, household, schooling or professional challenges imposed by their specific social contexts, work or living environments in a given health zone or health area. Such a thinking can be useful when designing baseline or end-line health programs surveys, as well as during monitoring and evaluation processes of health projects in resource-constrained and post-conflict settings. The gaol of each health system is to ensure people enjoy better and quality lives and not only to provide plain health services.

Another implication of our results is that policy and decision makers need make sure that not only do people have access to health services, but also ensure that health facilities, including hospitals, are utilised by those most in need regardless of specific disease labels. We found a tendency towards preference for more hospital utilisation than primary healthcare facilities by individuals who have formal work (and with stable source of revenue) compared with those with informal work. The informal sector dominates the employment market in DRC and those with formal salaries are likely to be more educated. Their health seeking behaviour seems to have been, at least partly, influenced by the increasing "marketing" of healthcare services because of the multiplication of private health facilities in DRC in the recent past on the one hand, and insufficient investments in primary healthcare programs, on the other. This situation can potentially lead to the creation of inverse healthcare law-like patterns whereby health services end up being disproportionately utilized by those in richest socio-economic classes who might not need them the most.<sup>10-12</sup> The DRC indeed saw an increasing number of doctors coming out of the new breed of medical schools uncontrollably created over the past decades<sup>13</sup>. The number of medical schools in DRC has risen from three public faculties of medicine in the 1980s to more than 57 in 2020. At the same time, the number of private and lucrative health facilities has also increased as a consequence of the crumbling of public regulatory powers and somehow in response to an increasing number of healthcare workers not absorbed by decaying public health institutions<sup>14</sup>. Against this background, many health facilities have limited their focus on developing selective health service packages that are most likely to generate revenues, leading eventually to unnecessary surgical interventions, increased drug prescriptions, longer hospital stay, etc. for the financial survival of the health facility. The potential consequences of this unfortunate development are the over-medicalization healthcare service provision, increased focus on the diseases rather than the person, development of health services that are skewed towards the richest who are able to pay for costly specialized services, and ultimately a stray away from a person-centered health system.

The health status typology and monitoring approach proposed in this thesis can also be useful in reorienting routine healthcare programming a health facility level. Studies are being conducted, parallel to this thesis and within the same broader research for development project, to examine a theory of change in how the health centre functioning can be reconfigured and re-centred to the person<sup>15</sup>. A personcentred measuring and classification of health status of the population utilising a primary health facility can help the local team redistribute the limited resources not only in terms of specific disease-labels, but in terms healthcare needs objectively assessed with person-centred tools. For instance, not all patients with chronic conditions need follow-up home visits, because, as shown in our studies, there were participants in the tracer group with better health capital (lower disability level) or whose health status deteriorates much more slowly than neighbours or informal caregivers without self-reported diabetes or hypertension. Also, for patients with high healthcare need (or higher disability level), time could be spared for deep multidisciplinary case discussion in lieu of routine morning discussions held as formality in many health facilities.

Among the vulnerability factors associated with higher healthcare needs (corresponding to a poorer health capital) were aging and gender (being female). When it comes to aging, low income countries considerably lag behind<sup>16</sup>, contrary to high-income countries where health programs are even claimed to be ageist<sup>17</sup>. The seeming neglect of aging in the public health debate in many low-income settings is partly due to the population age structure dominated by younger people and the high neonatal and infant mortality that have deservedly drawn much of all the attention in these settings. In this thesis, aging was unsurprisingly found to be a significant negative influencer of the health capital among the study populations. In DRC, an estimated 2,704,000 (3%) of the population is believed to be aged >65 years in 2020<sup>18</sup>; this number is expected to more than double by 2050, according to UN population

projections<sup>19</sup>. Older people in low-income countries turn out to be among those left far behind and often overlooked in public health debates.

In South Kivu, the Louvain cooperation NGO has been supporting three health areas in implementing a comprehensive person-centered approach of healthcare service provision with a clear focus on frailty associated with aging. In addition to provision of medico-psychosocial healthcare as described in previous sections of this thesis, a socio-economic support program was initiated to encourage the frail elderly to enlist into local saving and social support networks. The aim of creating such networks was to enhance the social capital of their members, increase access to healthcare services and create social bounds that allow community members to look after each other and stay connected with the health center that coordinates all these initiatives with the help of committees of community health workers. The efficacy, costeffectiveness and scalability of such interventions are yet to be investigated. The PRD framework under which this thesis was carried out is partly premised on the idea that if such an intervention can work and be scalable both to all the community members in need of medico psychosocial services beyond the elderly and to other health areas with different geographic, heath systems and security characteristics, then a person-centered primary healthcare system in DRC and other low-income countries is more than an empty rhetoric. It cannot be overstated that building health systems for the future in low-income countries will require addressing the challenges of today characterized by an unacceptably high maternal and child health burden and infectious diseases, but also investing in person-centered health systems bold enough to both explicitly acknowledge aging as a key driver of personal and community health, and integrate an ageist perspective into health programs design and planning<sup>20</sup>. Otherwise, the universal health coverage goal advocating quality and affordable health for all will remain irrelevant to a significant proportion of the population today and more in the near future.

In this thesis, we found that women's health was consistently and significantly worse than men's<sup>21</sup>, despite the same level of health facility utilization<sup>22</sup>, after accounting for all the other individual and social determinants of health studied. This finding was consistent with the general gender landscape of the DRC and although unsurprising, it was appalling. According to a 2018 UNDP report, the DRC was ranked 156<sup>th</sup> among 162 countries on the gender inequality index reflecting gender-based inequalities in reproductive health, empowerment, and economic activity<sup>23</sup>. The country was also ranked in the fifth and lowest group of countries based on the gender development index which combines three fundamental aspects of human

development, namely health (approximated by female and male life expectancy at birth), education attainment and economic empowerment (measured by female and male estimated gross national income per capita), empathized the same report. In DRC, a particular focus has been put on the destructive effects gender-based violence in the media, and in the public health and political debates because of armed conflicts. Though a lot of funds have been injected into projects targeting victims of gender-based violence, particularly in eastern provinces, the results have been mitigated because many of these projects have either fallen short of a deep analysis of the multidimensional nature of the problem or yielded to the temptation of "commercializing" the gender bias problem<sup>24</sup>. Quite recently, an ambitious and multidimensional model of care has started being implemented in South Kivu for victims of sexual violence against men and women. This approach (termed "onestop care model") comprises four complementary and interwoven packages encompassing the medical care, psychosocial management, socio-economic empowerment and integration, and legal assistance. This model of holistic care, similar in many aspects to what is suggested in our PRD, is shaped by each women's personal experience and aims at restoring a person's whole life and dignify for individual and societal benefits<sup>25</sup>. It is worth noting however that gender inequalities impact health and its natural course even beyond the notion of sexual violence, as shown in our studies and elsewhere in the Kivu<sup>26</sup>, particularly in rural settings. The sustainability and scalability of such useful and complex approach to the management of gender-driven inequalities at peripheral level of the health system and beyond sexual violence is likely to be cost-intensive.

The potential public health and development benefits associated with investing in women's health in low-income countries make it compelling to consider developing impact evaluation and cost-effectiveness analysis of gender-sensitive personcentered approaches to providing healthcare. Despite existing gaps in public health literature on how more gender-oriented healthcare programs can be developed and harnessed to tackle gender inequalities worldwide, it is asserted that delivering person-centered care for women may serve as an crucial means of reducing gendered disparities<sup>27</sup>. We previously mentioned that a theory of change aiming at implementing a more general person-centered custom in the way healthcare services are being organized at primary healthcare level is being implemented in three pilot health areas in South Kivu, using existing human and organizational potentials at the health center<sup>15</sup>. The success of the proposed theory of change of our PRD is likely contingent on how healthcare providers are sensitized to and equipped to integrate in the prioritization and planning process local struggles faced by women and driving the gender-based imbalance observed in our studies. Efforts to build gender-sensitive person-centered health systems in DRC require boldly addressing structural social and cultural determinants of gender inequalities and inequities. Healthcare provision strategies in low-income countries will never succeed to be person-centered without a bold recognition of the gender-driven social imbalance in (human) health capital<sup>24,28</sup>. This visionary project, if proved successful, will require audacious political will beyond the remit of the Ministry of Health, and involvement of multilateral partners of the DRC government to meaningfully impact people's lives at provincial and national level.

# 5.3.3. A way forward: research perspectives

## 5.3.3.1. Agent-based modelling

A health centre with its catchment population, health infrastructures and system organisation, and internal and external actors, can be viewed as a complex adaptive system. We cannot fully comprehend the change dynamic of the population health without a clear understanding of the complex interactions between community members and the other agents of the system<sup>29,30</sup>. The 'classical' methodological study designs used in this thesis may not be totally sufficient to help understand all the drivers of change in health status of an agent within a complex adaptive system. Over the recent decades, system thinking approaches such as the agent-based modelling (ABM) has been developed and applied to the understanding of complex public health problems<sup>31</sup>. In our case, an ABM would probably have helped answer the question of what is the influence of different interactions at community level on the medico-psychosocial situation of an individual. One could have used agent-based models to test a set of theories and mechanisms that may explain the dynamic or statics of change in the way medico-psychosocial situations are or need to be handled at primary health care level in South Kivu and other low-income settings affected by or recovering from conflict. The goal would be to test a bunch of possible scenarios taking into account a number of health facility attributes, agents and rules. In this exercise, community could be defined as a group agents with different types of medico-psychosocial conditions and in a certain geographical area, and agents could be community members, individuals with medico-psychosocial conditions and the health centre. Each scenario would be tested in terms of "what would happen if?". Such an ABM exercise can draw on the theory of change developed by Molima et  $al.^{15}$ 

Another aspect that would require further research is the study of how the strategy for classifying and evaluating the dynamic of individual and population health, and the health facility utilisation patterns reported in these relatively small-scale studies can inform agent-based models and theory of change building processes aiming at identifying drivers of change in the implementation of a person-centre approach at country or province-level.

#### 5.3.3.2. Qualitative, system thinking and validation studies

Any research intending to understand the drivers of change in the way health is understood, both on the supply (health system) and demand (population) sides, is somehow incomplete if it does not address the perception, acceptability and attitude of health system actors towards such a (r)evolutionary way of viewing health. The role of qualitative research cannot be overemphasized search to understand the barriers and facilitators of change in the implementation process of person-centred thinking at primary healthcare level in low-income settings. Findings from a recent qualitative study from the Netherland suggested that viewing health with a personcentred mind-set may be conducive to the creation of a health-promoting societal context; but this new way of looking at individual health may lead to widening of health inequalities, especially for people who are not able to "self-manage" or adapt to their environment<sup>32</sup>. Qualitative research can also help identify cultural and organizational factors that can facilitate or undermine the effort to embed the personcentre thinking into existing (public) health systems in sub-Saharan Africa, similarly to what is being suggested by studies from high income settings<sup>33</sup>. As part of the research project for development under which this thesis was conducted, qualitative studies are being conducted among healthcare workers from primary health facilities to understand their perception of the person-centred approach, and barriers and facilitators of adopting such a philosophy in routine primary health service programming and provision<sup>15</sup>. Future studies should focus on assessing how both qualitative and system thinking methods can complement traditional quantitative epidemiological study designs in enhancing the understanding of drivers of change in the implementation of person-centred approaches to measuring (population) health a primary health care levels, particularly in settings where resources are scarce.

In these exploratory studies, we devised new approach to measuring health a primary healthcare level using a somewhat convenience sample. Our approach will surely need to be validated on a larger scale and on more random and representative sample. Further studies are also needed to define and test health capital cut-offs from WHODAS scores to facilitate the use of such an approach by healthcare providers and public health professionals for programming and priority setting. For instance, median WHODAS scores for each cluster from the baseline study<sup>21</sup> (5.2, 31.7 and 61.2) may be tested as cut-offs for the creation of health capital classes that can be easily used by health professionals for decision-making.

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Chapter 6. CONCLUSIONS
# **CONCLUSION**

Many LMIC are experiencing the triple burden infectious diseases, noncommunicable diseases with the epidemiological transition and the impact of sociopolitical instability on the structure, governance and functioning of the health system. Against this backdrop, we must confront the fact that for decades we have been using a far too narrow approach to measuring and conceptualizing individual and population health in the medical and public health practice as well as in research. In sub-Saharan Africa, health has been looked at quasi-exclusively from the perspective of disease-driven indicators since the colonial era when countries were heavily burdened by malaria, trypanosomiases and vaccine-preventable diseases. The disease-centered conception of health systems has led to tremendous progress in prevention of maternal and child health morbidity and mortality. However, with the universal health coverage vision of the SDG agenda, the goal of health systems encompasses and transcends the short-sighted objectives of the past, limited to avoiding deaths and diseases.

What we have learned from this thesis is that the framing of future health systems geared towards proving quality health for all and everywhere rather than pursuing

the narrow objective of curing diseases will require ministries of health, health agencies and frontline healthcare workers at the primary level of health systems to change their mindset. Indeed, the traditional disease-based metrics and prioritization strategies will fail short of delivering quality health for all, unless a person-centered view of health is widely embraced to account for each person's contextual challenges and experiences in decision making and priority settings at primary healthcare level.

Although the enrolment status of the study participants was significantly associated with the baseline health status clustering observed in our cohort, not everyone in the tracer group experienced a low health capital (or a high level of healthcare need). Likewise, some participants in the group of non-diseased (informal caregivers and neighbors) were found in the cluster of high healthcare need. Interestingly, the enrolment status showed little effect on the evolution of a participant's health capital. Our findings indicate that a broader vision in healthcare services organization insisting on what matters the most to each person in their unique context than to the health services supply side, is possible and needed at the primary level of the health system in DRC.

A person-centered view of health should no longer remain an agenda only for richer nations, since our studies provide a substantive evidence that health can be measured and monitored with such lenses even in a sub-Saharan post-conflict setting. A new look at population health beyond the sole biomedical dimension should guide efforts to rebuild health systems in post-conflict settings in a manner that is sensitive to each person's age, gender, medical history, contextual challenges and health care needs. The most important consequence of viewing health from a person-centered perspective underscore its multidimensional nature. The complex vulnerability of older people, women, people with chronic morbidities and those living in rural areas lays bare the truth now increasingly acknowledged in high-income countries, that no matter how effective a treatment, the pursuit of a purely biomedical solution to people's health needs will fail to reach the promise of good quality health (and life) for all in a way that is cost-effective and sustainable. Further study will be necessary to assess the health system and societal dividends of broadening our vision of health and promoting a person-centered thinking in medical and public health practice in LMCs.



# ADDENDUM

# ADDENDUM

In this section, we address some of the comments made by readers on an earlier version of this thesis. Other changes have been directly incorporated into previous sections of this thesis.

Study I: A new look at population health through the lenses of cognitive, functional and social disability clustering in eastern DR Congo: a communitybased cross-sectional study

# 1. Erratum

In the data analysis section of the published version of Study I, it is written that "...we did the inter-cluster comparison using a mixed-effects ordinal (proportional odds) logit regression model with cluster as a fixed effect and health area as a random effect." This sentence has been corrected in this thesis to: "...we did the inter-cluster comparison using a mixed-effects ordinal (proportional odds) logit regression model with health area as a random effect."

# 2. Additional analytical considerations

# Methods

Informal caregivers and patients were selected form the same households and have identical socio-economic characteristics. Our models did not account for the potential clustering effect that might be observed at household level. Such a cluster structure may result in the inflation of the statistical significance of the coefficients by underestimation of the true standard errors if the autocorrelation between household variables is strong.

In Study 1, autocorrelation between explanatory variables was suspected if the variance inflation factor (VIF) was greater than or equal to 4. In addition to the VIF, we examined the correlation between explanatory variables using **correlate** routine in Stata that helped generate a correlation matrix. Considering a correlation coefficient  $\geq$ 4 as suspect of autocorrelation, we found that the variables socioeconomic position and listening to the radio were strongly auto-correlated (Table 1).

|    | Variables                          | 1     | 2     | 3     | 4     | 5     | 6     | 7     | 8     | 9     | 10    | 11    | 12   |
|----|------------------------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|------|
| 1  | Status of the participant          | 1     |       |       |       |       |       |       |       |       |       |       |      |
| 2  | Age                                | 0.34  | 1.00  |       |       |       |       |       |       |       |       |       |      |
| 3  | Health zone                        | -0.02 | 0.05  | 1.00  |       |       |       |       |       |       |       |       |      |
| 4  | Sex                                | 0.09  | -0.12 | -0.11 | 1.00  |       |       |       |       |       |       |       |      |
| 5  | Living in conjugal union           | -0.06 | 0.10  | 0.09  | -0.14 | 1.00  |       |       |       |       |       |       |      |
| 6  | Education (head of household)      | -0.04 | -0.16 | -0.29 | -0.02 | 0.07  | 1.00  |       |       |       |       |       |      |
| 7  | Household size                     | 0.07  | -0.06 | -0.12 | 0.02  | 0.08  | 0.14  | 1.00  |       |       |       |       |      |
| 8  | Socio-economic position            | -0.03 | -0.08 | 0.33  | 0.02  | 0.01  | -0.41 | -0.15 | 1.00  |       |       |       |      |
| 9  | Acute illness during prior 30 days | 0.38  | 0.22  | -0.05 | 0.06  | 0.05  | -0.11 | 0.02  | 0.00  | 1.00  |       |       |      |
| 10 | Child severe acute malnutrition    | 0.19  | -0.16 | -0.05 | 0.10  | 0.04  | -0.04 | 0.07  | 0.16  | 0.00  | 1.00  |       |      |
| 11 | Listening to radio                 | -0.05 | 0.08  | 0.02  | -0.13 | 0.08  | 0.22  | 0.10  | -0.55 | -0.01 | -0.14 | 1.00  |      |
| 12 | Occupation                         | -0.01 | 0.09  | -0.05 | -0.01 | -0.13 | -0.39 | -0.09 | 0.25  | -0.01 | 0.00  | -0.24 | 1.00 |

# Table 1. Correlation between explanatory variables used in Study 1

We conducted sensitivity analyses that treated auto-correlated variables in separate regression models. It is worth clarifying that in our model building process, we did not rely on proportional odds assumptions tests as they can be misleading by prompting the rejection of a true null hypothesis when in fact the parallel slopes assumption holds<sup>1</sup>.

We initially set to select variables in multivariable models using a backward elimination strategy, guided by Wald's tests and the principle of parsimony. We ended up maintaining all the variables analyzed in simple regression models, based on a p value  $\leq 0.2$  and/or on public health plausibility.

# Results

Results of the sensitivity analysis accounting for the auto-correlation between socioeconomic position and listening to radio (a proxy of access to information) are presented below. By removing "listening to radio" in the model, the odds of being in a higher healthcare need cluster among the poorest compared to the least poor slightly decreased from 2.6 (95 % CI: 1.22–5.56, p=0.014) to 1.90 (95% CI: 1.01– 3.91, p=0.046), without change in the significance of the association (Table 2).

| Table 2. Regression analysis of the determinants of health clustering with    |  |
|---|--|
| regard to social and functional disability, without the variable listening to |  |
| radio   |  |

| Variable                  | COR (95% CI)      | P value | AOR (95% CI)      | P value |
|---------------------------|-------------------|---------|-------------------|---------|
| Status of the participant |                   |         |                   |         |
| Neighbors                 | 1 (reference)     |         | 1(reference)      |         |
| Caregivers                | 0.68 (0.58-1.31)  | 0.497   | 0.62 (0.36-1.07)  | 0.087   |
| Patients                  | 9.56 (6.62–12.86) | < 0.001 | 3.34 (1.87–5.97)  | < 0.001 |
| Health zone               |                   |         |                   |         |
| Bagira                    | 1 (reference)     |         | 1(reference)      |         |
| Miti-Murhesa and Katana   | 1.20 (0.579–2.50) | 0.114   | 1.94 (0.84–4.49)  | 0.119   |
| Walungu                   | 2.79 (1.35-5.76)  | < 0.006 | 4.98 (2.21–11.21) | < 0.001 |
| Sex                       |                   |         |                   |         |
| Male                      | 1 (reference)     |         | 1 (reference)     |         |
| Female                    | 1.91 (1.33–2.30)  | < 0.001 | 1.85 (1.21–2.81)  | 0.004   |
| Age                       | 1.07 (1.06–1.08)  | < 0.001 | 1.05 (1.04–1.07)  | < 0.001 |
| Household size            | 0.94 (0.9–0.98)   | 0.005   | 1.02 (0.95–1.08)  | 0.655   |

| Living in conjugal union<br>Yes<br>No  | 1 (reference)<br>0.63 (0.48–0.84)  | 0.001                                     | 1 (reference)<br>1.36 (0.79–2.32)  | 0.264                                     |
|--|--|---|--|---|
| Education of head of household   | 0.91 (0.88–0.94)   | < 0.001                                   | 0.97 (0.92–1.02)   | 0.186                                     |
| Occupation head<br>Employed<br>Informal work<br>Petty trading/farming<br>No occupation<br>SES<br>Least poor<br>Middle<br>Poorest | 1 (reference)<br>0.48 (0.27–0.84)<br>1.01 (0.63–1.61)<br>1.91 (1.12–3.28)<br>1 (reference)<br>0.87 (0.60–1.26)<br>1.28 (0.88–1.86) | 0.010<br>0.974<br>0.018<br>0.455<br>0.200 | 1 (reference)<br>0.34 (0.16–0.73)<br>0.41 (0.21–0.80)<br>0.94 (0.42–2.11)<br>1 (reference)<br>1.61 (0.89–2.89)<br>1.99 (1.01–3.91) | 0.006<br>0.009<br>0.877<br>0.114<br>0.046 |
| Listening to radio   |  |   |  |   |
| No   | 1 (reference)  |   |  |   |
| Yes  | 0.88 (0.68–1.42)   | 0.342                                     |  |   |
| Acute illness during past 30<br>days   |  |   |  |   |
| No   | 1 (reference)  |   | 1 (reference)  |   |
| Yes  | 5.08 (3.81-6.78)   | < 0.001                                   | 2.13 (1.25–3.62)   | 0.005                                     |
| Child severe acute<br>malnutrition   | 1 (reference)  |   | 1 (reference)  |   |
| Ves  | 0.81(0.40, 1.62)   | 0.549                                     | 0.81(0.29, 2.29)   | 0.607                                     |
| 1 05   | 0.81 (0.40–1.02)   | 0.349                                     | 0.81 (0.29–2.29)   | 0.097                                     |
| Chronic morbidity  |  |   |  |   |
| Absent<br>Diabetes or hypertension   | 1 (reference)<br>7.66 (5.58–10.52)   | < 0.001                                   | 1 (reference)<br>2.70 (1.62–4.49)  | < 0.001                                   |
| Diabetes and hypertension  | 15.09 (7.85–<br>29.02)   | < 0.001                                   | 6.37 (2.67–15.19)  | < 0.001                                   |

Also, removing the socio-economic position variable from the multivariable model while maintaining the variable listening to radio did not result in any notable change in the magnitude and significance of the associations initially reported, except for the association between living in the Miti-Murhesa and Katana health zones and belonging to a higher healthcare need cluster that became statistically significant (Table 3).

| Variable  | COR (95% CI)   | P value         | AOR (95% CI)   | P value         |
|---|--|-----------------|--|-----------------|
| Status of the participant<br>Neighbours<br>Caregivers       | 1 (reference)<br>0.68 (0.58–1.31)                      | 0.497           | 1(reference)<br>0.65 (0.38–1.12)                       | 0.120           |
| Patients  | 9.56 (6.62–12.86)                                      | < 0.001         | 3.22 (1.79–5.78)                                       | < 0.001         |
| Health zone<br>Bagira<br>Miti-Murhesa and Katana<br>Walungu | 1 (reference)<br>1.20 (0.579–2.50)<br>2.79 (1.35–5.76) | 0.114<br><0.006 | 1 (reference)<br>2.39 (1.12–5.10)<br>5.91 (2.83–12.32) | 0.024<br><0.001 |
| Sex<br>Male<br>Female                                       | 1 (reference)<br>1.91 (1.33–2.30)                      | <0.001          | 1 (reference)<br>1.92 (1.26–2.93)                      | 0.003           |
| Age   | 1.07 (1.06–1.08)                                       | < 0.001         | 1.05 (1.03—1.06)                                       | < 0.001         |
| Household size  | 0.94 (0.90-0.98)                                       | 0.005           | 1.00 (0.91–1.11)                                       | 0.928           |
| Living in conjugal union                                    |  |                 |  |                 |
| Yes<br>No   | 1 (reference)<br>0.63 (0.48–0.84)                      | 0.001           | 1 (reference)<br>1.36 (0.79–2.33)                      | 0.263)          |
| Education of head of household                              | 0.91 (0.88–0.94)                                       | < 0.001         | 0.95 (0.91–1.11)                                       | 0.928           |
| Occupation head   |  |                 |  |                 |
| Employed<br>Informal work                                   | 1 (reference)<br>0.48 (0.27–0.84)                      | 0.010           | 1 (reference)<br>0.36 (0.17–0.78)                      | 0.010           |
| Petty trading/farming<br>No occupation<br>SES               | 1.01 (0.63–1.61)<br>1.91 (1.12–3.28)                   | 0.974<br>0.018  | 0.48 (0.25–0.94)<br>1.14 (0.51–2.57)                   | 0.031<br>0.755  |
| Least poor<br>Middle  | 1 (reference)<br>0.87 (0.60–1.26)                      | 0.455           |  |                 |
| Poorest   | 1.28 (0.88–1.86)                                       | 0.200           |  |                 |

Table 2. Regression analysis of the determinants of health clustering with regard to social and functional disability, without the variable "socio-economic position"

| Listening to radio                       |                    |         |                    |         |
|--|--------------------|---------|--------------------|---------|
| No                                       | 1 (reference)      |         | 1 (reference)      |         |
| Yes                                      | 0.88 (0.68–1.42)   | 0.342   | 1.13 (0.7–1.70)    | 0.572   |
| Acute illness during past 30 days        |                    |         |                    |         |
| No                                       | 1 (reference)      |         | 1 (reference)      |         |
| Yes                                      | 5.08 (3.81-6.78)   | < 0.001 | 2.15 (1.24–3.71)   | 0.006   |
| Child severe acute<br>malnutrition<br>No | 1 (reference)      |         | 1 (reference)      |         |
| Yes                                      | 0.81 (0.40–1.62)   | 0.549   | 0.95 (0.34–2.70)   | 0.928   |
| Chronic morbidity                        |                    |         |                    |         |
| Absent                                   | 1 (reference)      |         | 1 (reference)      |         |
| Diabetes or hypertension                 | 7.66 (5.58–10.52)  | < 0.001 | 2.61 (1.62-4.21)   | < 0.001 |
| Diabetes and hypertension                | 15.09 (7.85–29.02) | < 0.001 | 6.00 (2.59 (13.90) | < 0.001 |

In addition to the comments made on the results presented in the published version of Study 1, some findings necessitate further attention. In simple regression analysis, the odds of belonging to a higher healthcare need cluster appeared to significantly decrease with increased household size (COR: 0.94; 95% CI: 0.90-0.98, p=0.005). This association lost its statistical significance in multivariable regression analysis (Table 2). In fact, the age-adjusted association between household size and belonging to a higher healthcare need cluster is not statistically significant (95% CI:0.95-1.04; p=0.825), suggesting that age is a positive confounder of this association.

A positive confounding effect of the head of household's level of education on the association between being in conjugal union and belonging to higher healthcare need clusters was also noticed. Indeed, the odds of being in a higher-level healthcare need cluster changed from 0.63 (95% CI: 0.48–0.84; p=0.001) in crude regression analysis to 0.95 (95% CI: 0.66–1.36; p=0.780) in front of the variable living in conjugal union.

The variable education of head of household was significantly associated with being in a higher healthcare need level cluster in crude analysis, but this association became statistically insignificant when to the other socio-demographic variables (sex, age and occupation) were added to the regression model.

Lastly, living in a household where the head is a farmer appeared to be significantly associated with the probability of being in higher healthcare need clusters compared to living in a household where the head is a formal salaried, after adjusting for the level of education of the head of household. In crude analysis, this association was statistically insignificant.

| Variable                  | COR (95% CI)                 | P value | AOR (95% CI)       | P value |
|---------------------------|------------------------------|---------|--------------------|---------|
| Status of the participant |                              |         |                    |         |
| Neighbors                 | 1 (reference) $(0.58, 1.21)$ | 0.407   | 1(reference)       | 0.007   |
| Caregivers                | 0.68(0.58-1.31)              | 0.49/   | 0.62(0.36-1.07)    | 0.08/   |
| Patients                  | 9.50 (0.02–12.80)            | <0.001  | 3.34 (1.87-3.97)   | <0.001  |
| Health zone               |                              |         |                    |         |
| Bagira                    | 1 (reference)                |         | 1(reference)       |         |
| Miti-Murhesa and Katana   | 1.20 (0.579–2.50)            | 0.114   | 1.94 (0.84–4.49)   | 0.119   |
| Walungu                   | 2.79 (1.35-5.76)             | < 0.006 | 4.98 (2.21–11.21)  | < 0.001 |
|                           |                              |         |                    |         |
| Sex                       |                              |         |                    |         |
| Male                      | 1 (reference)                | .0.001  | 1 (reference)      | 0.004   |
| Female                    | 1.91 (1.33–2.30)             | <0.001  | 1.85 (1.21–2.81)   | 0.004   |
| Age                       | 1.07 (1.06–1.08)             | < 0.001 | 1.05 (1.04–1.07)   | < 0.001 |
|                           |                              |         |                    |         |
| Household size            | 0.94 (0.90–0.98)             | 0.005   | 1.02 (0.95–1.08)   | 0.655   |
| Living in conjugal union  |                              |         |                    |         |
| Yes                       | 1 (reference)                |         | 1 (reference)      |         |
| No                        | 0.63(0.48-0.84)              | 0.001   | 1.36(0.79-2.32)    | 0.264   |
|                           | ()                           |         | ,                  |         |
| Education of head of      | 0.91 (0.88–0.94)             | < 0.001 | 0.97 (0.92–1.02)   | 0.186   |
| household                 |                              |         |                    |         |
| Occupation head           |                              |         |                    |         |
| Employed                  | 1 (reference)                |         | 1 (reference)      |         |
| Informal work             | 0.48(0.27-0.84)              | 0.010   | 0.34(0.16-0.73)    | 0.006   |
| Petty trading/farming     | 1 01 (0 63 - 1 61)           | 0 974   | 0.41 (0.21 - 0.80) | 0.009   |
| No occupation             | 1.91(1.12-3.28)              | 0.018   | 0.94(0.42-2.11)    | 0.877   |
| SES                       | 1.91 (1.12 0.20)             | 0.010   | 0.5 (0.12 2.11)    | 0.077   |
| Least poor                | 1 (reference)                |         | 1 (reference)      |         |
| Middle                    | 0.87 (0.60–1.26)             | 0.455   | 1.61 (0.89–2.89)   | 0.114   |
| Poorest                   | 1.28 (0.88–1.86)             | 0.200   | 1.99 (1.01–3.91)   | 0.046   |

| Listening to radio              |                    |         |                   |         |
|---------------------------------|--------------------|---------|-------------------|---------|
| No                              | 1 (reference)      |         |                   |         |
| Yes                             | 0.88 (0.68–1.42)   | 0.342   |                   |         |
| Acute illness during past 30    |                    |         |                   |         |
| days                            |                    |         |                   |         |
| No                              | 1 (reference)      |         | 1 (reference)     |         |
| Yes                             | 5.08 (3.81-6.78)   | < 0.001 | 2.13 (1.25–3.62)  | 0.005   |
| Child severe acute malnutrition |                    |         |                   |         |
| No                              | 1 (reference)      |         | 1 (reference)     |         |
| Yes                             | 0.81 (0.40-1.62)   | 0.549   | 0.81 (0.29–2.29)  | 0.697   |
| Chronic morbidity               |                    |         |                   |         |
| Absent                          | 1 (reference)      |         | 1 (reference)     |         |
| Diabetes or hypertension        | 7.66 (5.58–10.52)  | < 0.001 | 2.70 (1.62–4.49)  | < 0.001 |
| Diabetes and hypertension       | 15.09 (7.85-29.02) | < 0.001 | 6.37 (2.67–15.19) | < 0.001 |

# Reference

1. Harrell F. Regression Modeling Strategies. 2001: 335.

Annexes

- WHODAS questionnaire
   PhD research papers

157

![](_page_157_Picture_0.jpeg)

WHODAS 2.0

WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE 2.0

# 36-item version, self-administered

This questionnaire asks about <u>difficulties due to health conditions</u>. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the <u>past 30 days</u> and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only <u>one</u> response.

| In the pa | In the past <u>30 days</u> , how much <u>difficulty</u> did you have in:      |      |      |          |        |                         |  |  |
|-----------|---|------|------|----------|--------|-------------------------|--|--|
| Understa  | Understanding and communicating   |      |      |          |        |                         |  |  |
| D1.1      | Concentrating on doing something for ten minutes?                             | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D1.2      | Remembering to do important things?   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D1.3      | Analysing and finding solutions to<br>problems in day-to-day life?            | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D1.4      | Learning a <u>new task</u> , for example, learning how to get to a new place? | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D1.5      | Generally understanding what people say?                                      | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D1.6      | Starting and maintaining a conversation?                                      | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| Getting   | around  |      |      |          |        |                         |  |  |
| D2.1      | <u>Standing</u> for <u>long periods</u> such as <u>30</u><br>minutes?         | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D2.2      | Standing up from sitting down?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D2.3      | Moving around inside your home?   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D2.4      | Getting out of your home?   | None | Mild | Moderate | Severe | Extreme or cannot do    |  |  |
| D2.5      | <u>Walking a long distance</u> such as a<br><u>kilometre</u> [or equivalent]? | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |

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![](_page_158_Picture_0.jpeg)

WHODAS 2.0 WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE 2.0

| 36   |  |
|------|--|
| Self |  |

| In the pas                | st <u>30 days,</u> how much <u>difficulty</u> did you have in     | 1:   |      |          |        |                         |  |  |
|---------------------------|---|------|------|----------|--------|-------------------------|--|--|
| Self-care                 | 3   |      |      |          |        |                         |  |  |
| D3.1                      | Washing your whole body?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D3.2                      | Getting <u>dressed</u> ?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D3.3                      | Eating?   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D3.4                      | Staying by yourself for a few days?                               | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| Getting along with people |   |      |      |          |        |                         |  |  |
| D4.1                      | Dealing with people you do not know?                              | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D4.2                      | Maintaining a friendship?   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D4.3                      | Getting along with people who are close to you?                   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D4.4                      | Making new friends?   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D4.5                      | Sexual activities?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| Life activ                | vities  |      |      |          |        |                         |  |  |
| D5.1                      | Taking care of your <u>household</u><br>responsibilities?         | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D5.2                      | Doing most important household tasks <u>well</u> ?                | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |  |
| D5.3                      | Getting all the household work <u>done</u> that you needed to do? | None | Mild | Moderate | Severe | Extreme or cannot do    |  |  |
| D5.4                      | Getting your household work done as<br><u>quickly</u> as needed?  | None | Mild | Moderate | Severe | Extreme or cannot do    |  |  |

Please continue to next page ...

![](_page_159_Picture_0.jpeg)

If you work (paid, non-paid, self-employed) or go to school, complete questions D5.5–D5.8, below. Otherwise, skip to D6.1.

| Because of your health condition, in the past <u>30 days</u> , how much <u>difficulty</u> did you have in: |   |      |      |          |        |                         |  |
|--|---|------|------|----------|--------|-------------------------|--|
| D5.5   | Your day-to-day <u>work/school</u> ?                      | None | Mild | Moderate | Severe | Extreme or cannot do    |  |
| D5.6   | Doing your most important work/school tasks <u>well</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do    |  |
| D5.7   | Getting all the work <u>done</u> that you need to do?     | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |
| D5.8   | Getting your work done as <u>quickly</u> as needed?       | None | Mild | Moderate | Severe | Extreme or<br>cannot do |  |

| Participa  | ition in society  |      |      |          |        |                         |
|------------|---|------|------|----------|--------|-------------------------|
| In the pas | st <u>30 days</u> :   |      |      |          |        |                         |
| D6.1       | How much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can? | None | Mild | Moderate | Severe | Extreme or<br>cannot do |
| D6.2       | How much of a problem did you have because of <u>barriers or hindrances</u> in the world around you?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |
| D6.3       | How much of a problem did you have <u>living</u><br>with dignity because of the attitudes and<br>actions of others?   | None | Mild | Moderate | Severe | Extreme or cannot do    |
| D6.4       | How much <u>time</u> did <u>you</u> spend on your health condition, or its consequences?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |
| D6.5       | How much have <u>you been emotionally</u><br>affected by your health condition?   | None | Mild | Moderate | Severe | Extreme or<br>cannot do |
| D6.6       | How much has your health been a <u>drain on</u><br><u>the financial resources</u> of you or your<br>family?   | None | Mild | Moderate | Severe | Extreme or cannot do    |
| D6.7       | How much of a problem did your <u>family</u> have because of your health problems?  | None | Mild | Moderate | Severe | Extreme or<br>cannot do |
| D6.8       | How much of a problem did you have in doing things <u>by yourself</u> for <u>relaxation or pleasure</u> ?   | None | Mild | Moderate | Severe | Extreme or cannot do    |

Please continue to next page ...

![](_page_160_Picture_0.jpeg)

| H1 | Overall, in the past 30 days, <u>how many days</u> were these difficulties present?  | Record number of days |
|----|--|-----------------------|
| H2 | In the past 30 days, for how many days were you <u>totally</u><br><u>unable to carry out your usual activities or work because of</u><br>any health condition?                                     | Record number of days |
| H3 | In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition? | Record number of days |

This completes the questionnaire. Thank you.

# **RESEARCH ARTICLE**

# A new look at population health through the lenses of cognitive, functional and social disability clustering in eastern DR Congo: a community-based cross-sectional study

Espoir Bwenge Malembaka<sup>1,2\*</sup>, Hermès Karemere<sup>1</sup>, Ghislain Bisimwa Balaluka<sup>1</sup>, Anne-Sophie Lambert<sup>2</sup>, Fiston Muneza<sup>3</sup>, Hedwig Deconinck<sup>2</sup> and Jean Macq<sup>2</sup>

# Abstract

**Background:** The importance of viewing health from a broader perspective than the mere presence or absence of disease is critical at primary healthcare level. However, there is scanty evidence-based stratification of population health using other criteria than morbidity-related indicators in developing countries. We propose a novel stratification of population health based on cognitive, functional and social disability and its covariates at primary healthcare level in DR Congo.

**Method:** We conducted a community-based cross-sectional study in adults with diabetes or hypertension, mother-infant pairs with child malnutrition, their informal caregivers and randomly selected neighbours in rural and sub-urban health zones in South-Kivu Province, DR Congo. We used the WHO Disability Assessment Schedule 2.0 (WHODAS) to measure functional, cognitive and social disability. The study outcome was health status clustering derived from a principal component analysis with hierarchical clustering around the WHODAS domains scores. We calculated adjusted odds ratios (AOR) using mixed-effects ordinal logistic regression.

**Results:** Of the 1609 respondents, 1266 had WHODAS data and an average age of 48.3 (SD: 18.7) years. Three hierarchical clusters were identified: 9.2% of the respondents were in cluster 3 of high dependency, 21.1% in cluster 2 of moderate dependency and 69.7% in cluster 1 of minor dependency. Associated factors with higher disability clustering were being a patient compared to being a neighbour (AOR: 3.44; 95% CI: 1.93–6.15), residency in rural Walungu health zone compared to semi-urban Bagira health zone (4.67; 2.07–10.58), female (2.1; 1.25–2.94), older (1.05; 1.04–1.07), poorest (2.60; 1.22–5.56), having had an acute illness 30 days prior to the interview (2.11; 1.24–3.58), and presenting with either diabetes or hypertension (2.73; 1.64–4.53) or both (6.37; 2.67–15.17). Factors associated with lower disability clustering were being informally employed (0.36; 0.17–0.78) or a petty trader/farmer (0.44; 0.22–0.85).

**Conclusion:** Health clustering derived from WHODAS domains has the potential to suitably classify individuals based on the level of health needs and dependency. It may be a powerful lever for targeting appropriate healthcare service provision and setting priorities based on vulnerability rather than solely presence of disease.

Keywords: Health clustering, WHODAS, Medico-psychosocial, Disability, Community, Eastern DR Congo

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![](_page_161_Picture_14.jpeg)

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![](_page_161_Picture_19.jpeg)

## Background

The importance of viewing health from the standpoint of functional, cognitive and social disability dimensions is critical at primary health care level. It is no longer debatable that health is a dimension inextricably interwoven with all other aspects of life, daily life, working life, family life, and community life [1]. Health is increasingly considered as a human capital resource and a whole, personal, situation-specific phenomenon [2], rather than the absence of disease [3–5]. Despite such a consensus, primary care activities are still largely structured around diseases control and mortality of sub-populations rather than promoting comprehensive person-centered care [6].

When one addresses a person's health or community health, the life situation as a whole must be put into perspective and strategies for improving health needs must be grounded on factors conducive to good quality of life. Therefore, prioritising (community) care through population stratification based on functional, cognitive and social disability dimensions may be useful for comprehensiveness and quality of service provision. This has not yet been sufficiently explored in low- and middle-income countries (LMICs). Few studies from both high-income countries and LMICs examined these health dimensions of sub-populations, but mostly in the elderly or had a limited focus on hospital- and disease-based outcomes [7].

The literature is insistently advocating the necessity to broaden the perspective of 'health measurement' by looking at functional and social status as part of individual and community health [8, 9]. With recognition that health complexity encompasses and transcends the mere concept of physical morbidity, good health can be viewed as the ability to adapt and to self-manage, with emphasis put on social and personal resources as well as physical capacity [10]. In the era of steadily rising high burden of chronic comorbidities, new health considerations such as functional dependence, cognitive functioning, disability and frailty are becoming of greater importance. But little is known on how these innovating insights into individuals and community health can be leveraged so that to ensure appropriate health services to people most in need and pave the way to universal health coverage and progress towards the health sustainable development goals (SDGs).

The World Health Organization (WHO), echoing the need for a holistic approach to assessing health both at individual and community levels, developed appropriate tools that allow a better understanding and estimation of the impact of any health condition in term of functioning. The International Classification of Functioning, Disability and Health (ICF) published by the WHO in 2001 has proved to be a useful and valid framework integrating function and disability with health conditions and contextual factors [11]. Besides, the WHO Disability Assessment Schedule 2.0 (WHODAS), drawing essentially on the ICF framework, provides a standardized approach to measuring health and disability across cultures [12].

Primary health care services in sub-Saharan Africa and other low- and middle-income, particularly in post-war settings, are often considerably configured to donors-dictated disease-based indicators [13]. To some extent, this furtively leads to denaturalisation of the fundamental goal of primary health care. In such situations, individual and community health are confined to the narrow physical or biological aspects of health, ignoring the broader dimensions of health that are useful for a person's life. There is dearth of context-specific data on how to identify vulnerability-based subpopulations of complex patients who may benefit from targeted care management strategies in resourcesconstrained settings.

The aim of this study was twofold. First, we propose a new stratification of population health in a sample of adults with diabetes or hypertension, mothers of children with acute malnutrition as well as their respective informal caregivers and neighbours from the standpoint of functional, cognitive and social disabilities. Second, we identified covariates of population health in rural and semi-urban eastern DR Congo settings. Our overall goal is to better inform healthcare strategies and improve health services organisation in rural and/or post-war settings.

#### Methods

We conducted a community-based cross-sectional survey in adults with self-reported diabetes and/or hypertension, mother-infant pairs with severe acute malnutrition, and their informal caregivers and neighbours between December 2017 and March 2018. These sub-population categories were deliberately selected to help gain a better insight into diverse perspectives of health status patterns observable at primary healthcare level in South Kivu. In addition, we deemed high the likelihood of complex medicopsychosocial conditions among individuals presenting with these three 'tracer' conditions [14, 15]. Finally, these health problems are prevailing in South Kivu and are relatively easy to identify even at primary care level in resources-constrained settings. Indeed, the prevalence of acute malnutrition in South-Kivu is one of the highest in the world with up to 8% of children younger than 5 years being wasted [16]. In 2011, the estimated prevalence of diabetes in this region was 4.9% in urban areas and 3.2% in rural areas while hypertension was found in 41.4 and 38.1% of urban and rural residents respectively [17].

## Study settings

South-Kivu is an Eastern DR Congo province as large as 65,103 km<sup>2</sup>, lying in the Great Lakes region of Africa. This province shares land borders with Burundi and Rwanda and borders the provinces of North-Kivu, Maniema and Katanga. The Kivu region has been a theatre of civil and political unrest over the last two decades, resulting in socio-economic instability, destruction of societal structures and, to a significant extent, dysfunction of the health system. With an estimated population of 6,932,107 inhabitants in 2012 [18], South-Kivu is a predominantly rural province with nearly 70% of the population living in rural areas. The operational unit and primary care level of the health system in DR Congo is the health center with the health area as catchment unit.

#### Sampling procedure and selection of participants

A multi-stage sampling approach was used. Six health areas (Bideka, Burhale, Kabushwa, Lumu, Lwiro and Nyamuhinga) spanning four health zones (Bagira-Kasha, Katana, Miti-Murhesa and Walungu) were selected because of their large catchment area, geographical accessibility, experience and quality of records keeping. A strong network of over 240 community health workers (CHWs) operated in these health areas covering over 100,000 inhabitants. Given the logistic, geographical, time and-to a lesser extent-security constraints, we purposively confined the sampling to villages nearest to the health centre. This was also partly because this study was part of a broader and longer-term research for development project that set to find out whether changes in the way health services are provided (by focusing on psycho-medico-social status additionally to the disease) at health centres in rural and post-war African contexts would change the health status of a population.

We initially aimed to recruit at least 90 patients (with any of the three conditions aforementioned) and an equal number of informal caregivers and neighbours in each of the six selected health areas. Within each health area, villages nearest to the health centre were selected. At village level, CHWs were recruited. Studies have shown that, with a minimum training, CHWs can effectively participate in screening, health promotion interventions and management of malnutrition [19], diabetes or hypertension [20, 21]. They benefited from a half-day refreshment training on the community diagnosis of severe acute malnutrition based on mid-upper arm circumference measurement (MUAC) equal or below ( $\leq$ ) 11.5 cm and/or presence of nutritional oedema. The refreshment training was deemed necessary to ensure a correct identification of mother-infant pairs with child acute malnutrition given that untrained mothers or caretakers are unlikely to properly detect and self-report acute malnutrition in their children [22]. CHWs were also assigned to identify households in which adults with self-reported diabetes or hypertension lived. During the data collection phase, the data collection team was introduced to each household in which a person of interest was identified. The purpose of the study was explained to the head of the household and permission to carry out the interview was asked. People with diabetes and hypertension were selected if being diagnosed for at least 6 months. Mothers were selected if being a mother of a child presenting with severe acute malnutrition. If the targeted person was absent, the data collectors could proceed to the next targeted household on the list and come back the following day until the person was found. A written and signed consent to participate in the study was sought before the interview started in the same household, an informal caregiver was identified and asked to consent to the study. For caregivers below 18 years of age, the consent was required from a parent or guardian. For every household in which a patient was recruited, a community member in the nearest neighbourhood was randomly selected by spinning a pen and following the direction in which it pointed. At this stage, an adult with the closest age and ideally (but not always) with the same sex as the neighbour patient was approached and asked to participate in the study, after providing a written consent. If in the selected neighbouring household there was no consenting adult, interviewers could move to a next household chosen through the same random process until they found a consenting adult. At the end, all participants had to be residents of the health area for at least 6 months and at least 15 years of age. People who refused to provide an informed consent or were severely ill, physically or mentally unable to withstand an interview were excluded.

### Data collection and instruments

A simple identification form was used by the CHWs during the phase of identifying households in which patients with known morbidity lived, within the entire health area. This helped us generate a sampling frame with information on age, sex, village of residence and type of morbidity. A structured and pre-tested paper-based questionnaire designed to capture socio-demographic and health characteristics data was administered to a convenience sample all identified individuals living in villages nearest to health centres, their informal caregivers and randomly selected neighbours by trained research assistants who were all nurses.

To assess the functional and social disability related to health condition, we used the WHO Disability Assessment Schedule 2.0 (WHODAS). WHODAS is a multidimensional and cross-cultural questionnaire with 36 items assessing an individual's cognition, mobility, self-care, getting along with people, life activities and participation in society. It is short to administer (about 20 min) both at clinical and community levels and across all diseases. WHODAS has been validated and frequently used in LMICS [23, 24], with a high internal consistency (Cronbach's alpha) ranging from 0.77 in South-African women [25] to between 0.82 and 0.98 in people with severe mental disorders and their caregivers in rural Ethiopia. It also is able to detect small changes over time [26]. In addition, the WHODAS-child adapted from the adult WHODAS 2.0 has shown an 84% internal consistency with high test-retest and inter-rater reliability (r = 0.83 and intraclass correlation coefficient = 0.88) in Rwandan children [27].

The WHODAS was translated to Kiswahili (national language spoken in eastern DR Congo) according to a rigorous translation protocol to ensure cross-cultural and conceptual equivalence. One French-speaking translator from the school of languages of the Université Catholique de Bukavu and whose mother tongue is Kiswahili carried out the translation. A bilingual panel comprised of the principal investigator, key health professionals working in the health areas of study and community health workers leaders reviewed the translated version in order to address its potential cross-cultural inadequacies in terms of incomprehensibility or lack of clarity.

#### Variables and measurement

WHO developed a conceptual framework for action on the social determinants of health [28], which we found complementary to that developed earlier on by LF Berkman, T Glass, I Brissette and TE Seeman [29]. Drawing on both frameworks, we examined social (including social cohesion), demographic and economic status as possible explanatory parameters. Socio-demographic characteristics included among other variables age (measured on a continuous scale in completed years), gender (male or female), education (continuous variable measured as complete years of schooling) or household size (number of people sleeping in the same house and eating from the same cooking pot) or health zone of residence. Some categorical variables needed to be recoded to obtain sufficient numbers in strata for ease of the comparisons. This was, for example, the case for marital status, tribe or occupation. Social cohesion and networking were approximated by regularly attending church activities and being member of a local socio-economic or savings network. To define the socio-economic status, we ran a Multiple Correspondence Analysis on household assets and housing characteristics to create wealth indices [30] based on ownership of a television, a radio, a computer, a manufactured bed, small animals, cattle, land, a bicycle, a motorcycle and on housing characteristics including pavement and permanent, semi-permanent or temporary structure. We then derived five socio-economic quintiles from wealth indices. The two lowest (poorest 40%) and the two middle (40%) quintiles were respectively merged following an approach suggested by D Filmer and LH Pritchett [31]. We ended up with three socio-economic classes (least poor, middle poor, poorest).

The main dependant variable under study was functional and social disability defined as a three-level ordinal variable resulting from a Principal Component Analysis (PCA) with clustering performed on the six WHODAS domains scores (see explanation here below).

#### Data management and analyses

Data were entered in EpiInfo7 and exported to Stata 15 for exploratory analyses. We used a three-stage WHO-DAS scoring strategy based on the complex and Item Response Theory (IRT) scoring algorithm. We first added up the recoded item scores within each domain. All six domains scores were totaled prior to converting the summary score into a metric ranging from 0 to 100 (where 0 = no disability; 100 = full disability) (Üstün et al., 2010). This algorithm was implemented in Stata 15.

The distribution of continuous variables was assessed graphically and statistically using the Shapiro-Wilk test. Extreme and implausible outlying values were checked for and set to missing. Qualitative variables were summarized in frequencies and proportions while continuous variables were described in terms of mean with standard deviation (SD) or median with interquartile range (IQR) depending on the shape of the distribution.

To define medico-psychosocial clusters, we first ran a principal component analysis on seven summary scores of the WHODAS domains. We then performed a hierarchical clustering of the principal components based on Ward's method and using the FactoMineR software package in R [32]. Three ordered clusters were created and termed cluster 1, cluster 2 and cluster 3. We used chi-squared and Kruskal-Wallis tests to compare the characteristics of the study participants by enrolment status or clustering.

To establish the factors associated with functional and social disability clustering, we did the inter-cluster comparison using a mixed-effects ordinal (proportional odds) logit regression model with cluster as a fixed effect and health area as a random effect. This strategy enabled us to take into account the inherent non-independence of socio-demographic factors at health area level, thus ensuring more accurate standards errors for the measures of association between within-health area characteristics and disability clusters. The proportional odds model was favoured over the other ordinal models since the former is most suited to studies under which the outcome is obtained from categorizing a certain underlying continuum. In addition to its greater statistical power to detect differences in a relatively smaller sample [33], this model often generates much simpler interpretable coefficients, even when the order of the outcome is reversed (in which case only the sign of the coefficient is changed) [34]. We used a backward elimination strategy to build the regression model, guided by Wald's tests and the principle of parsimony. Variables were hierarchically selected into the multivariable model in three stages, based either on a *p*-value equal to or below 0.2 or on public health plausibility as suggested by CG Victora, SR Huttly, SC Fuchs and M Olinto [35]. Socio-demographic factors were selected first. We then included household attributes before adding proximate factors reflecting physical health impairment. Multicollinearity between explanatory variables was assessed using the Variance Inflation Factor (VIF). A VIF greater than 4 was suspected of collinearity. We reported Crude Odds Ratios (COR) and adjusted odds ratios (AOR) with their 95% confidence intervals and p values. We regarded a type one error ( $\alpha$ ) < 5% as statistically significant. We used R 3.3.5 and Stata 15 software for the analyses.

#### Ethical considerations

Respondents provided singed informed consent for participation in the study, either by written signature or by fingerprints, depending on literacy. Child assent was obtained for respondents below 18 years of age, after a parent or guardian's consent. Ethical approval for the study was obtained from the Université catholique de Bukavu Ethics Committee and the *Hospital*-Faculty *Ethics Committee* of UC Louvain.

### Results

### Background characteristics of the study population

Of the 1609 participants approached by data collectors in the field, 1266 provided valid information on functional and social disability. The general background characteristics of the study sample are presented in Table 1. The majority of the participants were female (63.6%), belonging to the indigenous Shi tribe (91.1%) and married (68.8%). The mean (SD) age was 48.3 (18.7) years. Participants lived in bigger size households [median (IQR): 6.5 (5–9)] compared to the national median of 5.3. Farming or petty trading were the main occupation for over half of the heads of households (55.8%). While 62.5% of the respondents claimed to be catholic, about one quarter (27.2%) reported to be members of any church organization with over half (52.4%) of all respondents attending church at least once a week. The median (IQR) duration of schooling was 6(3-10)years. Nearly six in ten respondents (57%) did not listen to radio even once a week and less than 19.3% reported being members of local saving cooperatives.

# Proposed clustering of the study population from the perspective of functional and social disability

The hierarchical clustering of the principal components of seven WHODAS domains scores resulted in three ordered categories of functional, cognitive and social disabilities termed cluster 1, cluster 2 and cluster 3 (Fig. 1).

The characteristics of the study population by cluster are displayed in Table 2. Of the 1226 respondents with valid WHODAS data, over two-thirds (69.7%) were found in cluster 1, with a median (IQR) WHODAS score [5.2 (0–10.9)] below that of the whole study population. Cluster 2 had 21.1% of the respondents with a median (IQR) WHODAS score of 31.7 (24.7–39.7). Respondents in cluster 3 (9.2%) had the poorest health status from the functional, cognitive and social disability standpoint with median (IQR) WHODAS score of 62.1 (53.2–75.7) (Table 3). The trend was consistent among all the WHODAS domains; the higher the cluster order, the more worrying the health status of the individuals. Half of the study population had a summary WHODAS score below 10.2 (Additional file 1).

The age of the respondents and the proportion of women increased with cluster ordering. The majority of respondents in cluster 3 were female (71.3%) and on average 63.0 (18.0 SD) years old and likely to be older than those in lower clusters (p < 0.001). The clustering was independent on the socio-economic status (p = 0.107) but dependent on the place of residence (p < 0.001). In fact, it was more likely to find participants in cluster 3 in rural areas (Miti-Murhesa, Katana and Walungu health zones) than in semi-urban areas (p < 0.001).

Clustering depended on the marital status of the respondents (p < 0.001). Only 1.8% of the respondents in cluster 3 never married, 57% were married and 41.1% either were divorced, separated or widowed. Clustering was also dependent on hypertension status, diabetes status and history of acute illness in the 30 days prior to the interview. Over two-thirds of the respondents in cluster 1 (68%) had a normal blood pressure, against 44.6% in cluster 2 and 27.8% in cluster 3 which had 62.6% of its constituents presenting with self-reported hypertension (Table 3). Diabetes was more common in cluster 3 (18.7%) than in other clusters (p < 0.001). Four in five people in cluster 3 reported an acute illness in the 30 days prior to the interview against 32.1% in cluster 1. Clustering was independent of acute malnutrition status of the child, tribe, religion and church attendance, but dependent on occupation. It was more likely to find individuals without profession in cluster 3 compared to cluster 2 and cluster 1 (p = 0.004) and respondents in 3 were more likely to be members of local saving or development cooperatives than those in cluster 2 and cluster 1 (p = 0.013). Listening to radio at least once a week, a

**Table 1** General characteristics of the study population

| Variable  | Descriptive statistics |
|---|------------------------|
| Health zone   |                        |
| Bagira  | 523 (34.1)             |
| Katana and Miti-Murhesa                             | 502 (32.7)             |
| Walungu   | 509 (33.2)             |
| Gender  |                        |
| Female  | 1003 (63.6)            |
| Male  | 573 (36.4)             |
| Age   | 48.3 (18.7)            |
| Socio-economic status                               |                        |
| Least poor  | 325 (20.3)             |
| Middle  | 659 (41.2)             |
| Poor  | 615 (38.5)             |
| Occupation of head of household                     |                        |
| Formal worker                                       | 155 (10.7)             |
| Informal worker                                     | 189 (13.0)             |
| Farmer or petty trading                             | 810 (55.8)             |
| No profession                                       | 298 (20.5)             |
| Participant   |                        |
| Patient   | 450 (32)               |
| Informal caregiver                                  | 492 (35)               |
| Neighbor  | 463 (33)               |
| Tribe   |                        |
| Shi   | 1446 (91.1)            |
| Others  | 142 (8.9)              |
| Marital status                                      |                        |
| Never married                                       | 168 (10.8)             |
| Married   | 1072 (68.8)            |
| Divorced/widowed/separated                          | 322 (20.4)             |
| Religion  |                        |
| Catholic  | 986 (62.5)             |
| Protestant  | 531 (33.6)             |
| Muslim and others                                   | 62 (3.9)               |
| Church membership                                   |                        |
| Yes   | 415 (27.2)             |
| No  | 1113 (72.8)            |
| Church attendance frequency                         |                        |
| < = Once a week                                     | 792 (52.4)             |
| 2–3 times a week                                    | 462 (30.5)             |
| > = 4 times a week                                  | 259 (17.1)             |
| Education (years)                                   | 6 (3–10)               |
| Household size                                      | 6.5 (5–9)              |
| Preschool aged children in household ( $n = 1011$ ) | 1 (0-2)                |
| School-aged children in household                   | 2 (1–3)                |
| Adults in household                                 | 3 (2–4)                |
|   |                        |

 
 Table 1 General characteristics of the study population (Continued)

| Variable                               | Descriptive statistics |
|--|------------------------|
| Saving organization membership         |                        |
| Yes                                    | 306 (19.3)             |
| No                                     | 1275 (80.7)            |
| Weekly frequency of listening to radio |                        |
| Less than once a week                  | 584 (57)               |
| At least once a week                   | 440 (43)               |
|  |                        |

Data are n (%), mean (SD) and median (IQR)

proxy for access to information, was likely to be more frequent in cluster 3 relative to cluster 2 and cluster 1 (p < 0.001).

#### Covariates of disability-based health status clustering

The crude and adjusted odds ratios of health status clustering based on functional, cognitive and social disability are presented in Table 3. The factors associated with clustering were being a patient compared to a neighbour (AOR: 4.67; 95% CI: 2.07-10.58), being a resident of rural Walungu health zone to semi-urban Bagira (AOR: 4.67; 95% CI: 2.07-10.58), being female (AOR: 2.1; 95% CI: 1.25-2.94), aging (AOR: 1.05; 95% CI: 1.04-1.07), doing informal work compared with being employed (AOR: 0.36; 95% CI: 0.17-0.78), being petty trader or farmer relative to being employed (AOR: 0.45; 95% CI: 0.22–0.85), being poorest compared to being least poor (AOR: 2.60; 95% CI: 1.22-5.56), acute illness 30 days prior to the interview (AOR:2.11; 95% CI: 1.24-3.58), and presenting with either diabetes or high blood pressure (AOR: 2.73; 95% CI:1.64-4.53) or both (AOR: 6.37; 95% CI: 2.67-15.17) to not presenting with either condition.

#### Discussion

This community-based study proposes a new way of stratifying population health in function of dependency or disability and social context rather than in function of specific diseases. Similar approaches have been quite frequently studied in high-income countries but scantily tested in LMICs. The implied hypothesis is that this way of stratifying population health may be a powerful lever for change in healthcare prioritization processes.

# A three-layered stratification strategy focusing on functionalities and leading to new strategies

The pyramidal distribution of the study population in three clusters with 9.2% participants with higher disability scores (cluster 3) is different from the few available studies using similar grouping approaches, which nearly all come from high-income countries. SI Vuik, E Mayer and A Darzi [36] classified patients based on healthcare

![](_page_167_Figure_2.jpeg)

utilization in England and identified 22% of the participants as patients with high health needs. A household-based survey conducted in France by T Lefevre, C Rondet, I Parizot and P Chauvin [37] found that 30% of the study participants were in the cluster of largest primary care users, which may correspond to cluster 3 in our analyses. The observed differences in the proportion of individuals in high healthcare needs clusters between our findings and those from high-income settings can partly be due to the heterogeneity in study design and outcome measurements; therefore, the comparison with our study can only be indirect. Both studies based their outcome measurements on health service utilization. Moreover, the former study used hospital data that may represent people with lower access to healthcare services or with tacit non-disease based healthcare needs, such as social support of social participation. Additionally, a higher life expectancy and aging of the population in high-income countries could explain the higher proportion of individuals with more healthcare needs in these studies compared to our study.

In our study sample, the participants in cluster 3 (117 or 9.2%) would need particular healthcare attention compared to those with middle health and disability concerns in cluster 2 (267 or 21.1%) or those with minor health and disability concerns in cluster 1 (882 or 69.7%). Furthermore, by changing the prioritization process, not all diseased people need the same level of support. For example, 18.7% (148) of the participants in cluster 1 were living with diabetes or hypertension, or were mothers with an acutely malnourished child, while 23.5% (24) of the respondents in cluster 3 had no tracer condition. We also found that individuals in this high dependency cluster had a higher likelihood of presenting with both acute and chronic morbidities. They were sustaining complex medico-psychosocial problems that would require targeted healthcare interventions, such as systematic home visits and care, multidisciplinary case discussion and management, involving psychologist and social assistants. Individuals in the middle disability cluster may benefit more from health coaching strategies aiming to empower people to self-manage their health conditions, in addition to primary prevention of acute and chronic conditions. These strategies have proven useful and cost-effective in the management of chronic conditions and in averting or delaying disability [38–40].

| Table 2 Distribution | of the study | population by | <ul> <li>clusters of</li> </ul> | f functional | and social | disability | representing | the levels | of complex |
|----------------------|--------------|---------------|---------------------------------|--------------|------------|------------|--------------|------------|------------|
| medico-psychosocia   | l problems   |               |                                 |              |            |            |              |            |            |

| Variable                            | Cluster 1    | Cluster 2        | Cluster 3        | P value |
|-------------------------------------|--------------|------------------|------------------|---------|
| WHODAS and morbidity factors        |              |                  |                  |         |
| Overall WHODAS                      | 5.2 (0-10.9) | 31.7 (24.7–39.7) | 62.1 (53.2–75.7) | 0.001   |
| Communication and understanding     | 0 (0–12.5)   | 41.7 (25–54.2)   | 70.8 (54.2–91.7] | 0.001   |
| Mobility                            | 0 (0–5.0)    | 30.0 (20.0–45.0) | 65.0 (50.0-80.0) | 0.001   |
| Self-care                           | 0 (0–0)      | 0 (0–12.5)       | 50.0 (31.2–75.0) | 0.001   |
| Getting along with people           | 0 (0–15.0)   | 25.0 (15.0–35.0) | 55.0 (30.070.0)  | 0.001   |
| Household activities                | 0 (0–12.5)   | 43.7 (25.0–56.2) | 75.0 (62.5–93.7) | 0.001   |
| Work or school activities           | 0 (0–12.5)   | 43.7 (31.2–56.2) | 81.2 (68.7–93.7) | 0.001   |
| Social participation                | 0 (0–16.6)   | 40.6 (28.1–53.1) | 71.9 (59.4–84.4) | 0.001   |
| Enrolment status of the participant |              |                  |                  | < 0.001 |
| Patient                             | 148 (18.7)   | 133 (58.3)       | 78 (76.5)        |         |
| Caregiver                           | 333 (42.2)   | 44 (19.3)        | 13 (12.8)        |         |
| Neighbor                            | 309 (39.1)   | 51 (22.4)        | 11 (10.8)        |         |
| Acute illness/30 days               |              |                  |                  | < 0.001 |
| No                                  | 599 (67.9)   | 113 (43.3)       | 21 (18)          |         |
| Yes                                 | 283 (32.1)   | 154 (57.7)       | 96 (82)          |         |
| Child malnutrition                  |              |                  |                  | 0.417   |
| No                                  | 843 (95.6)   | 259 (97)         | 114 (94.4)       |         |
| Yes                                 | 39 (4.4)     | 8 (3)            | 3 (2.6)          |         |
| Blood pressure                      |              |                  |                  | < 0.001 |
| Normal                              | 543 (68.6)   | 115 (44.6)       | 32 (27.8)        |         |
| Self-reported HT                    | 147 (18.6)   | 120 (46.5)       | 72 (62.6)        |         |
| Fortuitous HT discovery             | 101 (12.8)   | 23 (8.9)         | 11 (9.6)         |         |
| Diabetes                            |              |                  |                  | < 0.001 |
| No                                  | 758 (94.7)   | 192 (80.3)       | 87 (81.3)        |         |
| Yes                                 | 42 (5.3)     | 47 (16.7)        | 20 (18.7)        |         |
| Socio-demographic characteristics   |              |                  |                  |         |
| Place of residence                  |              |                  |                  | < 0.001 |
| Urban                               | 329 (39)     | 67 (26.2)        | 28 (24.6)        |         |
| Rural                               | 514 (61)     | 189 (73.8)       | 86 (75.4)        |         |
| Age                                 | 42.9 (16.4)  | 58.2 (15.3)      | 63.0 (18.0)      | < 0.001 |
| Sex                                 |              |                  |                  | 0.001   |
| Female                              | 519 (59.9)   | 187 (70.6)       | 82 (71.3)        |         |
| Male                                | 348 (40.1)   | 78 (29.4)        | 33 (28.7)        |         |
| SES                                 |              |                  |                  | 0.107   |
| Least poor                          | 199 (22.6)   | 49 (18.5)        | 19 (16.2)        |         |
| Middle                              | 361 (40.9)   | 102 (38.5)       | 44 (37.6)        |         |
| Poorest                             | 322 (36.5)   | 114 (43)         | 54 (46.2)        |         |
| Health zone                         |              |                  |                  | < 0.001 |
| Bagira                              | 329 (39.0)   | 67 (26.2)        | 28 (24.6)        |         |
| Miti-Katana                         | 324 (38.4)   | 67 (26.2)        | 48 (42.1)        |         |
| Walungu                             | 190 (22.6)   | 122 (47.6)       | 38 (33.3)        |         |

| Variable                       | Cluster 1  | Cluster 2  | Cluster 3   | P value |
|--------------------------------|------------|------------|-------------|---------|
| Marital status                 |            |            |             | < 0.001 |
| Never married                  | 116 (13.4) | 3 (1.2)    | 2 (1.8)     |         |
| Married                        | 628 (72.4) | 192 (73.8) | 64 (57.1)   |         |
| Divorced/widowed/separated     | 123 (14.2) | 65 (25)    | 46 (41.1)   |         |
| Tribe                          |            |            |             | 0.073   |
| Shi                            | 782 (89.4) | 249 (93.6) | 108 (93.10) |         |
| Others                         | 93 (10.6)  | 17 (6.4)   | 8 (6.9)     |         |
| Religion                       |            |            |             | 0.254   |
| Catholic                       | 524 (59.4) | 96 (36)    | 41 (35)     |         |
| Others                         | 358 (40.6) | 171 (64)   | 76 (65)     |         |
| Listening to radio             |            |            |             | < 0.001 |
| No                             | 346 (39.2) | 80 (30)    | 32 (27.4)   |         |
| At least once a week           | 536 (60.8) | 187 (70)   | 85 (72.7)   |         |
| Occupation                     |            |            |             | 0.004   |
| Formal salaried                | 85 (10.4)  | 19 (7.8)   | 15 (14.4)   |         |
| Informal                       | 213 (25.9) | 26 (10.7)) | 13 (12.5)   |         |
| Farmer/petty trading           | 359 (43.7) | 147 (60.2) | 42 (40.4)   |         |
| No profession                  | 164 (20)   | 52 (21.3)  | 34 (32.7)   |         |
| Saving organization membership |            |            |             | 0.013   |
| No                             | 699 (80)   | 225 (85.2) | 84 (72.4)   |         |
| Yes                            | 175 (20)   | 39 (14.8)  | 32 (27.6)   |         |
| Church attendance/week         |            |            |             | 0.170   |
| <= 1 time                      | 452 (54.1) | 125 (48.6) | 56 (51.4)   |         |
| 2–3 times                      | 235 (28.2) | 93 (36.2)  | 32 (29.6)   |         |
| >=times                        | 148 (17.7) | 39 (15.2)  | 21 (19.3)   |         |

**Table 2** Distribution of the study population by clusters of functional and social disability representing the levels of complex medico-psychosocial problems (*Continued*)

SES socio-economic status, HT hypertension

Our findings also suggest people with health morbidities can still enjoy better cognitive, functional and social life through the transformation of their health conditions into 'life conditions'. This may be achieved through development of Kaiser-like integrated healthcare models and health promotion programmes enabling clients to take charge of their own health to lead an acceptable and good quality life [41–44].

# Vulnerability factors associated with the population health strata

Our study also identified socio-economic risk factors of cognitive, functional and social dependency. Indeed, the odds of being in higher disability clusters were significantly higher for individuals with poor socio-economic background and empowerment, such as being a woman, elderly, rural resident and with acute or chronic morbidity. We observed that vulnerability factors such as lower socio-economic status, older age, being a female or rural resident were significantly associated with higher odds of being in higher disability clusters than cluster 1. These findings are substantiated by results from studies from both high- and LMICs [45-49]. However, education had a significant effect on disability in the bi-variable analysis but was no longer significant after adjustment for potential confounders. A multi-country study on disabilitymeasured by WHODAS in adults aged 50 and abovefound no association between education and disability in Ghana whereas a protective effect of education was reported in Russia, China, India and South Africa [46]. Post-hoc analysis in individuals aged 50 and above did not change the pattern of association in our study. This difference may be related to the heterogeneity in socio-economic structure between low-income countries like DR Congo and Ghana and middle- or high-income countries. Health status approached through disability dimensions is more common among the poorer. Thus, in low-income countries like DR Congo and Ghana, confounding by socioeconomic background may underestimate the beneficial effects of education on cognitive,

|           |   |               |               | C . I   |                | C 1 |               |           |          |       | C I               | 1 · · · · · · · · · · · · · · · · · · · |
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| Variable                          | COR (95% CI)       | P value | AOR (95% CI)      | P value |
|-----------------------------------|--------------------|---------|-------------------|---------|
| Status of the participant         |                    |         |                   |         |
| Neighbours                        | 1 (reference)      |         | 1(reference)      |         |
| Caregivers                        | 0.68 (0.58–1.31)   | 0.497   | 0.63 (0.37-1.09)  | 0.098   |
| Patients                          | 9.56 (6.62–12.86)  | < 0.001 | 3.44 (1.92-6.15)  | < 0.001 |
| Health zone                       |                    |         |                   |         |
| Bagira                            | 1 (reference)      |         | 1 (reference)     |         |
| Miti-Murhesa and Katana           | 1.20 (0.579–2.50)  | 0.114   | 1.90 (0.82–4.41)  | 0.134   |
| Walungu                           | 2.79 (1.35–5.76)   | < 0.006 | 4.67 (2.07–10.58) | < 0.001 |
| Sex                               |                    |         |                   |         |
| Male                              | 1 (reference)      |         | 1 (reference)     |         |
| Female                            | 1.91 (1.33–2.30)   | < 0.001 | 2.1 (1.25-2.94)   | 0.003   |
| Age                               | 1.07 (1.06–1.08)   | < 0.001 | 1.05 (1.04–1.07)  | < 0.001 |
| Household size                    | 0.94 (0.9–0.98)    | 0.005   | 1.01 (0.95–1.08)  | 0.760   |
| Living in conjugal union          |                    |         |                   |         |
| Yes                               | 1 (reference)      |         | 1 (reference)     |         |
| No                                | 0.63 (0.48–0.84)   | 0.001   | 1.37 (0.80–2.35)  | 0.760   |
| Education of head of household    | 0.91 (0.88–0.94)   | < 0.001 | 0.97 (0.92–1.02)  | 0.213   |
| Occupation head                   |                    |         |                   |         |
| Employed                          | 1 (reference)      |         | 1 (reference)     |         |
| Informal work                     | 0.48 (0.27–0.84)   | 0.010   | 0.36 (0.17–0.78)  | 0.010   |
| Petty trading/farming             | 1.01 (0.63–1.61)   | 0.974   | 0.45 (0.22–0.85)  | 0.016   |
| No occupation                     | 1.91 (1.12–3.28)   | 0.018   | 1.01 (0.45–2.29)  | 0.975   |
| SES                               |                    |         |                   |         |
| Least poor                        | 1 (reference)      |         |                   |         |
| Middle                            | 0.87 (0.60–1.26)   | 0.455   | 1.67 (0.93–3.02)  | 0.088   |
| Poorest                           | 1.28 (0.88–1.86)   | 0.200   | 2.60 (1.22–5.56)  | 0.014   |
| Listening to radio                |                    |         |                   |         |
| No                                | 1 (reference)      |         | 1 (reference)     |         |
| Yes                               | 0.88 (0.68–1.42)   | 0.342   | 1.49 (0.91–2.45)  | 0.113   |
| Acute illness during past 30 days |                    |         |                   |         |
| No                                | 1 (reference)      |         | 1 (reference)     |         |
| Yes                               | 5.08 (3.81–6.78)   | < 0.001 | 2.11 (1.24–3.58)  | 0.006   |
| Child severe acute malnutrition   |                    |         |                   |         |
| No                                | 1 (reference)      |         | 1 (reference)     |         |
| Yes                               | 0.81 (0.40–1.62)   | 0.549   | 0.84 (0.30–2.37)  | 0.739   |
| Chronic morbidity                 |                    |         |                   |         |
| Absent                            | 1 (reference)      |         | 1 (reference)     |         |
| Diabetes or hypertension          | 7.66 (5.58–10.52)  | < 0.001 | 2.73 (1.64–4.53)  | < 0.001 |
| Diabetes and hypertension         | 15.09 (7.85–29.02) | < 0.001 | 6.37 (2.67–15.17) | < 0.001 |

COR crude odds ratio, AOR adjusted odds ratio

functional and social disability because individuals with higher disability scores will tend to be poorer.

Though the likelihood of being in higher disability clusters was higher in rural areas in general compared to

urban areas, there were clear disparities between health zones within rural areas. In fact, participants form Walungu health zone were worse off in terms of functional, cognitive and social disability compared to those living in Katana and Miti-Murhesa health zone. This difference is substantiated by the fact that Walungu zone had experienced longer and more direct effects of armed conflicts than Katana and Miti-Murhesa. It has been shown that the severity and gender dimensions of armed conflicts in Walungu has compromised family relationships and social interaction [50-52], resulting in long-lasting effects of war including post-traumatic disorders, depression, destruction of the social structure and economy of the region [53]. This protracted fragile context explains the higher burden of complex medico-psychosocial conditions observed in Walungu compared to other rural health zones and calls for rethinking healthcare programs in post-conflict regions in order to develop healthcare programs that are responsive to people's individual healthcare needs and context.

In this study, we found no significant association between the child's acute malnutrition status and the probability of a mother falling in higher disability clusters. We hypothesized that most severe cases of child malnutrition with a higher likelihood of impacting on the mother's functional, cognitive and social ability were more likely taken care of as inpatients in therapeutic feeding centers rather than in the community. Future studies involving mothers of inpatient children with severe acute malnutrition and by including qualitative approaches may clarify such a link.

#### Strengths and limitations

This study had some limitations. First, these findings have limited generalisability to people living with other health conditions and which are difficult to reliably identify at community level in settings where patient's medical records are not available. Neither can our findings be generalisable to individuals severely physically or mentally impaired to the extent that they could not consent to the study or withstand the interview. However, we believe that by having extended the sampling to caregivers and randomly selected individuals in the neighborhood contributed to gaining insights in health status of individuals not presenting with the tracer conditions aforementioned and helped alleviating the effect of this potential bias. The sampling was also confined to villages close to the health centre in each health area in order to be able to assess how change in the way healthcare services are being provided at the health centre may have impacted on the health status of the population, in the framework of the research for development project on which this study draws. The sample selection was based on the assumption that people in villages far away from the health centre were more likely to seek health services from health centres in neighboring health areas, therefore would have been hard to follow up with linkage to the research for development project on which this study is drawn. in the framework of the research for development project on which this study draws. This selection might have induced a selection bias whereby individuals living in remote villages relative to the health centre may have limited access to health services, which in turn may impact on their health outcomes.

Sixty three percent of our respondents were female. This may partly be explained by the fact that the great majority of women in eastern DR Congo were housewives and more likely to be present at home when the interviewers passed by, with men moving around looking for occasional job opportunities in a region where the informal work sector or daily labour reigns. This may have resulted in a sampling bias, over representing women. We do acknowledge that such a bias might result in overestimating associations since women are more likely to score higher on WHODAS than men [54, 55]. Our results should be interpreted accordingly. However, the replication of the associations observed across different settings with heterogeneous confounding structure suggests that this potential sampling bias likely has little effect on the pattern of associations we observed.

Akin to other observational studies, our analysis is subject to residual confounding. For example, we did not have data on psychosocial factors like anxiety and depression that are shown to be associated with higher disability scores [56]. In addition, we could not directly measure the effect of family and social interactions on health status clustering. A recent systematic review stressed the link between social relationship, mental health and wellbeing in physical disability [56]. Further studies are needed to explore the extent to which these factors may influence health status clustering.

Our study also has a number of strengths. It provides a unique insight into health status clustering of individuals at community level in a post-conflict setting. Based on modern and robust cluster analysis tools, this study proposes an innovative and programmatically useful approach to measuring health status and disability of individuals using the WHODAS. Our results can guide design and implementation of appropriate healthcare programs that fit people's needs and leverage the overall human health capital. This study also provides precise measures of associations estimates with narrow confidence intervals suggesting a sample size large enough, in a region relatively hard-to-reach and to some extent scientifically isolated.

### Conclusion

Population health stratification based on cognitive, functional social dependency at primary healthcare level may be a powerful lever for prioritization, design, implementation and scale-up of integrated care interventions with a great potential to improve quality of lives of people living in LMICs. The hierarchical health status clustering implies the necessity for a programmatic approach to the provision of healthcare services for individuals and communities in settings where resources are scarce. Our results suggest that health clustering derived from WHODAS domains scores has the potential to appropriately discriminate individuals based on the levels of health needs and increase the likelihood of appropriate healthcare service provision to all, included to those with vulnerabilities who could be easily overlooked by the usual disease-based classification of a population.

## **Additional file**

Additional file 1: Distribution of the summary WHODAS score and sub-group analysis. Figure S1. shows the distribution of the summary WHODAS score in the overall study population and by health clusters. Table S1. reports the morbidity factors and WHODAS domains scores of the three enrolment groups. The characteristics of informal caregivers and patients are described in Table S2 and Table S3 respectively. (DOCX 86 kb)

#### Abbreviations

AOR: Adjusted odds ratio; COR: Crude odds ratio; DR: Democratic Republic; HT: Hypertension; ICC: Intraclass correlation coefficient; IQR: Interquartile range; LMICs: Low- and middle-income countries; SD: Standard deviation; SES: Socio-economic status; VIF: Variance inflation factor; WHO: World Health Organisation; WHODAS: World Health Organisation Assessment Schedule

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#### Availability of data and materials

All relevant data are within the manuscript.

#### Authors' contributions

The study was conceived and designed by EBM, HK, GBB and JM. EBM coordinated the data collection and management. EBM and ASL performed the statistical analyses. The report was drafted by EBM and JM and reviewed by FM, HD and HK. All authors have approved the final report.

#### Ethics approval and consent to participate

Respondents provided singed informed consent for participation in the study, either by written signature or by fingerprints, depending on literacy. Child assent was obtained for respondents below 18 years of age. Ethical approval for the study was obtained from the Université Catholique de Bukavu ethics committee and the *hospital*-faculty *ethics committee* of the Université Catholique de Louvain.

#### Consent for publication

N/A

## **Competing interests**

The authors declare that they have no competing interests.

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## **ORIGINAL ARTICLE**

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# Are people most in need utilising health facilities in post-conflict settings? A cross-sectional study from South Kivu, eastern DR Congo

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### ABSTRACT

**Background**: The disruptive effect of protracted socio-political instability and conflict on the health systems is likely to exacerbate inequities in health service utilisation in conflict-recovering contexts.

**Objective**: To examine whether the level of healthcare need is associated with health facility utilisation in post-conflict settings.

**Methods**: We conducted a cross-sectional study among adults with diabetes, hypertension, mothers of infants with acute malnutrition, informal caregivers (of participants with diabetes and hypertension) and helpers of mothers of children acutely malnourished, and randomly selected neighbours in South Kivu province, eastern DR Congo. Healthcare need levels were derived from a combination, summary and categorisation of the World Health Organisation Disability Assessment Schedule 2.0. Health facility utilisation was defined as having utilised in the first resort a health post, a health centre or a hospital as opposed to self-medication, traditional herbs or prayer homes during illness in the past 30 days. We used mixed-effects Poisson regression models with robust variance to identify the factors associated with health facility utilisation.

**Results**: Overall, 82% (n = 413) of the participants (N = 504) utilised modern health facilities. Health facility utilisation likelihood was higher by 27% [adjusted prevalence ratio (aPR): 1.27; 95% CI: 1.13–1.43; p < 0.001] and 18% (aPR: 1.18; 95% CI: 1.06–1.30; p = 0.002) among participants with middle and higher health needs, respectively, compared to those with low healthcare needs. Using the lowest health need cluster as a reference, participants in the middle healthcare need cluster tended to have a higher hospital utilisation level.

**Conclusion**: Greater reported healthcare need was significantly associated with health facility utilisation. Primary healthcare facilities were the first resort for a vast majority of respondents. Improving the availability and quality of health service packages at the primary healthcare level is necessary to ensure the universal health coverage goal advocating quality health for all can be achieved in post-conflict settings.

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# Background

The sustainable development goals (SDG) target 3.8 advocates the principle of universal health coverage (UHC), stressing the importance of health services provision to all people in need in a way that ensures the health and wellbeing of individuals and communities are improved at an affordable cost [1]. Inequitable utilisation of health facilities continues to pose a major threat to the progress towards UHC in resource-constrained settings, particularly in post-conflict contexts [2,3]. Reports from high and low middle-income countries (LMIC) suggest higher utilisation of healthcare services by people with higher socio-economic status [4–6] (vertical inequality). Although modern health facility utilisation (HFU) is not an end on its own, it indicates that people are

seeking care and accessing facilities where services are likely to be available and of acceptable quality.

Globally, there is growing recognition of the need for health systems to shift from being disease-centred to assuming a broader and person-centred perspective that accounts for social and environmental factors, as well as for the uniqueness and complexity of each person's life, needs and goals [7–11]. However, the definition of essential health services and the notion of equity in access to healthcare are not yet person-centred in many LMICs [12,13], where disease control and mortality reduction for specific population groups are still at the centre. A recent study conducted in the Democratic Republic of Congo (DRC) province of South Kivu premised on a broader view of health and proposed a new way of defining health status and care

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needs at community level in LMIC by focussing on people's capacities and abilities to cope with day-today physical, social and emotional challenges [14]. By approaching individual health through measurement of performance in various life domains, including cognition, mobility, self-care, getting along with others, domestic and professional duties, social life and participation, the study revealed a clear needs gradient among community members which goes beyond the mere presence or absence of disease or disability.

Ensuring equitable utilisation of healthcare according to needs remains a challenge in postconflict, resource-constraint settings like the DRC. The health system has been fragilised by nearly three decades of socio-political turmoil in the eastern provinces. Because of decreasing public funding and insufficient leadership, health financing heavily relies on out-of-pocket payments and external aid (mainly humanitarian assistance) [15]. The distribution of health service utilisation is likely to be skewed towards the richest in urban areas [15], potentially perpetuating the inverse care law pattern [16,17] whereby the health service utilisation balance is deteriorated against those most in need, leaving individuals in complex medico-psychosocial situations behind.

In the era of the SDG 3.8, assessing the link between health needs and health facility utilisation is necessary for the development of health systems that are responsive to people's need for autonomy, self-management and coping with life's physical, emotional, and social challenges [18]. This is even more true in resourcelimited and post-conflict settings where horizontal inequalities can also contribute to instability. Given that protracted socio-political instability and conflict are likely to exacerbate inequities in health service utilisation in post-conflict and fragile contexts, in this study we set to examine the association between healthcare needs and modern health facility utilisation (HFU) in South Kivu.

# Methods

# Study design, settings and population

This cross-sectional study was carried out in four health zones (HZ) of South Kivu Province in eastern DRC: one semi-urban (Bagira) and three rural (Miti-Murhesa, Katana and Walungu). Bagira HZ is located on the periphery of the province capital (Bukavu). Katana and Miti-Murhesa HZ span the national road connecting Bukavu and Goma, the two major cities of the Kivu. Walungu was one of the most conflictaffected HZ in the previous decades. The instability in the Kivu exacerbated population poverty, caused the collapse of local markets and diminished livestock production to almost its disappearance [19], thus creating the conditions for a vicious cycle of sociopolitical instability [20]. From the health system point of view, each province in DRC is organized in health zones, and these in turn in health areas (HA). Within each HZ primary healthcare services are offered through health centres providing the minimum service package. This focuses on maternal and child preventive and curative care [15]. There are on average 15 HA per health zone in South Kivu. Secondary care is provided at HZ level hospitals offering inpatient and reference services, in addition to technical support to health centres through integrated supervision.

Six HA (estimated population of 105,047 inhabitants in 2017) were purposively selected for this study based on security constraints, geographical accessibility and availability and quality of data at the health centres. The study population is comprised of three separate groups: 1) the tracer group: i.e. adults in one of the following conditions: either being a mother of a child with global acute malnutrition (defined as MUAC  $\leq 11.5$  or nutritional oedema); or an individual with history of self-reported diabetes and/or hypertension; 2) their caregiver (or helper of mothers with a malnourished child), and 3) a randomly selected neighbour. Participants were aged at least 15 years. These sub-population categories were defined to gain better insight into different perspectives of health disability levels observable at primary healthcare facilities in eastern DRC. The likelihood of complex health situations spanning the medical, psychological and social spheres of an individual's life was deemed high in these sub-populations [21,22]. The selected health conditions are prevailing in South Kivu [23-25], are relatively easy to identify and manageable even at primary care level when without complications.

# Sampling procedure and selection of participants

This study is nested in a broader research project that aims to investigate to what extent modifying how health services are provided at primary care level can influence the perceived health status of community members. For the current analysis, we used data from the baseline cross-sectional survey of the cohort that is enrolled in the main research project. The baseline study was conducted in villages around six health centres in the selected health areas. Within villages, households with individuals with self-reported diabetes, hypertension or child acute malnutrition were pre-identified by community health workers. Subsequently, one caregiver living in the same household as the participant with the tracer condition and one random neighbour were selected by trained data collectors (locally recruited nurses). In each village, data collectors were guided by community health workers during the door-to-door visits. Further details on this methodology are provided elsewhere [14].

Overall, 1266 participants who provided valid data on cognitive, functional and social disability were included in the main research study. Of these, we extracted a sub-sample of 553 participants who reported an acute illness during the 30 days preceding the interview for the current study. A set of questions were asked about the history of a possible acute illness in the past 30 days prior to the interview and if and where treatment was sought in the first resort. Questions covered a broad range of acute health conditions, either self-diagnosed or diagnosed by a health professional, such as fever, diarrheal, abdominal or generalized pain, difficulty in breathing, pneumonia, syncope, malaria, flu-like syndrome or any other acute conditions (to be specified if possible). We used this inclusion criteria to reduce recall bias.

# Data collection and variables

A structured and pre-tested questionnaire was used to collect data on socio-demographics, social integration and health facility utilisation between December 2017 and March 2018. The 36-item WHODAS 2.0 questionnaire was used to examine the cognitive, functional and social disability of the participants [26]. WHODAS 2.0 is a standard tool with cross-cultural validity extensively used across WHO regions to measure the impact of any health condition in terms of performance in a given life domain. WHODAS 2.0 covers following domains: cognition (understanding and communicating), mobility (moving and getting around), self-care (ability to attend to personal hygiene and safety), getting along (interacting with other people), life activities (home responsibilities, leisure, work and school) and social participation (joining in community activities, social participation and engagement). The WHODAS 2.0 was translated to and back translated from Kiswahili (the national language widely spoken in eastern DRC), to ensure cross-cultural and conceptual equivalence [27]. Details about the translation process are provided elsewhere [14]

WHODAS 2.0 measures decrement in performance in life domains making it a valuable instrument for health needs identification and monitoring; interventions design, and assessment of their outcomes and effectiveness; priority setting and resource allocation [26]. WHODAS 2.0 was used to define the main predictor variable under this study. A principal component analysis of the seven summary scores of the WHODAS 2.0 domains was performed with the use of the FactoMineR software package in R, prior to a hierarchical clustering of the principal components and guided by Ward's method [28]. Three health needs clusters were generated and used as a threelevel ordinal variable reflecting the healthcare needs gradient corresponding to low, moderate and high disability levels.

# Dependent variable

The primary outcome is modern health facility utilisation, a binary variable referring to whether or not a person has utilised in the first resort a health post, a health centre or a hospital as opposed to selfmedication, traditional herbs or prayer homes during the illness episode in the 30 days preceding the survey.

As secondary outcomes, two additional binary variables were defined as follows: 1) utilisation of primary health facilities (coded as 1 if a person reported having utilised as a first resort either a health post or centre during the 30 days prior to the interview, and as 0 if otherwise); 2) hospital utilisation coded as 1 if a person reported having utilised as a first resort a secondary level health facility during the 30 days prior to the interview, and as 0 if otherwise. Primary health facilities are officially run by nurses and offer the minimum package of activity. Secondary level health facilities are those, both public and private, with permanently appointed medical doctors, offering the complementary package of activity through hospitalisation and reference services.

# Independent variables

A wealth status variable was created in three steps. First, a Multiple Correspondence Analysis was run on housing characteristics (pavement and permanent, semi-permanent or temporary structure) and ownership of a television, a radio, a computer, a manufactured bed, small animals, cattle, land, a bicycle, a motorcycle to create a socio-economic index. Five socio-economic quintiles were then derived from wealth indices, following an approach commonly used in Demographic and Health Surveys conducted in low- and middle-income countries. To create the three socio-economic classes (least poor, middle poor, poorest), the two lowest (poorest 40%) and the two middle (40%) quintiles were, respectively, merged as suggested by Filmer and Pritchett [29].

Social cohesion and networking have been shown to be important social determinants of health and primary healthcare utilisation [30,31]; they were approximated in this study by belonging to local social and saving cooperatives and attendance to religious activities.

Other independent variables included in the analyses were sociodemographic characteristics (sex and age of the respondent, occupation of the head of household), health zone of residence and the enrolment status of the participant (as described above, either an adult with self-reported chronic morbidity or a mother of child with acute malnutrition, a caregiver and a randomly selected neighbour).

# **Statistical analyses**

Chi-squared and Student's t tests were used to compare the general characteristics of the study population by HFU. To examine the association between HFU and health needs clustering, we run bivariable and multivariable mixed-effects Poisson regression models with robust variance. In these models, health needs level was treated as a fixed effect and health area as a random effect to account for the intrinsic non-independence of observations in the same health area. The choice of a modified Poisson regression over a logistic regression was justified by the fact that in presence of common outcomes (i.e. prevalence higher than 10%), odds ratios derived from logistic regression tend to bias the association away from the null. In such a scenario, alternative models directly estimating prevalence ratio (PR) are preferred to generate more accurate point and interval estimates [32,33]. All the study variables examined in the univariate regression models were maintained in multivariable models based on either a conservative p-value  $\leq 0.2$  or on public health plausibility. Multicollinearity between explanatory variables was suspected on the basis of a variance inflation factor greater than 10. We used Stata 15 for the analyses. The significance was set to p < 0.05 (two-sided test).

### **Ethical considerations**

Ethical clearance was obtained from the Faculty of Medicine of Université Catholique de Bukavu and the Université Catholique de Louvain. Written informed consent was received from all participants, either by signature or fingerprint, depending on literacy. Child assent was obtained for respondents below 18 years of age, after a parent or guardian's consent. The research tools, including the consent forms, were translated to Kiswahili. Data collectors were trained on ethics and were requested to fully read out and explain the aim of the study to the respondents prior to enrolment in the study. Participants were clearly informed they were free to drop out of the interview at any time they would deem it necessary.

# Results

## Characteristics of the study participants

It was found that 59.5% of the study participants were enrolled in the tracer group; neighbours and informal caregivers were 20.9% and 19.6%, respectively. Over half of the participants (52.2%) were in the lower health need level and 18.9% in the highest health needs level. The mean age was 53.2 (SD: 18.2), men were more represented in the study sample (67.1%) and 56.1% of the participants reported attending church at least twice a week. HFU was dependent on the health needs level (p < 0.001) and unrelated to wealth class (p = 0.772) (Table 1).

### Factors associated with health facility utilisation

Among the study participants who reported being sick 30 days prior to being interviewed, 18.1% did not use any formal health facility, rather resorted to traditional healers, prayer homes or self-medication; 12.1% went to hospitals (Table 2).

Health needs level was significantly associated with high HFU. In fact, the level of HFU was higher by 27% [adjusted prevalence ratio (aPR): 1.27; 95% CI: 1.13–1.43; *p* < 0.001] and 18% (aPR: 1.18; 95%) CI: 1.06–1.30; p = 0.002) among participants with middle and higher health needs, respectively, compared to those with lower health needs (Table 3). Other factors independently and positively associated with HFU were attending church services at least four times a week compared to attending once or less (aPR: 1.17; 95% CI: 1.15–1.20; *p* < 0.001), and being in the middle wealth group compared to being in the poorest group (aPR: 1.12; 95% CI: 1.06-1.19; p < 0.001). Factors independently and negatively associated with HFU were the health status of the participant at enrolment, with caregivers (aPR: 0.77; 95% CI: 0.68–0.88; p < 0.001) and participants in the tracer group (aPR: 0.73; 95% CI: 0.57–0.95; p = 0.017) being less likely to utilise health facilities than neighbours; and younger age (aPR: 0.997; 95% CI: 0.995-0.999; p = 0.017).

Analysis of secondary outcomes is reported in Tables 4 and 5. Compared to those with lower health needs, participants with middle health needs were less likely to use primary health facilities (PR: 0.93; 95% CI: 0.88–0.99; p = 0.015) and much more likely to use hospitals (PR: 2.17; 95% CI: 1.44–3.29; p < 0.001). Additionally, participants in the tracer group (PR: 3.75; 95% CI: 1.22–11.57; p = 0.021) and their caregivers (PR: 6.55; 95% CI: 5.25–8.18; p < 0.001) had significantly higher hospital utilisation levels compared to neighbours.

# Discussion

This community-based cross-sectional study is one of the first studies to apply a comprehensive approach to measuring healthcare needs and its association with health facility utilisation at community level in post-conflict settings. We investigated HFU in a heterogeneous group composed of adults with diabetes, hypertension, mothers of children with acute malnutrition, their informal caregivers and randomly

Table 1. Characteristics of the study participants by health facility utilisation status.

|   | Health facili | ty utilisation |             |         |
|---|---------------|----------------|-------------|---------|
| Characteristics                                     | Yes           | No             | Total       | P value |
| Enrolment status (N = $445$ )                       |               |                |             | 0.195   |
| Neighbours  | 78 (83.9)     | 15 (16.1)      | 93 (20.9)   |         |
| Informal caregivers                                 | 66 (75.9)     | 21 (24.1)      | 87 (19.6)   |         |
| Tracer group  | 223 (84.2)    | 42 (15.8)      | 265 (59.5)  |         |
| Healthcare needs and disability level ( $N = 418$ ) |               |                |             | < 0.001 |
| Low   | 159 (72.9)    | 59 (27.1)      | 218 (52.2)  |         |
| Moderate  | 111 (91.7)    | 10 (8.3)       | 121 (29.0)  |         |
| High  | 63 (79.8)     | 16 (22.2)      | 79 (18.9)   |         |
| Zone $(N = 519)$                                    |               |                |             | < 0.001 |
| Bagira  | 127 (79.9)    | 32 (20.1)      | 159 (32.5)  |         |
| Miti-Murhesa and Katana*                            | 172 (76.4)    | 53 (23.6)      | 255 (46.0)  |         |
| Walungu   | 99 (94.3)     | 6 (5.7)        | 105 (21.5)  |         |
| Sex $(N = 499)$                                     |               |                |             | 0.445   |
| Female  | 131 (79.9)    | 33 (20.1)      | 164 (32.9)  |         |
| Male  | 277 (82.7)    | 58 (17.3)      | 335 (67.1)  |         |
| Age (mean), $(N = 494)$                             | 54.8 (17.7)   | 52.1 (18.8)    | 53.2 (18.2) | 0.195   |
| Age group (N = 494)                                 |               |                |             | 0.124   |
| <40 years   | 89 (76.1)     | 28 (23.9)      | 117 (23.7)  |         |
| 40–59 years   | 132 (85.7)    | 22 (14.3)      | 154 (31.2)  |         |
| ≥60 years   | 183 (82.1)    | 40 (17.9)      | 223 (54.1)  |         |
| Saving membership (N = 504)                         |               |                |             | 0.277   |
| Yes   | 315 (80.8)    | 75 (19.2)      | 390 (78.2)  |         |
| No  | 93 (85.3)     | 16 (14.7)      | 109 (21.8)  |         |
| Weekly church attendance ( $N = 483$ )              |               |                |             | 0.011   |
| ≤1 time/week  | 163 (76.9)    | 49 (23.1)      | 212 (43.9)  |         |
| 2–3 times   | 135 (83.9)    | 26 (16.1)      | 161 (33.3)  |         |
| ≥4 times  | 99 (90)       | 11 (10)        | 110 (22.8)  |         |
| Chronic morbidity ( $N = 467$ )                     |               |                |             | 0.021   |
| Absent  | 139 (76.0)    | 44 (24.0)      | 183 (39.1)  |         |
| Diabetes or hypertension                            | 214 (84.9)    | 38 (15.1)      | 252 (53.9)  |         |
| Diabetes and hypertension                           | 30 (90.9)     | 3 (9.1)        | 33 (7.0)    |         |
| Wealth class (N = $504$ )                           |               |                |             | 0.772   |
| Least poor  | 86 (83.3)     | 16 (15.7)      | 102 (20.2)  |         |
| Middle poor   | 175 (81)      | 41 (19)        | 216 (42.9)  |         |
| Poorest   | 152 (81.7)    | 34 (18.3)      | 186 (36.9)  |         |
| Head of household's occupation ( $N = 459$ )        |               |                |             | 0.706   |
| Formal work   | 54 (87.1)     | 8 (12.9)       | 62 (13.5)   |         |
| Informal work                                       | 67 (81.7)     | 15 (18.3)      | 82 (17.9)   |         |
| Petty trade/farming                                 | 175 (80.7)    | 42 (19.3)      | 217 (47.3)  |         |
| No occupation                                       | 81 (82.7)     | 17 (17.3       | 98 (21.3)   |         |
|   |               |                |             |         |

Data are n (%), unless otherwise specified. \*: Miti-Murhesa and Katana health zones are grouped since they were formerly constituting the Katana health zone. They share the same characteristics in terms of health coverage, location and level of past exposure to conflict. Enrolment of the participants spanned villages across the border between the two health zone borders.

selected neighbours. The majority of them utilized health facilities as a first resort in case of illness. Informal caregivers and participants in the tracer group were less likely to utilise modern health facilities compared to neighbours. Participants with moderate and higher level of health needs and disability were also more likely to utilise modern health facilities compared to those in with lower health needs and disability level. They tended to seek care at hospital level rather than at primary healthcare facilities, possibly expecting a more comprehensive management of their condition.

The level of HFU observed in this study is slightly higher than the 76.7% reported in a Kenyan study [34]. This relatively high HFU could be an effect of a selective sample of people with known morbidities. However, data from a study conducted in another eastern DRC province showed a similarly high HFU [35], suggesting additional explanations are plausible. For example, in post-conflict settings, a considerable number of humanitarian actors provide financial and capacity building support to health facilities, thus helping them remain functional. Despite (or thanks to) the ongoing conflict, the health system in South Kivu is the best funded in the country, if humanitarian aid is taken into account [15]. Other factors such as population resilience and adaptation capacity of health providers might also contribute to maintain this level of HFU in health zones of South Kivu that are progressively recovering from conflict. Further research to inform health service provision strategies in post-conflict settings is needed for cross-country learning.

 Table 2. Health facility utilisation among study participants

 who reported being sick 30 days prior to the survey.

| Health facility type                    | N (%)      |
|---|------------|
| Health post                             | 36 (7.1)   |
| Public health centre in the health area | 248 (49.2) |
| Private health centre                   | 68 (13.5)  |
| Hospital                                | 61 (12.1)  |
| Traditional healers                     | 16 (3.2)   |
| Prayer homes                            | 5 (1.0)    |
| Self-medication and other               | 70 (13.9)  |

| Table J. Factors associated with health facility utilisation | Table | 3. | Factors | associated | with | health | facility | utilisation |
|--|-------|----|---------|------------|------|--------|----------|-------------|
|--|-------|----|---------|------------|------|--------|----------|-------------|

| Variable                              | Unadjusted PR (95% CI) | P value | Adjusted PR (95% CI) | P value |
|---------------------------------------|------------------------|---------|----------------------|---------|
| Healthcare needs and disability level |                        |         |                      |         |
| Low                                   | Ref.                   |         | Ref.                 |         |
| Moderate                              | 1.27 (1.10–1.48)       | 0.002   | 1.27 (1.13–1.43)     | <0.001  |
| High                                  | 1.11 (1.01–1.20)       | 0.022   | 1.18 (1.06–1.30)     | 0.002   |
| Enrolment status                      | · · · ·                |         | · · · ·              |         |
| Neighbours                            | Ref.                   |         | Ref.                 |         |
| Caregivers                            | 0.90 (0.86-0.95)       | < 0.001 | 0.77 (0.68-0.88)     | <0.001  |
| Tracer group                          | 1.00 (0.91–1.11)       | 0.939   | 0.73 (0.57–0.95)     | 0.017   |
| Health zone                           |                        |         |                      |         |
| Bagira                                | Ref.                   |         | Ref.                 |         |
| Miti-Murhesa and katana               | 0.96 (0.92-0.99)       | 0.025   | 0.92 (0.74-1.14)     | 0.462   |
| Walungu                               | 1.18 (1.13–1.23)       | < 0.001 | 1.18 (0.90–1.53)     | 0.233   |
| Education (years)                     | 1.00 (0.99–1.02)       | 0.657   | 0.99 (0.97-1.02)     | 0.688   |
| Sex                                   |                        |         |                      |         |
| Male                                  | Ref.                   |         | Ref.                 |         |
| Female                                | 1.04 (0.98–1.11)       | 0.206   | 1.06 (0.96–1.17)     | 0.238   |
| Age                                   | 1.00 (1.00-1.00)       | 0.162   | 1.00 (0.99–1.00)     | 0.017   |
| Saving membership                     |                        |         |                      |         |
| No                                    | Ref.                   |         | Ref.                 |         |
| Yes                                   | 1.05 (0.97–1.15)       | 0.222   | 0.98 (0.88-1.10)     | 0.773   |
| Church attendance                     |                        |         |                      |         |
| ≤1 time/week                          | Ref.                   |         | Ref.                 |         |
| 2–3 times                             | 1.10 (1.03–1.17)       | 0.003   | 0.98 (0.90-1.06)     | 0.616   |
| ≥4 times                              | 1.19 (1.02–1.39)       | 0.029   | 1.17 (1.15–1.20)     | < 0.001 |
| Occupation of head of household       |                        |         |                      |         |
| Formal salaried                       | Ref.                   |         | Ref.                 |         |
| Informal worker                       | 0.94 (0.82-1.08)       | 0.356   | 1 (0.71–1.40)        | 0.985   |
| Petty trade/farming                   | 0.92(0.83-1.02)        | 0.129   | 0.89 (0.70-1.14)     | 0.362   |
| No occupation                         | 0.95 (0.87-1.05)       | 0.302   | 0.87 (0.64-1.18)     | 0.375   |
| Wealth class                          |                        |         |                      |         |
| Poorest                               | Ref.                   |         | Ref.                 |         |
| Middle poor                           | 1.00 (0.89–1.11)       | 0.940   | 1.12 (1.06–1.19)     | < 0.001 |
| Least poor                            | 1.03 (0.87–1.22)       | 0.702   | 1.06 (0.87–1.31)     | 0.548   |
| Chronic morbidity                     |                        |         |                      |         |
| Absent                                | Ref.                   |         | Ref.                 |         |
| Diabetes or hypertension              | 1.12 (1.05–1.19)       | <0.001  | 1.14 (0.92–1.41)     | 0.234   |
| Diabetes and hypertension             | 1.20 (1.09–1.32)       | <0.001  | 1.24 (0.95–1.62)     | 0.114   |

Ref.: reference category. The factors included in the multivariable regression analysis are healthcare needs and disability level, enrolment status, health zone of residence, education (years of schooling), being member of a local saving organisation, church attendance, occupation of the head of household, wealth class and history of chronic morbidity (diabetes and hypertension).

Participants enrolled in the tracer group and their caregivers were unexpectedly less likely to utilise modern health facilities, but had higher hospital utilisation level than their neighbours. This may reflect the traditional organisation of healthcare services whereby chronic diseases are managed at the hospital level in most LMIC settings [36,37], including South Kivu. However, most vertical or selective donorfunded health programs are disproportionately focused on mortality reduction and disease indicators rather than on person-centred approaches of healthcare service organisation. This may lead to a shrinking role of primary healthcare for chronic patients and an increased utilisation of costly hospital-based curative services in post-conflict settings where the government leadership and health regulatory powers are weak. Further research is needed to understand how primary healthcare priorities for chronic conditions should be set in conflict-affected settings to overcome the potential competing visions between international donors' vertical approaches and local government ambitions of building strong and sustainable primary healthcare systems [38-40].

Being part of a social network can influence health-seeking behaviour and healthcare service

utilization. All studied health centres facilitate social initiatives to enhance the economic and social capital of vulnerable community members. These include, for example, the small-scale village saving and loan cooperative AVEC (from French 'Association Villageoise d'Epargne et de Credit') or social support clubs for the elderly. Although these initiatives make the health centre pivotal to community dynamics and are expected to encourage their members to resort to modern health facility services [41,42], we could not find such an effect in our study. The lower HFU observed among members of local saving cooperatives could reflect a reverse causation whereby those joining saving cooperatives are more likely to be young and economically active, thus less prone to severe health problems that would require health care. It could also mirror the positive effects of social integration and connectedness on self-esteem, sense of well-being, social competence, self-efficacy in management of chronic conditions, depression and stress responses [30].

Questions about the link between religion and health have often raised stormy debates [43]. Attendance of religious services has been associated with modern HFU and positive health outcomes
Table 4. Factors associated with the utilisation of primary healthcare facilities

| Variable                              | Unadjusted PR (95% CI) | P value | Adjusted PR (95% CI) | p value |
|---------------------------------------|------------------------|---------|----------------------|---------|
| Healthcare needs and disability level |                        |         |                      |         |
| Low                                   | Ref.                   |         | Ref.                 |         |
| Moderate                              | 0.93 (0.85-1.03)       | 0.154   | 0.93 (0.88–0.99)     | 0.015   |
| High                                  | 0.84 (0.71-1.00)       | 0.050   | 1.00 (0.83–1.19)     | 0.970   |
| Enrolment status                      |                        |         |                      |         |
| Neighbours                            | Ref.                   |         | Ref.                 |         |
| Caregivers                            | 0.89 (0.80-0.99)       | 0.026   | 0.85 (0.76-0.94)     | 0.003   |
| Tracer group                          | 0.88 (0.75-1.04)       | 0.129   | 0.93 (0.80-1.07)     | 0.290   |
| Health zone                           |                        |         |                      |         |
| Bagira                                | Ref.                   |         | Ref.                 |         |
| Miti-Murhesa and katana               | 1.01 (0.92–1.11)       | 0.813   | 0.78 (0.56-1.08)     | 0.133   |
| Walungu                               | 1.20 (1.14–1.26)       | < 0.001 | 1.01 (0.80–1.28)     | 0.915   |
| Education (years)                     | 0.99 (0.97-1.00)       | 0.13    | 1.00 (0.98–1.02)     | 0.927   |
| Sex                                   |                        |         |                      |         |
| Male                                  | Ref.                   |         | Ref.                 |         |
| Female                                | 0.96 (0.90-1.02)       | 0.182   | 1.03 (0.94–1.11)     | 0.562   |
| Age                                   | 1.00 (1.00-1.00)       | 0.943   | 1.00 (1.00–1.00)     | 0.620   |
| Saving membership                     |                        |         |                      |         |
| No                                    | Ref.                   |         | Ref.                 |         |
| Yes                                   | 0.97 (0.88-1.06)       | 0.45    | 0.91 (0.85–0.98)     | 0.013   |
| Church attendance                     |                        |         |                      |         |
| ≤1 time/week                          | Ref.                   |         | Ref.                 |         |
| 2–3 times                             | 1.03 (0.93–1.14)       | 0.553   | 1.25 (1.18–1.32)     | < 0.001 |
| ≥4 times                              | 0.99 (0.94-1.05)       | 0.851   | 1.11 (1.03–1.18)     | 0.004   |
| Occupation of head of household       |                        |         |                      |         |
| Formal salaried                       | Ref.                   |         | Ref.                 |         |
| Informal worker                       | 1.27 (1.08–1.49)       | 0.004   | 1.13 (0.92–1.39)     | 0.254   |
| Petty trade/farming                   | 1.32 (1.03–1.70)       | 0.028   | 1.32 (1.15–1.52)     | < 0.001 |
| No occupation                         | 1.16 (0.99–1.35)       | 0.069   | 1.02 (0.75–1.39)     | 0.883   |
| Wealth class                          |                        |         |                      |         |
| Poorest                               | Ref.                   |         | Ref.                 |         |
| Middle                                | 0.99 (0.95-1.02)       | 0.407   | 1.09 (0.98–1.21)     | 0.094   |
| Least poor                            | 0.84 (0.71-0.98)       | 0.028   | 1.00 (0.86–1.17)     | 0.977   |
| Morbidity                             |                        |         |                      |         |
| Absent                                | Ref.                   |         | Ref.                 |         |
| Diabetes or hypertension              | 0.93 (0.79-1.08)       | 0.348   | 0.79 (0.69–0.91)     | 0.001   |
| Diabetes and hypertension             | 0.80 (0.64–1.00)       | 0.047   | 0.76 (0.57–1.01)     | 0.06    |

Ref.: reference category. Primary health facilities include health posts and health centres. The factors included in the multivariable regression analysis are healthcare needs and disability level, enrolment status, health zone of residence, education (years of schooling), being member of a local saving organisation, church attendance, occupation of the head of household, wealth class and history of chronic morbidity (diabetes and hypertension).

[44–46]. Our finding may reflect high religious service attendance among participants with higher perceived health needs and vulnerability. In South Kivu, many health facilities are owned by and located near churches. Religious services attendance may also be an opportunity for social interaction, integration, and positive attitudes sharing, which can, in turn, exert a positive influence on health-seeking behaviours [44,47,48].

The association between wealth status and modern HFU [4,49] is not clear in our study. While respondents in the middle wealth level seemed to have higher utilization than those in the poorest group, utilization of primary health care and hospitals was comparable across wealth levels, as it was also the case in a study from Kenya [34]. This may be due to little heterogeneity across the asset-based wealth index in this predominantly rural population. Furthermore, in some post-conflict health zones of the Kivu, specific health services related to chronic diseases are subsidised by humanitarian organisations and are provided free of charge irrespectively of the patient's wealth status. This is the case for insulin and some oral antidiabetic drugs, treatment services for

child malnutrition or management of pregnancyrelated conditions, among other services.

With regard to household head's occupation, our results seem suggesting a differential health-seeking behaviour between households headed by petty trader or farmer, and those headed by formal salaried. Farmers and petty traders are likely to have a lower socio-economic position and education level, and more limited access to specialized and often expensive health services offered at hospitals compared to formal salaried [50]. On the other hand, the quality of services offered at primary healthcare level may be deemed sub-optimal by richer and more educated individuals. This finding supports the claim that one of the most efficient ways of bringing quality care to the most vulnerable in poor and post-conflict fragile contexts is to invest in strong primary healthcare schemes [51,52].

#### Study limitations

This is one of the first studies to apply a comprehensive approach to measuring healthcare needs and its association with health facility utilisation at the community

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| Variable                              | Unadjusted PR (95% CI) | P value | Adjusted PR (95% CI) | P value |
|---------------------------------------|------------------------|---------|----------------------|---------|
| Healthcare needs and disability level |                        |         |                      |         |
| Low                                   | Ref.                   |         | Ref.                 |         |
| Moderate                              | 2.38 (1.53-3.72)       | < 0.001 | 2.17 (1.44–3.29)     | < 0.001 |
| High                                  | 2.92 (2.43-3.51)       | < 0.001 | 1.30 (0.87–1.93)     | 0.194   |
| Enrolment status                      |                        |         |                      |         |
| Neighbours                            | Ref.                   |         | Ref.                 |         |
| Caregivers                            | 2.25 (0.92-5.49)       | 0.076   | 6.55 (5.25-8.18)     | <0.001  |
| Tracer group                          | 3.72 (1.53–9.07)       | 0.004   | 3.75 (1.22–11.57)    | 0.021   |
| Health zone                           |                        |         |                      |         |
| Bagira                                | Ref.                   |         | Ref.                 |         |
| Miti-Murhesa and katana               | 0.91 (0.60-1.40)       | 0.674   | 3.69 (0.42-32.85)    | 0.241   |
| Walungu                               | 0.19 (0.04-1.096)      | 0.044   | 1.04 (0.24-4.42)     | 0.962   |
| Education (years)                     | 1.07 (0.98–1.17)       | 0.149   | 0.99 (0.88–1.11)     | 0.849   |
| Sex                                   |                        |         |                      |         |
| Male                                  | Ref.                   |         | Ref.                 |         |
| Female                                | 1.28 (0.87–1.90)       | 0.209   | 0.98 (0.45-2.10)     | 0.952   |
| Age                                   | 1.01 (1.00–1.02)       | 0.163   | 1.0 0 (0.98–1.02)    | 0.944   |
| Saving membership                     |                        |         |                      |         |
| No                                    | Ref.                   |         | Ref.                 |         |
| Yes                                   | 1.27 (0.89–1.83)       | 0.193   | 1.38 (0.59–3.22)     | 0.454   |
| Church attendance                     |                        |         |                      |         |
| ≤1 time/week                          | Ref.                   |         | Ref.                 |         |
| 2–3 times                             | 0.99 (0.50–1.96)       | 0.979   | 0.21 (0.07–0.63)     | 0.005   |
| ≥4 times                              | 1.15 (0.74–1.79)       | 0.535   | 0.70 (0.55–0.89)     | 0.004   |
| Occupation of head of household       |                        |         |                      |         |
| Formal salaried                       | Ref.                   |         | Ref.                 |         |
| Informal worker                       | 0.46 (0.28–0.75)       | 0.002   | 0.89 (0.08–9.40)     | 0.919   |
| Petty trade/farming                   | 0.29 (0.11–0.76)       | 0.011   | 0.27 (0.12–0.61)     | 0.001   |
| No occupation                         | 0.78 (0.53–1.13)       | 0.188   | 1.06 (0.10–10.83)    | 0.96    |
| Wealth class                          |                        |         |                      |         |
| Poorest                               | Ref.                   |         | Ref.                 |         |
| Middle                                | 0.98 (0.72–1.33)       | 0.887   | 0.66 (0.22–1.95)     | 0.450   |
| Least poor                            | 2.23 (1.21–4.10)       | 0.010   | 1.00 (0.33–3.05)     | 0.995   |
| Morbidity                             |                        |         |                      |         |
| Absent                                | Ref.                   |         | Ref.                 |         |
| Diabetes or hypertension              | 2.61 (1.16–5.87)       | 0.021   | 3.64 (1.82–7.27)     | <0.001  |
| Diabetes and hypertension             | 4.72 (1.77–12.58)      | 0.002   | 4.77 (1.52–14.95)    | 0.007   |

Ref.: Reference category. The factors included in the multivariable regression analysis are healthcare needs and disability level, enrolment status, health zone of residence, education (years of schooling), being member of a local saving organisation, church attendance, occupation of the head of household, wealth class and history of chronic morbidity (diabetes and hypertension).

level in post-conflict settings. Using a sample of people with self-reported diabetes, hypertension and mothers of infant with malnutrition selected from villages around the health centres limits the generalisability of our findings. Besides, this study may not reflect the situation of the most hard-to-reach and remote areas with active armed conflict in South Kivu and where the health needs and service utilisation may be different. Therefore, additional investigations are needed to cover such contexts. That our sample size was not estimated for this study is less likely to introduce a bias given the high precision of point intervals reflected in narrow confidence intervals. We did not do post-hoc power calculations since this practice is increasingly seen as obsolete and discouraged [53]. Although we used a cross-sectional study design, the strength of the associations observed between explanatory factors and HFU despite multivariable adjustment for extensive confounders suggests the associations are real. Our findings may still be subject to residual confounding and unmeasured factors such as distance to health facilities or financial inaccessibility [54]. Furthermore, some of the study participants who reported illness might have not necessarily felt the need to attend a health facility, therefore caution needs to be exerted while interpreting findings about the level of HFU. Finally, the effect estimates

might have been influenced by both social desirability bias and the interviewer effect as data collectors were nurses living in the study sites and the questionnaire could not be self-administered given the low literacy level in these predominantly rural settings. This may have led participants to conceal information about seeking care from informal sources, in which case modern HFU will end up over reported.

## Conclusion

In this post-conflict setting, healthcare need was significantly associated with health facility utilisation whereby those with greater reported needs were more likely to utilise health facilities. Primary healthcare facilities were the first resort for a vast majority of respondents. There is a need to rethink priorities regarding the provision of quality primary healthcare in post-conflict settings. This is critical to achieving the UHC goal of advocating quality health for all.

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## **Author contributions**

The study was conceived and designed by EBM and JM. EBM coordinated the data collection and management and performed the statistical analyses. The manuscript was first drafted by EBM and JM, with input from GBB, HK, CA, MAO, SML and RBN. All authors have approved the final manuscript.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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# **Ethics and consent**

The ethical review boards of the Faculty of Medicine of Université Catholique de Bukavu and the Université Catholique de Louvain cleared the study. A written informed consent was obtained from all participants, either by written signature or by fingerprints, depending on literacy. Child assent was obtained for respondents below 18 years of age, after a parent or guardian's consent.

### Paper context

The disruptive effect of socio-political instability and conflict on the health systems is likely to exacerbate inequities in health in fragile settings. We examined the association between healthcare needs and health facility utilisation in eastern DR Congo. Our study suggests that vulnerable people are using primary health facilities as a first resort. Improving the availability and quality of primary healthcare is critical to the achievment of universal health coverage in post-conflict settings.

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