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"It was just a cold..."

**Circumstances of death in urban West Africa:
A classification of final care pathways of adults in
Ouagadougou (Burkina Faso)**

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Abstract

Identifying the barriers to healthcare access is crucial for public health action. In sub-Saharan Africa, healthcare provision is better in urban than in rural areas. However, costs of consultations and medication remain major obstacles, particularly for adults that rarely benefit from free healthcare programs. Few data are available to study these barriers. At local level, demographic and health surveillance sites (HDSS) collect mortality data. When a death is reported, illness history and symptoms are collected from the next of kin to identify probable cause(s). These verbal autopsies also collect data on the circumstances of death and qualitative narratives of the events leading to death. Rarely used, they could shed light on barriers to access care and improvable circumstances. Using 1,175 VAs of adult deaths (15 and older) from the HDSS of Ouagadougou (2010-2019), we propose a data-driven method to identify typical care pathways using Multiple Correspondence Analysis followed by Hierarchical Clustering, illustrating each cluster by a random sample of relatives' narratives.

We identify five clusters: 35% of deaths occurred at hospital without any specific issue in healthcare reported, 17% died at hospital with cost or healthcare issues, 17% experienced a cessation of care largely induced by costs, 25% occurred at home with no care and 7% of deaths occurred in public spaces, before any care could be received. Beyond the difficulties of the healthcare system to handle cancers and strokes, we highlight some the higher risks of elderly and widowed individual to experience an absence or a cessation of care.

1 Introduction: identifying barriers to accessing care through final care pathways

The identification of obstacles to the use of healthcare services is crucial for public health action. According to WHO and the World Bank, at least half of the world’s population lacks access to essential health services, with an important proportion in sub-Saharan Africa as the sub-continent ranked last on the constructed healthcare coverage index (World Health Organization & World Bank, 2017). In urban settings, the supply of healthcare services is higher than in rural areas (Harang & Varenne, 2013; World Health Organization & World Bank, 2017). However, with the rise in non-communicable diseases (NCDs), urban dwellers, particularly adults, are facing multiple and chronic health issues that are poorly managed (Duthé, 2020). Little is known about healthcare barriers related to adults in an urban context.

If geographic accessibility is a crucial factor (Falchetta et al., 2020; Geldsetzer et al., 2020), living relatively close to health structures does not guarantee efficient healthcare (Gulliford et al., 2002). The costs of consultations and medication remains a major obstacle (World Health Organization & World Bank, 2017). Only a few targeted programs provide free healthcare, mainly for HIV/AIDS, for maternal and child health or for the very poor and elderly (Rossier et al., 2019). In addition, they remain inconsistently implemented due to limited means (Ridde et al., 2013) and difficulty reaching the target populations (Beaugé et al., 2021; Louart et al., 2021). This issue is exacerbated for adults suffering from chronic conditions. Moreover, healthcare services do not necessarily provide adequate or advanced treatments, especially for NCDs, as healthcare systems have been historically targeted towards infectious diseases (Barr et al., 2016). Difficulties in recognizing the need for healthcare and unsatisfactory relationships with healthcare actors (Jaffré & de Sardan, 2003) represent additional obstacles to efficient and timely care.

Yet few data sources allow for a comprehensive assessment of these compounding factors. Indeed, many studies rely on hospital data to reconstruct patient pathways to care-seeking and in-facility care (treatments, referrals, and treatments outcome) (Bonnet et al., 2018; Hanson et al., 2017). However, this by definition excludes individuals who do not access care, arguably the most crucial population to identify.

Just as cause-of-death constitutes crucial information on the epidemiological profile of a population, the analysis of socio-medical circumstances of deaths can reveal the state of healthcare access in a community. When data is available, some studies focus on the place of death as a proxy indicator for healthcare use (Anteneh et al., 2013; Chisumpa et al., 2017). While available data is scarce in Western Africa, a study of a district in rural Burkina Faso highlighted that more than half of deaths occurred at home between 2008 and 2010, a proportion that increases with age (Bado et al., 2016). This reveals that many deaths occur outside of health facilities. In resource-limited contexts, verbal autopsies (VA) aim to estimate biological causes of death via structured interviews with the final caregivers of the deceased about their medical history and symptoms. In contrast, social autopsy ambitions to investigate the contributions of social, behavioral and health-system factors to death (Kalter et al., 2011; Moyer et al., 2017). Based on a similar interview process that can extend to healthcare professionals, it provides additional information about the deceased, including illness recognition, healthcare use, costs and socio-economic circumstance. The idea of the social autopsy method is not only to understand the medical cause of death but also the contextual reason why the deceased did not recover. It has been created and mainly used in the context of maternal and child deaths, considered to be preventable (D’Ambruso et al., 2010; Price, Lee, et al., 2019; Thaddeus & Maine, 1994). Integrating these two approaches, the WHO verbal autopsy standard has included since 2012 questions about circumstances of death (recognition, cost, transportation, perceived quality of care) (D’Ambruso et al., 2016; Hussain-Alkhateeb et al., 2019). While measuring care failures, they make it possible to identify obstacles that could be avoided or alleviated in accessing and receiving care.

However, this information (referred to as CoM or Circumstances of Mortality) has rarely been analysed outside of rural South Africa, where transportation and distance are dire issues (D’Ambruso et al., 2016; Fraser et al., 2020; Hussain-Alkhateeb et al., 2019; Price, Willcox, et al., 2019; Vay et al., 2021). With the exception of a pilot study in Dakar (Senegal) of which only brief descriptive results have been published (Niang et al., 2023), CoM have never been studied in an urban population where the epidemiological context is very different. Moreover, despite increased life expectancy and projected population aging, access to care and circumstances of death in adults have received little attention. In order to address this disparity, we

mobilise data from the Ouagadougou Health and Demographic Surveillance System (OPO) in Burkina Faso to study the circumstances of adult deaths.

Research questions and objectives

Inspired by the patient pathway model, our objective is to identify the final care journeys of adults in the HDSS of Ouagadougou: what care pathways do adult residents of Ouagadougou experience before they die ? Developed in the context of care management in hospital, the concept of care pathway ambitions to present a high-level view of the whole healthcare systems providing more efficient tools to quantify and improve the processes in place (Mould et al., 2010). A synthesised vision of patients' final pathways could provide the key to effective strategies for increasing access to care.

We propose a descriptive data-driven method to identify typical care pathways, by building clusters of deaths occurring in similar circumstances. We chose to broaden the definition of care pathways to include components outside of health facilities. This encompasses processes from recognising (or not) the need for care, to seeking care all the way to reaching and receiving care, with all the possible hurdles that can be encountered along the way. By describing the most common types of care pathway, we hope to (i) identify the difficulties that might have contributed to death and their most frequent combinations, in order reflect on how they could have been prevented and (ii) to better understand the specific challenges faced by the urban population.

This method allows us to present an overall vision of the relationship of adult with the healthcare system in their final days, and could be applied to other contexts. By summarizing information in a clear yet comprehensive way, we believe it can become a powerful tool to communicate with policy-makers and healthcare professional to help them develop improve access to care, and could be applied to other contexts.

2 Data and Methods: classifying care pathways from verbal autopsies

The Health and Demographic Surveillance System of Ouagadougou (Burkina Faso) and VA data collection

The HDSS of Ouagadougou is part of the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH), a network gathering around fifty surveillance sites around the world. It is one of only two urban sites in Africa, alongside the HDSS of Nairobi (Kenya). Established in 2008, it monitors the population of five neighbourhoods at the periphery of the capital of Burkina Faso (Rossier et al., 2012; Rossier et al., 2019). These areas were chosen to represent the socio-economic diversity of this rapidly expanding city. Three of them are informal neighbourhoods and concentrate a poor and migrant population, with little to no access to running water and electricity. In contrast, the two formal neighbourhood are linked to electric and water facilities and characterised by a wealthier population.

In regard to health facilities, the HDSS residents have access to important and varied supply services in terms of geographical proximity. Indeed, in Burkina Faso as in many other West African countries, health facilities are organised pyramidally. At the base there are local health services usually headed by an accredited nurse constitute a first level of contact. When needed patients should theoretically be referred to a second-level structure, CM¹ or CMA² headed by a chief-physician, and to the third level constituted by regional and university hospitals (Harang & Varenne, 2013). This organisation tends to centralise higher levels in urban areas and specifically the capital. A 2009 survey organised by the HDSS (Rossier et al., 2019) identified 93 public health structures in the capital, among them two of the three university hospitals in the country. More than 250 private institutions were also enumerated, half of which were first contact services, above all private practices run by nurses.

In the HDSS, vital events (births, deaths, unions, migration events) of all inhabitants are recorded through annual census surveys. As of January 2019, 98,000 individuals were monitored by the Ouagadougou HDSS.

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When a death is registered, a trained fieldworker returns to the bereaved households to perform a verbal autopsy. Since 2013, the Ouagadougou HDSS has adopted the 2012-WHO verbal autopsy standard in order to determine the probable cause(s) of death automatically through InterVA-4 (Byass et al., 2012). This questionnaire, which includes questions about the circumstances of death, will be the basis of our investigation.

Studied population: 1,175 adult deaths (2010-2019)

For the purposes of this study, we focus on the pre-Covid period, in order to exclude the possible exogenous shocks brought about by the pandemic. Hence, we only include data collected up to October 2019, the last round of household visits before the onset of the pandemic.

Between 2010 and 2019, 1,193 deaths over the age of 15 were documented with the 2012 VA standard questionnaire (representing 70% of documented deaths of all ages). Among them, 18 deaths did not report the place or region of death and were excluded from the analysis that we finally conducted on 1,175 deaths. Only 96 (8.2%) of these deaths occurred between 2010 and 2012 (see Table 1). During this period the questionnaire was only used on a subset of the recorded deaths to test the new standard in the HDSS. From 2013 onwards, all VAs were conducted using this questionnaire, and are part of our dataset (1,079 VAs). They represent 70% of recorded adult deaths in the HDSS from 2013 to 2019. The remaining 30% were not documented through VA, usually due to the lack of a relevant respondent or their occasional refusal. The frame *Variables and measures* presents the extracted and linked information from these VA used to carry out our analysis.

Variables and measures

Circumstances of death

This 2012 VA standard includes questions on the circumstances of death (see Appendix 1) that will be the basis of our investigation. These questions are first and foremost the ten CoM indicators relating to recognition of the need for care (doubts about the need of care, use of traditional medicine), barriers in accessing care (burdensome costs, use of a cellphone to call for help, distance to the nearest health facility, visit to a health facility in the final days and the use of motorised transport to get there) and perceived quality of care (problems during admission, treatment or in obtaining the prescribed medications) (D’Ambruoso et al., 2016).

We also considered two questions not traditionally part of CoM indicators: if the deceased received any form of treatment, and if he or she was discharged from a health facility very ill. As Vay et al. (2021) have done in the study of cardiovascular mortality, we decided to include the latter, as hospital discharge represent a key information to capturing long care pathways, and possible treatment failures of the healthcare system. We also chose to integrate in the analysis the question about the administration of any form of treatment, because, while regrettably vague, this question allowed us to capture the use of (unprescribed) over-the-counter medication, or at-home treatments, not covered by other indicators, without substantially changing the conclusions of our analysis.

Finally, we also incorporated in the analysis information about the place of death (at home, at the hospital or another health facility or elsewhere) and the geographical location of death (in or outside of Ouagadougou and its immediate surroundings, the region *Centre*), also collected in the VA questionnaire. While the questionnaire makes a distinction between hospital and other health facilities for the place of death, the open narratives (see below) indicate that the categorisation was not always consistent, especially for level two structures that are in fact in between local health facilities and hospitals. Hence, we decided to not distinguish between structures.

Cause of death and socio-economic characteristics

To complete our analysis, we used the available data to identify characteristics associated with healthcare access and place of death. Firstly, VAs collect socio-demographic information about the deceased : sex, age at death, marital status at death, education, migrant status, type of neighbourhood of residence (formal or informal), as well as the most probable cause of death attributed by InterVA-4 (Byass et al., 2012).

To obtain information about the economic status of the deceased, we linked the VAs with the last known wealth index of the household in which they died. Indeed, the HDSS of Ouagadougou conducts every two to three demographic rounds (or census) a household goods survey, and is used to construct a household wealth index through a principal component analysis (PCA) (Rossier et al., 2019, p.60). Based on this index, the households have then been grouped into three economic levels: lower, intermediate and upper. The poorer households own no home electronic devices (television or refrigerator), and no motorised means of transportation (scooter or car), whereas most middle-class households own a scooter and half of them a television. Finally, the wealthiest households are characterised by the ownership of television and a refrigerator, and a motorised mean of transportation (Rossier et al., 2019, p.60). As economic data are collected only at some specific rounds (every three or four rounds), we have not been able to characterise the economic status of 11% of our deceased population (see Table 1), mainly for deaths occurring in households that were created between two surveys.

Open narratives: relative's free account of the death

Finally, we had access to the relative's answer to the following open-ended question: "*Could you describe the illness or the events leading to death?*"^a. These free narratives of 75 words on average offer a precious qualitative perspective on the events preceding deaths, allowing for a better understanding of the context and mechanisms of healthcare use (as shown notably in Vay et al. (2021) and Fraser et al. (2020)). Digitally transcribed in 2020, these relative's accounts are available for 1,009 (86%) of the analysed VAs (166 questionnaires were not found).

^aOriginal question in French: « *Pouvez-vous me raconter la maladie ou les évènements qui ont conduit à sa mort?* »

Table 1 briefly describes the characteristics of the studied population. Among these adult deaths 64% occurred after 50 years old, and only 18% occurred before the age of 35³. With more males (56%) than females, the vast majority of the deceased (nine in ten) were part of the majority ethnic group in the capital, the Mossi, limiting our ability to investigate ethnic differences in accessing care. Most decedents had been in union during their lifetime (64% in union at the time of death, and 25% widowed or separated), with only 9% never married, reflecting the older age composition of this population. Among these deaths, 56% belonged to households of the intermediate economic class (i.e. owning a motorised vehicle - scooter or car), 10% to the upper class (owning a means and electrical devices - refrigerator and television), and 22% to most economically vulnerable population (no motorised means of transportation and no electrical devices). Six in ten deceased were living in a formal neighbourhood, reflecting the older age structure of those areas with more durable housing and longer term settlements. Most deceased (65%) had received no formal education.

In regards to medical causes of death, Table 2 summarizes the most probable cause assigned to each death by InterVA-4. To create groups, we selected among diseases the five most frequent well-defined causes (Stroke, acute respiratory diseases including pneumonia, malaria, HIV/AIDS and pulmonary tuberculosis), and regrouped others according to their aetiologies (see Appendix Table 7 for more details). We also decided to regroup acute respiratory diseases and malaria, as the two causes present similar symptomatology in the absence of diagnostic tests and have been shown to be prone to confusion by physicians (Källander et al., 2004) and by InterVA4 (Sessego et al., 2021).

³To facilitate comparisons, these age groups were created to respect the reference age groups of InterV4 (15-49; 50-64; 65+), while allowing for more refined analysis

Table 1: Studied population

	Frequency	Percentages
Demographic characteristics		
Age group		
15-34 years	210	17.9
35-49 years	230	19.6
50-64 years	266	22.6
65-74 years	227	19.3
75 + years	242	20.6
Sex		
Male	656	55.8
Female	519	44.2
Ethnicity		
Mossi	1062	90.4
Other	113	9.6
Socio-economic characteristics		
Marital status		
Never married	107	9.1
Married/Cohabiting	749	63.7
Widowed/Divorced/Separated	291	24.8
Unkown.	28	2.4
Economic status		
Lower	263	22.4
Intermediate	663	56.4
Upper	118	10.0
Unkown	131	11.1
Neighbourhood of residence		
Formal	687	58.5
Informal	488	41.5
Education level		
None	766	65.2
Primary	240	20.4
Secondary or more	169	14.4
Year of death		
2010-2012	96	8.2
2013-2016	561	47.7
2017-2019	518	44.1

Population: 1,175 completed VAs of adult (≥ 15 years old), Ouagadougou HDSS, 2010-2019

Among all deaths, more than one in two (56%) have been attributed to non-communicable diseases. In particular, cardiovascular diseases and diabetes account for a quarter of all deaths, with 150 deaths associated with stroke (13% of all deaths), and cancers represent 12% of deaths. Comparable to the estimations obtained in a 2019 pilot study in Dakar (Niang et al., 2023), this is characteristic of urban population already at an advanced stage of the epidemiological transition (Omran, 1971) in West Africa. Together with HIV/AIDS (4%) and pulmonary tuberculosis (4%), these non-communicable causes are often linked to chronic diseases and the need for consistent care, substantiating the need for a better understanding of healthcare access for these pathologies. Among infectious, parasitic and nutritional diseases accounting for 31% of deaths, respiratory diseases were the leading causes: malaria and acute respiratory infections including pneumonia

was associated with 206 deaths (18%). Injuries and violent deaths on the other hand represented 8% of all deaths, most of them due to road accidents pervasive in the capital (Fillol et al., 2016a). In regards to maternal deaths, 23 were recorded, restricting our ability to investigate in detail their circumstances of death.

Table 2: Most probable causes of death

	Frequency	Percentages
Infectious, parasitic and nutritional diseases	361	30.7
Malaria and acute resp infect incl pneumonia	206	17.5
HIV/AIDS related death	52	4.4
Pulmonary tuberculosis	48	4.1
Other infectious, parasitic and nutritional diseases	55	4.7
Maternal CoD	23	2.0
Non-communicable diseases	659	56.1
Stroke	150	12.8
Other cardiovascular diseases and diabetes	163	13.9
Cancers	143	12.2
Other non-communicable diseases	203	17.3
Injuries and violent deaths	88	7.5
Indeterminate	44	3.7

Cause of death estimated via InterVA-4.

Population: 1,175 adult deaths (≥ 15 years old) with completed VAs, Ouagadougou HDSS, 2010-2019.

A mixed-method approach: hierarchical clustering and qualitative analysis of sampled narratives

Recent developments in the analysis of circumstances of death have led to the creation of Circumstances Of Mortality CATegories (COMCATs), automatically attributed to VA-recorded deaths through a bayesian algorithms (Hussain-Alkhateeb et al., 2019). However, our data based on the older 2012 VA standard did not allow us to run it. Moreover, investigating the lesser understood urban context, our goal was first and foremost to provide descriptive insight, leading us to present the following approach.

First, to investigate the final patient pathways of deceased adults, we briefly present the different covariates used for characterizing the circumstances of death (for the list see frame *Variables and measures*).

Excluding the information about the use of motorised transportation (limited sample size), and the use of a mobile phone (difficult to interpret in this urban context), we conduct a multiple correspondence analysis (MCA) to take into account the multiple dimensions of healthcare barriers and their associations and a hierarchical clustering (HC) to identify 5 clusters of deaths grouped according to similar circumstances (see Husson (2010), Roux and Rouanet (2004) for references on these methods). Identifying their associated characteristics with the help of chi-squared tests, we then determine the care pathways corresponding to each cluster.

Finally, we analyse the factors associated with each care pathway through a multinomial logistic regression and carry out a discourse analysis of relatives' open narratives to better understand the barriers faced to accessing care. To facilitate the thematic review of the texts, we carry out this qualitative analysis on a sample of narratives: the first five most representative individuals (paragons) and a randomly drawn sample of 50 individual for each cluster. The paragons allow us to better characterisation of their typical care pathways. The random sample, drawn out of the 1,009 VAs where the narrative was available (see frame *Variables and measures*), enables us to deepen our understanding of these identified care pathways and their variations, as well as the obstacles encountered.

3 Results: from dying on your way to the hospital to being sent back home to die - the space of final healthcare pathways

3.1 Descriptive analysis: the need for a broader context

Table 3 presents the distribution of circumstances of death in our studied population (for the precise definition of each covariate, see Appendix Table 6). We excluded missing and unknown values of the computation of percentages, as their number is relatively low (at most 3% -33 deaths- for the question regarding doubts about the need of care).

Although all deceased were residents of Ouagadougou - i.e. had been living in neighbourhoods monitored by the HDSS for more than 6 months at the time of households visits -, 5% (57 individuals) died outside of the capital or its immediate surroundings (the region *Centre*). With 70% of HDSS residents born outside of Ouagadougou (Rossier et al., 2019), this attests to the ties of the capital to the rest of the country, and could indicate the desire of certain individuals to return to their community of origin during their final days, as Lankoandé et al. (2018) suggests.

A little less than half of deaths (46%) occurred in a health facility, with a similar proportion taking place at home (48%). Yet, this distribution differs significantly with age (see Appendix Table 8) : while 58% of deaths under 65 occurred in a health facility, this is true for only 28% of deaths over 65. This decrease, consistently highlighted in the literature (Anteneh et al., 2013; Chisumpa et al., 2017; Lazenby et al., 2010), suggests a lower use of healthcare services among older adults. The remaining 6% of deaths occurred in other places, mostly in the street or on the way to the hospital, as a review of their narratives indicates. Comparable to those obtained in Dakar (Niang et al., 2023), these results confirm the higher healthcare access of urban compared to rural populations, with greater shares of deaths occurring in health facilities than the rural HDSSs of Kaya (Burkina Faso) and Mlomp (Senegal) (Lankoandé et al., 2018).

However, the place of death does not fully capture the extent of care use. Indeed, 67% of decedents went to a hospital or healthcare facility in their final days, and eight in ten (83%) reportedly received some sort of treatment for their final illness. Even though this last category does not include traditional medicine⁴, it still remains unfortunately vague. Nonetheless, it allows us to identify milder forms of treatments that can be received outside of health facility, such as self-medication, or treatments for long-term conditions that do not require frequent hospital visits (hypertension, diabetes, disabilities...), which was probably the case for the remaining 16% who did not visit a health facility.

Among those who visited a healthcare facility, the overwhelming majority (96%) used motorised transport to get there. A little more than one in four (26%) reported problems during their visit: 11% during admission, 15% during in-facility treatment (difficulties with medical treatment, procedures, interpersonal attitudes, respect, dignity, etc), and 17% in obtaining the prescribed medication or test (that could be linked to their cost, mostly borne by the patient). These shares are remarkably higher than those reported in rural South Africa -where they ranged from 2 to 4% (D'Ambruso et al., 2016)-, but remain hard to interpret as they could either reflect higher expectations of healthcare services or a poorer quality of care. In addition, 16% of decedents were discharged from hospital very ill, among which 38 individuals (20%) were not reported having visited a healthcare facility in the final days by their caregivers, suggesting that their being discharged happened some time before their death.

One in three deceased persons (37%) used traditional medicine during their final days. Moreover, its use did not exclude the utilisation of healthcare facilities ; in fact, 64% of those who used traditional treatment also went to a healthcare facility⁵. Finally, in 38% of deaths, a phone was used to call for help. Far smaller than the 62% recorded in rural South Africa (D'Ambruso et al., 2016) this share is hard to interpret and could reflect proximity to healthcare facilities, the emergency of a sudden death or illness, or difficulty to call for help.

⁴Only 19% of those reporting the use of traditional medicine also reported receiving some sort of treatment (see Appendix, Table). In addition, this question is asked as a preliminary to report any specific disease-targeted treatment (oral rehydration salts, antibiotics, perfusion...), hence is very much targeted towards conventional medicine.

⁵In comparison, 70% of those who did not use traditional medicine went to a healthcare facility. Both covariates are indeed only weakly related ($\chi^2=3.7$, $p = 0.052$).

Table 3: Distribution of reported circumstances of death

	Frequency of missing values	Frequency	Percentages*
Place of death			
Region			
Ouagadougou/Centre	0	1118	95.1
Other region or country		57	4.9
Location			
Home	0	568	48.3
Hospital or other health facilities		537	45.7
Other		70	6.0
Care pathway			
Received some sort of treatment	27	953	83.0
Went to the hospital or health services in the final days	6	784	67.1
<i>Among those who went to a health facility in the final days</i>			
<i>Used motorised transport to get there</i>	<i>0</i>	<i>749</i>	<i>96.3</i>
<i>Problems with admission</i>	<i>16</i>	<i>83</i>	<i>10.7</i>
<i>Problems during in-facility treatment</i>	<i>20</i>	<i>115</i>	<i>14.9</i>
<i>Problems obtaining the prescribed medication or test</i>	<i>23</i>	<i>131</i>	<i>17.1</i>
Used a phone to call for help	21	441	38.2
Used traditional medicine	29	417	36.4
Was discharged from hospital very ill	0	192	16.3
Barrier to access			
Burdensome costs of care	19	435	37.6
Doubts about the need of medical care	33	312	27.3
Nearest health facility > 2 hours away	26	16	1.4

Population: 1,175 adult deaths (≥ 15 years old) with completed VAs, Ouagadougou HDSS, 2010-2019.

* Percentages are calculated excluding the missing values

As for barriers in accessing care, geographical distance does not appear as an issue in the capital, as only 16 deaths (1.4%) were reported as having taken place more than two hours away from a health facility. However, costs represent an important difficulty for households, as for more than one in three (38%) deaths - 44% of those that received some treatment -, the relative declared that the cost of treatment had prohibited other household payments. The significance of this cost barrier could even be underestimated, as the question does not include treatments that were not administered because their cost was out of reach. Lastly, in 27% of deaths, the respondent declared doubts about the need of medical care, implying a lack of recognition of the severity of symptoms.

All in all, while these circumstances of death document important characteristics of care pathways, these circumstances remain difficult to interpret individually or even in pairs, as their meaning differs depending on the wider context of each death. Allowing for multidimensional descriptive analysis (Husson, 2010), the MCA will enable us to better disentangle these relationships and enable us to deepen our understanding of the obstacles and limitations encountered by individuals along their final care pathway.

Multiple correspondence analysis: the space of healthcare access

Multiple Correspondence Analysis (MCA)

MCA is a powerful method for analysing complex categorical data. It consists in transforming a table of i individuals characterised by n binary observations into a space of n -dimensions, where each point represents an individual and each dimension a characteristic. The aim of this method is to summarize this n -dimensional scatter plot into a few dimensions by identifying the axes that capture most of the variance among individuals. These axes are composed of a linear combination of the n characteristics and make it possible to summarise and visualise the data in this reduced space in which the proximity between categories or individuals reflects their similarity. The covariates used to build this space are called active variables, but MCA also enables us to visualise supplementary variables that do not contribute to the construction of the space, by projecting them onto the identified axes (Husson, 2010; Roux & Rouanet, 2004).

This technique enables the examination of interdependencies and interactions among categorical variables, uncovering patterns and providing insights into the underlying social or demographic dynamics.

To carry out this MCA, we chose the circumstances of death as active variables. However, we excluded two indicators: the use of mobile phones and the use of motorised transport to go to the hospital. The former is hard to interpret in an urban context, and we risked incorporating socio-economic characteristics linked to phone ownership, which we wanted to analyse separately. Whilst incorporating this does not meaningfully change our results, it obscured the interpretation of certain clusters. For this reason we decided to only project it as a supplementary variable. The use of motorised transportation was also removed from the analysis, because of the very small number of the deceased who did not use motorised transport to visit a health facility. Indeed, MCA does not respond well to categories with very low frequencies, which tend to disproportionately distort the dimensions identified (Husson, 2010). The same might be said for individuals who died more than two hours away from a health facility. However, we found that incorporating this data did not substantially alter our results but helped in the characterisation of axes 3 and 4, so we decided to keep it as an active variable.

Finally, we regrouped in one category all problems declared during the health facility visit, to avoid artificially increasing the differences between those who did not visit a health facility and those who did, as questions were only asked to the latter. The variable was hence recoded into three classes: those who did not go to a health facility, those who went and reported issues and those who went and reported no issues. As the declaration of these issues was highly correlated (see Appendix Figure 7), it did not lead to loss in terms of precision, but contributed to the better visualisation a continuum of care pathways⁶. Using an iterative regularised method (Josse et al., 2012), we also impute missing values in such a way as to not contribute to the construction of the axes, allowing us to analyse only the available information⁷. For more readability, the variables in the graphs were replaced by abbreviations (the list of equivalents is available in Appendix Table ??).

The first four dimensions of the MCA enable us to explain more than half (60%) of the variance observed in our dataset. Figure 1 presents the graph of individuals and variables for the first two dimensions, accounting respectively for 21% and 17% of the variance (additional material for interpretation is available in the Appendix Figure 4 & 5 and Table 9 to 15). The first dimension seems to summarize the care experience of the deceased: opposing those who received no treatment on the left-hand side and those who received care and experienced difficulties (with cost, during their healthcare visit, or being discharged from hospital) on the right, with in the middle those who received care and reported no issues. This first component could

⁶To validate this hypothesis of a continuum of care pathways between those who did and did not visit a healthcare facility in their final days, we also performed separate MCA for the two groups, which indeed revealed comparable opposition in each analysis (see Appendix, Figure 7 and 8).

⁷See Appendix Figure 6 for the preliminary MCA without imputation of any missing values.

perhaps be interpreted as the intensity of care. It is interesting to note that the positive side of this axis is also associated with doubts about the need for medical care. Surprisingly, doubts seem to be more strongly correlated with difficult care pathways, especially with a discharge from the hospital, than with the absence of treatment, suggesting that it rather reflects uncertainty about the ability for medical care to lead to recovery, rather than a lack of recognition of the illness.

The second dimension is mainly explained by the place of death, opposing those who died in a health facility (on the bottom) and those who died at home (on the top). This dimension is also significantly linked to the use of traditional medicine, associated with those dying at home rather than those dying in a health facility. The position of categories linked to the region where the person passed away, the distance from a health facility and those dying on the street or on the way to the hospital should however be considered with caution as the quality of their representation is very poor (see Appendix Table 10)

Explaining respectively 12% and 10% of the variance, the third and fourth dimension allow us to account for these characteristics (Figure 2). The first diagonal (from the top right to the bottom left corner) distinguishes deaths that occurred far from care (more than two hours away, outside of Ouagadougou, neither at home nor in a healthcare facility). The second diagonal opposes those who went to the hospital and declared no issues (on the top left corner) and those who went to the hospital and experienced problems (on the bottom left corner).

Five typical care pathways

Ascending Hierarchical Clustering on Principal Components (AHPC)

Cluster analysis is a method for grouping individuals, such that those in the same group (or cluster) are more similar than individuals in the other groups based on their characteristics. Ascending Hierarchical Clustering is one of the most commonly used methods for identifying clusters of individuals characterised by continuous variables. Starting with one group per individual, it successively regroupes clusters based on a measure of distance between them, such as to create a hierarchy of nested clusters (see Figure 3). The final groups are then selected in order to maximise the similarity of individuals within one group while minimizing the similarity between groups depending on a variety of metrics (Husson et al., 2010; Roux & Rouanet, 2004). Individuals lying at the centre of their cluster are considered the most representative of their groups, and are called paragons.

AHPC is a way of implementing ascending hierarchical clustering based on the results of an MCA. By characterising each individual by their position on the axes (or principal components) of the MCA, it provides a method for performing an AHC on categorical data.

On the basis of these four principal components, we carried out an AHPC using the Ward Method with a k-means consolidation, and identified five clusters. While four clusters would have been a better numerical compromise between the inter- and intra-class inertia, the fifth cluster made it possible to separate individuals who experienced issues during their hospital visit from those who did not, which we considered a more meaningful partition (see dendrogram, Figure 3). Using the active variables, we first characterise each cluster in terms of circumstances of death (Tables 11 to 15), showing how they correspond to specific care pathways, to then identify the socio-economic characteristics associated with each of them through a multinomial regression (Table 5), and to illustrate them with selected narratives.

Figure 1: Graph of the 1st and 2nd axis of the MCA



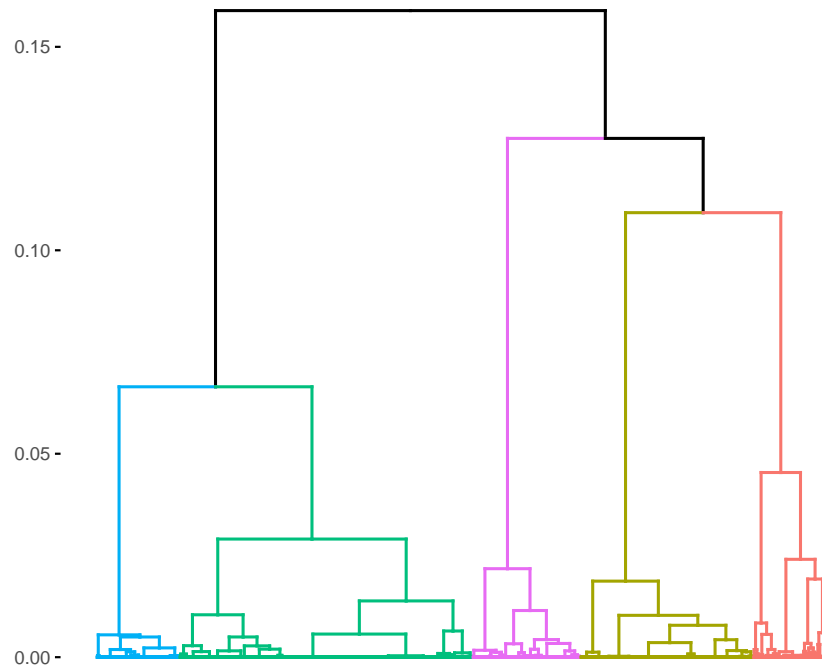
Data : Ouagadougou HDSS (2010–2019).
 Population : 1,175 deaths of adults (>=15) with a completed VA.
 Note: Active variables are displayed in blue, supplementary in green.

Figure 2: Graph of the 3rd and 4th axis of the MCA



Data : Ouagadougou HDSS (2010–2019).
 Population : 1,175 deaths of adults (>=15) with a completed VA.
 Note: Active variables are displayed in blue, supplementary in green.

Figure 3: Dendrogram of the classification



Method: HCPC using the Ward Method with k-means consolidation.
Note: The horizontal axis represents the individuals, the vertical, the distance between the groups identified.
Colors correspond to the clusters identified using the same legend as the previous figures.

A reference group? Dying at hospital while declaring no problems

The biggest cluster identified gathers 36% of deaths (417 individuals, Table 4). It is characterised by deceased who visited a health facility in their final days and declared no specific problem (99% of individuals in the cluster, see Table 13). The overwhelming majority died in a health facility (81%), and their relatives declared no doubts about the need for medical care (92%). Households of deceased belonging to this cluster declared relatively fewer costs issues (only one in four, compared to 40% among the total population, $v.test = -6.4$), and less use of traditional treatments (25% compared to 36%, $v.test = -5.1$).

This group seemed to have experienced the least number of problems during their final care pathways: the deceased sought care, received treatment and less burden of cost in the process. Reading the sampled narratives, the care pathways of deceased among this group are not exempt from difficulties, especially as healthcare or cost issues appear highly susceptible to under-reporting. Nonetheless, as they seem to have experienced relatively fewer hurdles in accessing care, they will constitute a realistic reference group to which we can compare the other clusters.

Dying at hospital with problems: the limitations of the healthcare system

This second cluster is the most similar to the previous group. Gathering 17% of deaths (196 deceased), it distinguishes individuals that sought care and died at hospital (90.8% of the cluster, see Table 14), but experienced difficulties related to healthcare (80%) and costs (70%). Interestingly, it is characterised by a relatively high proportion of deaths where relatives declared doubts about the need for medical care (55%

Table 4: Frequency of each identified cluster

	Frequency	Percentages
Died at home with previous care	195	16.6
Died at home, no care	289	24.6
Died at hospital, no issue	417	35.5
Died at hospital, problems	196	16.7
Died elsewhere	78	6.6

Source: VA from the HDSS Ouagadougou (2019-2019)

Population: deceased with a VA 15 years or older

compared to 27% in the total population, $v.test = 9.2$), and is also identified by relatively little use of traditional treatments (70% declared no use of traditional treatment, compared to 62% in the total population, $v.test = 2.7$).

Reviewing the accounts of their relatives, we can see that many experienced difficulty during their treatment because of shortages of equipment, drugs, or blood for transfusions. This is illustrated by the two narratives among the paragons (most representative individuals) of this cluster:

*"Following malaria problems, we went to the CMA[...]. After a consultation, malaria was confirmed, but they also found that he was lacking blood. So he was transferred to the CHU [university hospital]. The same day, his malaria was treated, but there was no blood available for transfusion. Hospitalised and waiting for blood, my child passed away around 8pm the next day."*⁸
 Mother testifying for her late 16-year-old son, paragon of this cluster. Most probable cause of death: malaria.

Difficulties and delays in getting admitted to the hospital are also related, particularly due to strikes of the medical personnel (that took place during a few weeks in 2016 and 2019):

*"He had a very bad stomach ache. We took him to the Yagaldo University Hospital where, after tests, it was confirmed that he was suffering from colon cancer. After the numerous strikes in Ouagadougou, we returned to the village [...] and went to the CHR [regional hospital] where he was treated. It was finally there that we were able to perform the operation, but he died on the operating table."*⁹
 Wife for her late 49-year-old husband, paragon of this cluster. Most probable cause of death: digestive neoplasm.

Few relational difficulties with healthcare professionals are reported, apart from two (out of fifty) sampled narratives in which family members mention that they were informed by the physician of their prognosis. However, we can also see that while declared in the closed questions, specific problems are not always related in the narratives, reflecting perhaps an unwillingness to criticise the healthcare system.

In terms of socio-economic characteristics, this group presents no significant difference in age or sex compared to those dying at hospital declaring no problems, once other covariates are controlled (Table 5). This could indicate that these problems are more situational or episodic difficulties of the healthcare system, and less related to individual characteristics, such as wealth. However, this cluster seems significantly associated with some causes of death: the risk of dying in a healthcare facility in which issues were reported as compared to no issues appears twice as high for individuals dying from cancer and pulmonary tuberculosis as for those

⁸ « Suite de troubles de paludisme, on s'est rendu au CMA [...]. Après consultation, le paludisme a été confirmé mais aussi qu'il lui manquait de sang. Alors on a été transféré au CHU [...]. Le même jour, son paludisme a été traité certes mais pas du sang disponible pour la transfusion. Hospitalisé et en attente de sang, mon enfant rendit l'âme vers 20h le lendemain. » Translated from the French by the author.

⁹ « Il avait très mal au ventre . On l'a amené séjourner au CHU de Yagaldo où après les examens on a constaté qu'il souffrait d'un cancer du colon. Bu les nombreuses grèves à Ouagadougou, on est rentré au village [...] et on allait au CHR [Centre Hospitalier Regional] où il était suivi. C'est finalement là-bas qu'on a pu faire l'opération, mais il est décédé sur la table d'opération. » Translated from the French by the author.

dying from other non-communicable diseases. This could be explained as both diseases are long-term illnesses, requiring expensive treatments over an extensive period of time, that are not easily available especially for cancers. The previous narrative could also illustrate this situation.

Among the relative's declaration in this cluster, 30% also report no specific healthcare problems, but rather underline the burdensome cost of care. This seems to be linked to longer care pathways compared to the cluster declaring no issues, with recurring treatments and longer hospitalisations. However, despite the important financial cost, the caregivers remain in the position to keep their relative hospitalised:

*"She was suffering from recurring fatigue. Each time she was prescribed a tonic. When it became too much, she had a check-up and it turned out to be a kidney problem. Since then, she's been in hospital [...] during 6 months. She received a lot of treatment but it didn't work."*¹⁰

Husband testifying for his late 31-year-old wife, Most probable cause of death: HIV/AIDS related death.

The unavailability or difficulty to obtain the appropriate treatment is often compounded with these long care pathways:

*"Her back was hurting. She couldn't bend over. The pain was getting more and more intense. When it got worse, we took her to hospital and we were told she had a nerve problem and needed an operation, which could only be done in Europe. Since we didn't have the money, we kept her in neurology. We couldn't do anything."*¹¹

Wife testifying for her late 65-year-old co-wife.

The positive association of secondary education compared the reference cluster ($p=0.063$), suggests a declaration bias. Providing that the educational level of the deceased and the respondent are correlated, more educated respondents would be more likely to report issues during the care pathway. This would indicate an underestimation of deceased that experienced this type of final care pathway

However, the higher percentage of relatives declaring doubts about the need for care is difficult to interpret. Longer care pathways and difficult access to the appropriate treatment could lead relatives to believe that medical care could do little to significantly improve the patient's state. Compared to the first cluster where there is no significant association, this second cluster is associated with a higher proportion of relatives calling for help (almost twice as much as the 37% in the total population, $p<0.0000$, $v.test = 7.2$). This could also indicate deaths characterised by a higher degree of emergency, where care is more time-sensitive, and delays in healthcare deliveries appear more dire and are hence more likely to be reported.

Dying at home with previous care: difficult care pathways

The third cluster, representing 17% of deaths (195 individuals), distinguished adults who were discharged very ill from the hospital (93% of deceased in the total population belong to this group, and they make up 92% of all deceased in the cluster, compared to 16% in the total population), and died at home (97% of deaths in the cluster, compared to 48% in the total population). It is characterised by higher doubt for the need of medical care (58% compared to 27%), higher use of traditional medicine (62% compared to 35%) and a higher declaration of burdensome costs (69% compared to 37%). Four in five declared having visited a healthcare facility in the final days (68% reporting no issues, 23% reporting difficulties), while 20% did not declare visiting a healthcare facility, probably because their discharge occurred a substantial amount of time before death.

This cluster seems characterised by even longer care pathways, and is even more associated with long-term illnesses. Indeed, compared to death due to other NCDs, deaths due to HIV/AIDS, pulmonary tuberculosis

¹⁰ « Elle souffrait chaque fois de fatigue. Chaque fois on lui prescrivait des remontrants. Quand c'était trop on lui a fait le bilan et il ressort qu'il y avait un pb de reins. Depuis, elle a été hospitalisée [...] pendant 6 mois. Elle a reçu beaucoup de soins mais ça n'a pas donné. » Translated from the French by the author.

¹¹ « Elle avait trop mal au dos. Elle ne pouvait pas se courber. La douleur devenait de plus en plus intense. Quand ça a empiré et qu'on l'a amené à l'hôpital, où on nous a dit qu'elle avait un pb de nerfs et qu'il fallait faire une opération qui ne peut se faire qu'en Europe. Vu qu'on n'a pas les moyens on l'a gardé en neurologie à Yagaldo. On a rien pu faire. » Translated from the French by the author.

and cancers are respectively eight times, five times, and five and a half times more likely to belong this cluster, in comparison with the cluster of hospital deaths with no issues. HIV/AIDS and tuberculosis are also diseases where medications can be administered at home, explaining why these deaths are more likely to occur at home.

Relatives' narratives seem to indicate that some of these home deaths reflect the preference of the deceased to return home to die close to their loved ones:

*"She had breast cancer. We operated on her five months after it started. She was doing very well. She had even put weight back on. That's what we thought. But in reality the disease continued from the inside and ate away at other organs like the lungs and liver. In reality, she wasn't fat but swollen, suffocating when she lay down. She couldn't breathe when we took her to hospital. She asked to be taken home to die in her room. That's what we did."*¹²

Daughter-in-law testifying for her late 61-year-old mother-in-law, Most probable cause of death: respiratory neoplasm.

However, the association with household wealth suggests this is not entirely by choice. Indeed, compared to households with an intermediate wealth index, the deceased living among the poorest households were almost twice as likely to belong to this cluster than those dying at hospital reporting no issues ($p=0.01$). Indeed, many of the narratives reviewed mention financial difficulties, with expressions such as *"lack of means"*¹³, *"we couldn't afford it"*¹⁴ being recurrent:

*"He was involved in a traffic accident two months before his death. He sustained a number of injuries to his head and legs. He had been treated, but since then his mobility had been reduced. He could no longer walk on his own, he would lose his balance. So we took him to the health centre, then to hospital for a general scan of his body, which had been requested by the doctors. We ended up being accepted at Yalgado, but we couldn't go because we couldn't afford it. We were saving up to take him, but unfortunately he died."*¹⁵

Daughter for her late 70-year-old father, Most probable cause of death: road traffic accident.

In contrast, treatments for malaria and acute respiratory diseases are relatively less expensive, the healthcare system being geared towards these acute infectious diseases. This would explain why deaths due to these diseases are three times less likely to belong to this cluster rather than the cluster of hospital deaths with no issues ($p=0.005$).

These prohibitive costs of care often seem to be combined with the perception that the treatments will not lead to recovery, leading families to stop expensive care and return home:

*"As usual, he got up in the morning and asked me to make his coffee. Then we went to a wedding. It was during the wedding that he collapsed. Suddenly he was paralysed on his left side, his mouth twisted, his tongue had filled his mouth, and he was rushed to hospital. We spent 3 months there. As his condition worsened and we could no longer afford it, we decided to take him home, where he died."*¹⁶

Wife for her late 73-year-old husband, Most probable cause of death: stroke.

¹² « Elle avait un cancer du sein. On a fait une opération cinq mois après son déclenchement. Elle se portait très bien. Elle avait même repris du poids. C'est ce qu'on pensait. Mais en réalité le mal a continué de l'intérieur et a rongé d'autres organes comme les poumons et le foie. En réalité elle n'était pas grosse mais enflée, elle suffoquait quand elle était couchée. Elle n'arrivait plus à respirer quand on l'a amené à l'hôpital. Elle a demandé qu'on la ramène à la maison pour qu'elle meurt dans sa chambre. C'est ce qu'on a fait. » Translated from the French by the author.

¹³ « manque de moyens »

¹⁴ « on avait pas les moyens »

¹⁵ « Il a subi un accident de la circulation deux mois avant son décès. Il a été touché à la tête et les jambes de quelques blessures. Il avait été soigné mais depuis lors sa mobilité était réduite. Il ne pouvait plus marcher seul, il perdait l'équilibre. Donc on l'a emmené au centre de santé, puis à l'hôpital pour un scanner général de son corps, qui avait été demandé par les médecins. On a fini par nous accepter à Yalgado, mais on n'a pas pu y aller parce que financièrement ça n'allait plus. On économisait pour l'emmenner, mais malheureusement il est décédé. » Translated from the French by the author.

¹⁶ « Comme d'habitude, il s'est levé le matin et a demandé qu'on lui fasse son café. Ensuite nous sommes allés à un mariage. C'est durant le mariage qu'il s'est effondré. Subitement il s'est paralysé du côté gauche, la bouche tordue, la langue avait rempli la bouche. on l'a évacué à l'hôpital. Nous y avons passé 3 mois. Et comme son état empirait et qu'on avait plus les moyens on a alors décidé de l'amener à la maison où il est décédé. » Translated from the French by the author.

This could explain why deaths occurring at older ages are more likely to belong to this cluster rather than deaths at hospital with no issues. With the same illness, a death at younger ages could be perceived as more preventable, and a death at home could be considered more suitable for those deemed to have already lived a long life.

The failure of conventional treatments and their deterring costs, also seem to explain the high use of traditional treatments in this cluster:

*"Se had a gastric problem. As soon as she ate, she immediately vomited. She was hospitalised [...] for a week. As soon as she had the transfusion, it seemed fine. But we stopped and it started again. A week later, we couldn't afford it any more, so we asked to go home. Two days later, we went to the village. We tried the traditional treatment but it didn't work, and four days later she died."*¹⁷

Daughter for her late 80-year-old mother, Most probable cause of death: diarrhoeal disease.

Indeed, among the fifty narratives reviewed in this cluster, only two mentioned the use of traditional treatments before a healthcare visit. Often interpreted as an indicator of delays in seeking care (Vay et al. 2021; D'Ambruso et al. 2016), the use of traditional treatment in this context seems rather considered to be a last resort when other types of care have failed or remain out of reach. They also seem to be often used in combination with treatment prescribed in a health facility, with baths and decoction depicted more as a complement than an alternative to conventional medicine.

Dying at home with no care: between rejection of the healthcare system and isolation

This fourth cluster is characterised by deceased who did not seek care (99% of all deaths in the cluster) and died at home (96%). This could not be explained by an increased distance to healthcare facilities, as almost all died in Ouagadougou (99.7%), nor healthcare costs, as 80% declared no cost issues. None had been discharged from hospital, and two in five (38%) had received no treatment at all, implying that a small majority had received some milder forms of treatment. The use of traditional medicine is slightly but significantly higher in this group compared to the general population (40% compared to 35%). Surprisingly, this cluster is significantly associated with a higher proportion of relatives declaring no doubts about the need of medical care (76% of deaths in the cluster), leaving the analyst wondering about the reasons to not seek care. This group also represents the second most numerous cluster, gathering 25% of all deaths (289 individuals).

The likelihood of belonging to this cluster compared to the reference group increases in magnitude and significance with the age of the deceased, with an odds ratio of 2 for ages 50 to 64 ($p=0.012$), 3 for 65 to 74 ($p=0.001$), and 9 for 75 and above ($p<0.001$), relative to 35 to 49 years old.

Some narratives suggest that the lack of care could be explained by a refusal to be treated on the part of the deceased, especially in a health facility, preferring to address the illness with "*street medicine*"¹⁸ or traditional treatments :

*"In reality he hadn't been feeling well for three or four months, but wasn't bed bound. He refused to go for treatment, saying that he couldn't afford it, and instead hoped that he would feel better. He wouldn't say exactly what he had, what he was suffering from, and spent his entire illness taking traditional medicines. All I know is that 3 days before he died, he complained of tiredness and said he was aching all over. That day he stayed in bed all day and said he felt dizzy. When he was alerted, his little brother arrived to take him to the CMA, but he objected, saying that he had concoctions that he was taking (traditional). He died the next day."*¹⁹

¹⁷ « Elle avait un pb gastrique. Dès qu'elle s'alimentait elle rejetait immédiatement. Elle a été hospitalisée [...] pendant une semaine. Dès qu'on lui mettait la perfusion ça semblait aller. Mais on arrête ça reprend. Une semaine après on avait plus les moyens, on a demandé de rentrer à la maison. Deux jours parés, on s'est rendu au village. On a essayer de traiter traditionnellement mais ça n'a pas marché, quatre jours après elle est décédée. » Translated from the French by the author.

¹⁸ Médicaments de la rue. Medicine obtained without prescriptions.

¹⁹ « En réalité il ne se sentait pas bien depuis trois ou quatre mois, mais il n'était pas couché. Il refusait d'aller en consultation en disant qu'il n'avait pas les moyens et espérait plutôt qu'il se sentirait mieux. Il ne disait pas au juste ce qu'il avait, de quoi il souffrait et passait tout au long de sa maladie à prendre des médicaments traditionnels. Tout ce que je sais c'est que 3

Son for his late 65-year-old father, Most probable cause of death: digestive neoplasms.

These narratives seem to indicate a fear of healthcare treatment, which could be due to both the dread of facing the illness, as well as difficult previous experiences with the healthcare system, or costs. This could explain the higher risk of deaths from cancer belonging to this cluster relative to the group of hospital death declaring no issues, as their diagnostic can be devastating, and the treatments perceived as dreadful. However, reading the narratives, we cannot help but wonder if this absence of formal care is not also linked to disregard for the severity of the symptoms in some older adults, partly rationalised in front of the interviewer as a dislike for treatments:

"It was just a cold. But by the third day he had a cough and a fever. It was serious. During the night, on the third day, his health deteriorated and we got ready to take him for a consultation. But we couldn't leave the house. It has to be said that he didn't receive any treatment because the old man was afraid to go to the clinic because of the injections and he didn't like taking the tablets."²⁰

Son for his late 65-year-old father-in-law, Most probable cause of death: acute respiratory infection.

Indeed, symptoms seem to systematically be minimised, leading to delayed or no decision to seek care:

"She wasn't sick. She had palpitations at 1pm. She went to bed and died around 3pm."²¹

Daughter-in-law for her late 65-year-old father-in-law, paragon of this cluster. Most probable cause of death: acute cardiac disease.

The association of this cluster with deaths occurring at older ages and for deceased that were no longer in a union at the time of deaths (odds-ratio 1.5, $p=0.05$) and females (with a p -value of 0.1) compared to the reference group seems to corroborate this hypothesis, as these three groups are relatively more likely to be socially isolated within the household and the community. This can be seen by examining the narratives, as one in two (47%) respondents of the VAs in this group are constituted of relative from the extended family (daughter- or son-in-law, nieces and nephews, neighbours...) compared to 35% in the total population, where spouses or children constitute a majority.

This cluster is also characterised by some sudden deaths, with a significantly higher risk of death associated with strokes and external causes of death compared to the reference group (with an odds-ratio of 2 and 2.4 respectively). But compared to the last cluster, there was no attempt to reach health facilities, as most deceased were discovered only after they died. This could be explained by the relative isolation of these individuals, and an underestimation of their symptoms:

"He had been complaining of vision problems for a few days. We didn't take the situation seriously. One evening, I felt him very calm, leaning against a jar outside his door. I asked him if he was all right. He told me no, that it was the previous day's blurred vision that was bothering him and he had a headache, but we gave him a paracetamol. [...] I spread a mat outside his door and he lay down [...]. It was my mother [the next day] who went to find him on the floor and alerted his family to the situation. We didn't know he had hypertension."²²

Neighbour for his late 74-year-old friend, Most probable cause of death: stroke.

However, we have to note that the number of deceased that received no care might be overestimated in this

jours avant son décès, il se plaignait de fatigue et disait avoir mal partout. Ce jour là il est resté couché toute la journée et disait avoir des vertiges. Alerté, son petit frere est arrivé pour l'emmener qu CMA mais il s'opposait en disant qu'il avait des concoctions qu'il prenait (traditionnel). Le lendemain il est décédé. » Translated from the French by the author.

²⁰ *« Ce n'était qu'un rhume. Mais troisième jour il toussait et avait la fièvre. C'était grave. Au cour de la nuit, au troisième jour, sa santé s'est dégradé on s'apprêtait à l'amener en consultation. Mais on a pas pu quitter la maison. Il faut dire qu'il n'a pas reçu de traitement parce que le vieux avait peur d'aller en consultation à cause des injection et il n'aimait pas prendre les comprimés. »* Translated from the French by the author.

²¹ *« Elle n'était pas malade . Elle a eu des palpitations à 13h. Elle s'est couchée et vers 15h elle est décédée. »* Translated from the French by the author. »

²² *« Il se plaignait de troubles de vision depuis quelques jours. On a pas pris la situation au sérieux. Un soir, je l'ai senti très calme, adossé à une jarre devant sa porte. Je lui ai demandé si ça allait. Il m'a dit que non que ce sont les trouble de vision de la veille qui l'embêtait et il avait mal à la tête mais on on lui a donné un paracétamol. [...] J'ai étalé une natte devant sa porte où il s'est couché [...]. C'est ma mère [le lendemain] qui est allée le trouver sur le sol, et qui a alerté sa famille de la situation. On ne savait pas qu'il était hypertensionnaire. [...] »*

cluster. The narrative indeed indicates that certain individuals had been followed by healthcare professionals for a long time and received home treatments from nurses, but were no longer regularly visiting a health facility:

*"My father-in-law had been suffering from high blood pressure for over 5 years and was undergoing treatment. Then he became paralysed and could no longer move around, so he stopped working as a dressmaker. A nurse came to give him treatment at home. Then, 3 days before his death, the illness worsened and he died."*²³

Daughter-in-law for her late 67-year-old father-in-law, Most probable cause of death: indeterminate.

Dying elsewhere: accidents and sudden deaths

The last cluster, representing 7% of deaths (78 individuals), is the most distinctive in terms of circumstances of death: it is the first to be isolated by the HCPC (Figure 3). It regroups almost all (89%) the deaths that occurred neither in a health facility nor at home, with almost three out of four (70%) of its deceased that did not visit a healthcare facility in their final days, and 64% that received no treatment at all.

Through the review of its narrative, we can see that it is overwhelmingly characterised by sudden deaths where the deceased succumbed immediately or on his way to a healthcare facility, and did not have time to receive any care. This is particularly true for injuries and violent deaths which, compared to NCDs, were seven times more likely to belong to this cluster rather than the reference group. The following excerpts summarize many of the relatives' narratives:

*"She was hit by a truck [...] and died on the spot. There was no time to get her to a health centre."*²⁴

Son for his late 45-year-old mother, Most probable cause of death: road traffic accident.

We can also read several accounts of acute cardiovascular diseases, even though the association is not quite significant all other things being equal ($p = 17\%$):

*"My husband got into the shower one morning to wash up. And, a moment later, I heard a noise. I ran to open the door but I couldn't. I called the children, who came to help me and when we opened the door he was on the floor saying he couldn't breathe. We then called an ambulance and it was on the way to the CMA that he died."*²⁵

Wife for her late 55-year-old husband.

Interestingly, this cluster is also characterised by a higher proportion of deaths that occurred outside of Ouagadougou (35%, compared to 5% in the total population), and more than two hours from a healthcare facility (13% of the cluster, with 63% of individuals declaring the characteristic being to the cluster). This suggests a higher difficulty to reach health facilities outside the capital, however this should be considered with caution considering the very small frequencies of both characteristics (respectively 57 and 16 individuals). Finally, this group is also associated with relatively more "I don't know" answers about treatment, cost, visit or distance to a health facility. This could indicate difficulties for relatives in answering certain questions, especially when the deceased died within the time of reaching a health facility, reflecting an in-between state where care was sought but not reached in time.

²³ « Mon beau-père souffrait d'hypertension depuis plus de 5 ans. Puis il a été paralysé et ne pouvait plus se déplacer, il avait donc arrêté son métier de couturier. Un infirmier venait lui administrer un traitement à domicile. Puis 3 jours avant son décès, le mal s'est aggravé et il est décédé. »

²⁴ « Elle a été percutée [...] par un camion où elle est décédée sur place. On n'a pas eu le temps de l'amener dans un centre de santé. » Translated from the French by the author.

²⁵ « Mon mari est rentré un matin dans la douche pour prendre son bain. Puis un instant après j'ai entendu du bruit. J'ai accouru pour ouvrir la porte mais je n'y arrivait pas. J'ai appelé les enfants, qui sont venu m'aider et quand nous avons ouvert il était à terre et disait qu'il n'arrivait pas à respirer. Ensuite nous avons appelé une ambulance et c'est en allant au CMA qu'il est décédé. » Translated from the French by the author.

Table 5: Relative risk for a death to belong to a cluster (Multinomial regression, odd-ratios, reference group: hospital, no issues)

	<i>Dependent variable:</i>			
	Hospital, problems (1)	Home with care (2)	Home no care (3)	Elsewhere (4)
15-34 years (Ref= 35-49 years)	1.081 p = 0.804	0.767 p = 0.492	0.952 p = 0.898	0.887 p = 0.779
50-64 years	1.159 p = 0.579	1.527 p = 0.158	2.107** p = 0.012	0.827 p = 0.651
65-74 years	0.974 p = 0.935	2.620*** p = 0.004	2.891*** p = 0.001	0.847 p = 0.732
75 + years	0.956 p = 0.904	3.411*** p = 0.001	9.317*** p = 0.000	0.985 p = 0.980
Female (Ref = Male)	0.916 p = 0.687	1.208 p = 0.411	1.410 p = 0.102	0.929 p = 0.827
Malaria and acute resp infect (Ref= Other NCDs)	0.802 p = 0.446	0.335*** p = 0.005	0.967 p = 0.905	0.510 p = 0.141
HIV/AIDS related death	1.192 p = 0.725	7.733*** p = 0.00001	1.461 p = 0.512	0.383 p = 0.378
Pulmonary tuberculosis	2.296* p = 0.083	4.758*** p = 0.001	1.667 p = 0.334	0.507 p = 0.534
Other infect parasitic nutrit dis	1.288 p = 0.538	0.691 p = 0.504	1.335 p = 0.502	0.230 p = 0.169
Maternal CoD	0.783 p = 0.685	0.00002 p = 0.944	0.380 p = 0.374	0.370 p = 0.377
Stroke	1.605 p = 0.148	1.801* p = 0.077	1.970** p = 0.028	0.705 p = 0.534
Other cardiovascular diseases and diabetes	1.133 p = 0.700	0.854 p = 0.648	1.443 p = 0.209	0.437 p = 0.170
Cancers	2.356*** p = 0.010	5.504*** p = 0.00000	2.470*** p = 0.009	0.598 p = 0.447
Injuries and violent deaths	0.313** p = 0.046	0.778 p = 0.648	2.352** p = 0.031	6.847*** p = 0.00001
Indeterminate	0.468 p = 0.205	0.337 p = 0.168	1.778 p = 0.189	1.157 p = 0.819
Lower (Ref = Intermediate)	0.959 p = 0.863	1.848*** p = 0.010	1.348 p = 0.179	0.847 p = 0.664
Upper	0.601 p = 0.113	0.749 p = 0.404	0.657 p = 0.168	1.855 p = 0.125
Unkown	0.805 p = 0.491	0.922 p = 0.817	1.638* p = 0.076	1.396 p = 0.427
Primary (Ref = No education)	1.240 p = 0.355	0.783 p = 0.352	0.756 p = 0.267	0.664 p = 0.273
Secondary or more	1.643* p = 0.063	0.849 p = 0.625	0.990 p = 0.974	0.914 p = 0.823
Never married (Ref = married)	1.383 p = 0.360	1.031 p = 0.950	1.146 p = 0.757	1.739 p = 0.225
Widowed/Divorced/Separated	1.659* p = 0.073	1.359 p = 0.270	1.638** p = 0.045	0.820 p = 0.686
Unkown	0.638 p = 0.508	1.505 p = 0.460	1.282 p = 0.656	0.416 p = 0.433
Informal neighbourhood (Ref = formal)	1.255 p = 0.255	1.148 p = 0.520	1.146 p = 0.475	1.006 p = 0.986
Constant	0.317*** p = 0.001	0.158*** p = 0.00000	0.128*** p = 0.000	0.194*** p = 0.001
Akaike Inf. Crit.	3,214.182	3,214.182	3,214.182	3,214.182

Note:

*p<0.1; **p<0.05; ***p<0.01
Source: 1,175 deaths of adults (>= 15) with a completed VA, Ouagadougou HDSS (2010-2019)

4 Discussion

In this study, we document the final care pathways of adults (aged 15 and above) and their associated socio-economic and medical factors, relying on circumstances of death data collected in VA (2012 WHO-standard and following versions) from the urban HDSS of Ouagadougou. We identify five distinctive groups of care pathways; compared to 35% of adults who died in a health facility with relatives reporting no healthcare issue, 17% died in hospital with relatives reporting problems and burdensome costs. Moreover, 17% died at home after a cessation of care largely induced by the inability to pay, and a worrying 25% of deceased received no treatment. Finally, around 7% succumbed to sudden deaths, dying in a public space or on their way to hospital.

Our results confirm that, while in urban settings geographical accessibility is not an issue, many barriers remain that impede efficient and timely access to care. Most importantly, cost of care remains a major obstacle: for one in three adult deaths, with relatives declaring that the total cost of care prohibited other household purchases, an answer that appears strongly associated with long-term illnesses, that necessitate recurring treatments. We also cannot help but wonder at the role played by those prohibitive costs for the 25% of decedents that did not seek care, or relied only on traditional and street medicine. Comparable in proportion to analyses of circumstances of death in rural South Africa (D’Ambruso et al., 2016), this burden is not restricted to the urban context and provides further evidence of the need for development of financial risk protection in order to achieve effective universal health coverage, defined in the Sustainable Development Goals (SDGs) as access to “quality health services [...], without financial hardship” (World Health Organization & World Bank, 2017, p.xiii). This is especially true for adults, as financial protection programs in sub-Saharan Africa are overwhelmingly geared towards child and maternal health (Rossier et al., 2019), leaving little capacity for adults to afford care for chronic and expensive illnesses more susceptible to occur at these stages of life, such as cancers and cardiovascular diseases.

We also highlight the higher risk faced by older adults (65 and above) to experience an absence or a cessation of care during their final pathway. These results are consistent with previous literature about places of death in sub-Saharan Africa, showing an increase in the proportion of home deaths with age in Addis Ababa (Ethiopia - Anteneh et al. (2013)), Botswana (Lazenby et al., 2010), Dakar (Senegal - Niang et al. (2023)) and semi-rural Burkina (Bado et al., 2016) (with the exception of Zambia in a study restricted to 18-59-year-olds finding no significant association - Chisumpa et al. (2017)). We provide evidence that those home deaths seem to reflect social and economical constraints rather than a choice on the part of the deceased, corroborating the hypothesis that high proportions of home deaths remain an adequate indicator of poor access to healthcare in sub-Saharan Africa, as compared to high-income countries (Gu et al., 2007; Houttekier et al., 2011). Among social constraints, we highlight the role of isolation within a household of older adults, particularly if they are out of a union, as possibly contributing to the minimisation of their symptoms and their need for care. This fatalistic vision of possibly preventable illnesses in older age, also documented in Ghana (van der Geest, 2004) and rural Senegal (Duthé et al., 2010), calls for further investigation and advocates for action to increase awareness in the benefits of care for older adults. As their number is projected to increase at a rapid rates in the following decades (Aboderin & Beard, 2015), strengthening the relationship of this population with the healthcare system should be considered a priority to allow for better prevention and treatments of avoidable ailments that represent a burden for the individuals and the community alike.

Finally, while our data does not allow us to evaluate adequacy of treatment when it was received, our results provide evidence of the difficulties of the healthcare system to handle specific diseases, particularly cancers. Deaths associated with cancer involved twice as much risk to be linked to a hospital death reporting cost and healthcare issues, and more than five times as much risk to be linked with a cessation of care than hospital deaths associated with no issues. These results, congruent with the inadequacy of resources in staff and equipment for cancer care in sub-Saharan Africa (Hamdi et al., 2021; Stefan, 2015), underline the need for the development of cancer treatment, as their incidence is projected to grow in the near future (Hamdi et al., 2021). Prevention also appears a cornerstone for such policies, as many cancers were only detected at advance stages, and were also associated with higher risk of not seeking care. Finally, cardiovascular diseases, in particular strokes, were also found to be associated with cessation or absence of care, suggesting a similar need for treatment accessibility and prevention. Injuries and violent deaths seem to be highly associated with those dying before reaching healthcare facilities, suggesting improvements could be made in prevention

(particularly road safety improvements) rather care.

However, certain limitations of this study have to be kept in mind. First, it looks at behaviours prior to death and does not take into account people who have been treated and recovered from their disease. It is particularly important to keep this in mind when looking at younger adults we assume that the majority of sick persons finally recover. This bias differs depending on the ability to recover which varies a lot from one disease to another but there is no data to measure it. The inclusion of “near-misses”, patients with vital prognostics at risk that finally recovered, as carried out in a study of road accident mortality and recovery in Ouagadougou (Fillol et al., 2016b), could help overcome this limitation, but would require important means of data collection and is nearly impossible to carry out without focusing on specific causes or diseases. Second, the information is not self-reported: on the one hand, those who are sick may hide certain symptoms or health conditions from their relatives, on the other hand, respondents may under-report certain symptoms if they feel guilty or are afraid to be judged, especially in case of absence of care. Qualitative interviews could help to shed light on such possible attitudes.

Nevertheless, this study provides an valuable method to for analysing circumstances of death in a quantitative yet inductive way, enabling us to contextualise each indicator within the context of individual care pathways. Indeed, without access to sequential data about care pathways, allows for the identification of five surprisingly coherent final care pathways, and their respective difficulties in accessing care. Going further than a dichotomous analysis, it shows that some indicators are difficult to analyse independently: particularly for the doubts expressed about the need for care, and the use of traditional medicine. Our analysis also suggests that extending circumstances-of-death indicators to longer periods of time could help better identify patient pathways, and that including categories about types of care (particularly home care) could help better distinguish death occurring at home by choice rather than due to constraints.

The ability to identify typical care pathways and the socio-economic and medical characteristics associated with them provides an expressive tool to communicate with policy-makers and healthcare professionals, and to raise awareness among the larger population. This is further strengthened by the ability to illustrate these pathways by narratives from relatives. However, it does not constitute a stable method of classification across space and time, as this approach is highly context-dependent, and the care pathway identified will differ widely according to the dataset used. It can constitute a tool to analyse short-term trends, as supplementary individuals can be projected into the MCA space and be attributed a cluster without contributing to their construction. This could be a method for exploring the impact of the Covid-19 pandemic on final care pathways of adult in Ouagadougou. However, in contrast to the CoM categories (Hussain-Alkhateeb et al., 2019) considering indicators independently, it would not be fit as the only tool to evaluate long-term trends in access to care, or to carry out large-scale comparisons across HDSS sites (Streatfield et al., 2014), attributes that constituted core principles for the development of VA methodology within the INDEPTH Network. Nevertheless, we hope it can provide insight for further development of circumstances-of-death classification, and that it could constitute, provided a sufficiently wide dataset in terms of context and socio-economic characteristics is used, a basis for the elaboration of an automatic algorithmic classification informed by the principal components decomposition.

5 Conclusion

In the African urban context, geographical accessibility is not an issue. However, in the studied population, one in three deceased did not visit a hospital or healthcare facility before they died. The purpose of this analysis was to go further than a dichotomous perspective of seeking or not seeking health care. It aims to look at the pathways and the reporting of potential issues: 35% of deaths occurred at hospital without any specific issue in healthcare reported. In contrast, 25% deaths occurred at home with no care. In between, 17% of adults died at hospital with relatives reporting several cost or healthcare issues, while a comparable proportion experienced a cessation of care largely induced by the inability to pay. Finally, 7% of deaths occurred in public spaces or on the way to the hospital, before any care could be received. In addition to difficulties of the healthcare system to handle cancers and strokes, we could highlight specific profiles of people more at risk of experiencing an absence or a cessation of care (in particular the elderly and widowed).

Advocating for a better contextualisation of circumstances of death, this study proposes a data-driven method to identify typical care pathways through VAs, and hopes to contribute to the development of VA methodology in the exploration of classifications for circumstances of death.

Appendixes

5.1 Circumstances of death questions

Table 6: VA questions used to characterise circumstances of death (English)

Question	Answer	MCA name
Did he/she receive a treatment for the illness that lead to death ?	Yes/No/I don't know	treat
Did he/she was discharged from the hospital very ill ?	Yes/No/I don't know	disch
In the final days before death, did (s)he travel to a hospital or health facility?	Yes/No/I don't know	shospf_issue
Did (s)he use motorised transport to get to the hospital or health facility?	Yes/No/I don't know	
Were there any problems during admission to the hospital or health facility?	Yes/No/I don't know	shospf_issue=issue
Were there any problems with the way (s)he was treated (medical treatment, procedures, inter-personal attitudes, respect, dignity) in the hospital or health facility?	Yes/No/I don't know	shospf_issue=issue
Were there any problems getting medications, or diagnostic tests in the hospital or health facility?	Yes/No/I don't know	shospf_issue=issue
Does it take more than 2 hours to get to the nearest hospital or health facility from the deceased's household?	Yes/No/I don't know	smore2
In the final days before death, were there any doubts about whether medical care was needed?	Yes/No/I don't know	sdoubt
In the final days before death, was traditional medicine used?	Yes/No/I don't know	stradm
In the final days before death, did anyone use a telephone or cell phone to call for help?	Yes/No/I don't know	
Over the course of illness, did the total costs of care and treatment prohibit other household payments?	Yes/No/I don't know	scosts

5.2 Recoding of causes of deaths

Table 7: Causes of death attributed by InterVA4: frequency and recoding

Freq	Cause	ICD-10 equivalent code	Category	Group
123	01.02 Acute resp infect incl pneumonia	J00-J22	Malaria and acute resp infect incl pneumonia HIV/AIDS related death Pulmonary tuberculosis	Infectious, parasitic and nutritional diseases
83	01.05 Malaria	B50-54		
52	01.03 HIV/AIDS related death	B20-B24		
48	01.09 Pulmonary tuberculosis	A15-A16		
1	01.01 Sepsis (non-obstetric)	A40-A41		
2	01.04 Diarrhoeal diseases	A00-A09		
0	01.06 Measles	B05		
27	01.07 Meningitis and encephalitis	A39; G00-G05		
0	01.08 & 10.05 Tetanus	A33-A35		
0	01.10 Pertussis	A37		
0	01.11 Haemorrhagic fever	A90-A99		
11	01.99 Other and unspecified infect dis	A17-A19; A20-A38; A42-A89; B00-B19; B25-49; B55-B99	Other infectious, parasitic and nutritional diseases	
8	03.01 Severe anaemia	D50-D64		
6	03.02 Severe malnutrition	E40-E46		
3	09.01 Ectopic pregnancy	O00	Maternal CoD	Maternal
1	09.02 Abortion-related death	O03-O08		
5	09.03 Pregnancy-induced hypertension	O10-O16		
8	09.04 Obstetric haemorrhage	O46;O67;O72		
1	09.05 Obstructed labour	O63-O66		
3	09.06 Pregnancy-related sepsis	O85; O75,3		
1	09.07 Anaemia of pregnancy	O99.0		
0	09.08 Ruptured uterus	O71		
1	09.99 Other and unspecified maternal CoD	O01-O02; O20-O45; O47-O62; O68-O70; O73-O84; O86-O99		

Table 7: Causes of death attributed by InterVA4: frequency and recoding (*continued*)

Freq	Cause	ICD-10 equivalent code	Category	Group		
150	04.02 Stroke	I60-I69	Stroke	Non-communicable diseases		
26	03.03 Diabetes mellitus	E10-E14	Other cardiovascular diseases and diabetes			
47	04.01 Acute cardiac disease	I20-I25				
0	04.03 Sickle cell with crisis	D57				
90	04.99 Other and unspecified cardiac dis	I00-I09; I10-I15; I26-I52; I70-I99				
6	02.01 Oral neoplasms	C00-C06			Cancers	
47	02.02 Digestive neoplasms	C15-C26				
28	02.03 Respiratory neoplasms	C30-C39				
12	02.04 Breast neoplasms	C50				
22	02.05 & 02.06 Reproductive neoplasms MF	C51-C58; C60-C63				
28	02.99 Other and unspecified neoplasms	C07-C14; C40-C49; C60-D48	Other non-communicable diseases			
21	05.01 Chronic obstructive pulmonary dis	J40-J44				
17	05.02 Asthma	J45-J46				
98	06.01 Acute abdomen	R10				
11	06.02 Liver cirrhosis	K70-K76				
29	07.01 Renal failure	N17-N19				
15	08.01 Epilepsy	G40-G41				
12	98 Other and unspecified NCD	D55-D89; E00-E07; E15-E35; E50-E90; F00-F99; G06G09; GG10-G37; G50-G99; H00-H95; J30-J39; J47-J99; K00-K31; K35-K38; K40-K93; L00-L99; M00-M99; N00N16; N20-N99; R00-R09; R11-R94				
56	12.01 Road traffic accident	V01-V89			Injuries and violent deaths	Injuries and violent deaths
10	12.02 Other transport accident	V90-V99				
0	12.03 Accid fall	W00-W19				
1	12.04 Accid drowning and submersion	W65-W74				
0	12.05 Accid expos to smoke fire & flame	X00-X19				
0	12.06 Contact with venomous plant/animal	X20-X29				
0	12.10 Exposure to force of nature	X30-X39				
0	12.07 Accid poisoning & noxious subs	X40-X49				
4	12.08 Intentional self-harm	X60-X84				
11	12.09 Assault	X85-Y09				
6	12.99 Other and unspecified external CoD	S00-T99; W20-W64; W75-W99; X50-X59; Y10-Y98				
44	99 Indeterminate	R95-R99	Indeterminate	Indeterminate		

Cause of death estimated via InterVA-4.

Population: 1,175 completed VAs of adult (>= 15 years old), Ouagadougou HDSS, 2010-2019.

5.3 Descriptive analysis

Table 8: Distribution of the place of death according to age groups

	Other	Hospital or other health facilities	Home	n
15-64 years	8.4	57.8	33.8	699
65 + years	2.3	27.9	69.7	476

Note:

Population: 1,175 completed VAs of adult (≥ 15 years old), Ouagadougou HDSS, 2010-2019.

5.4 Multiple Correspondence analysis

Figure 4: Variance explained by each dimension of the MCA

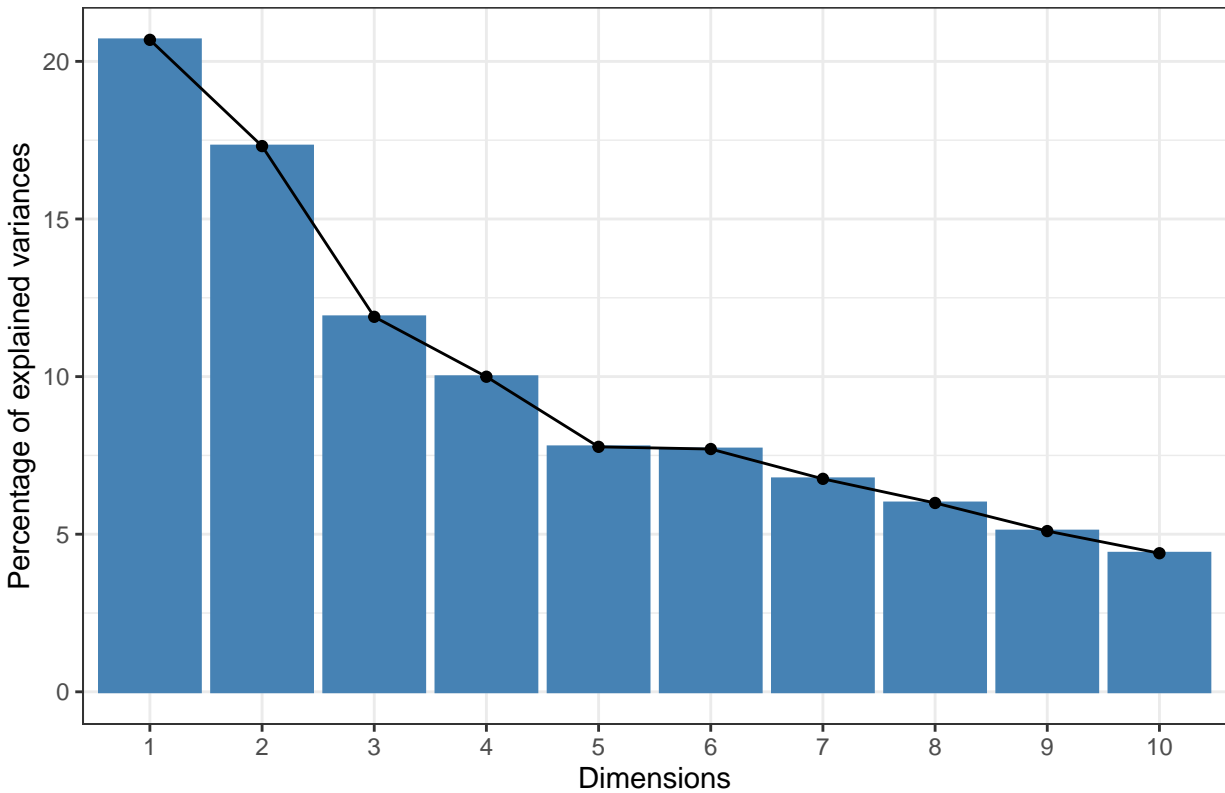
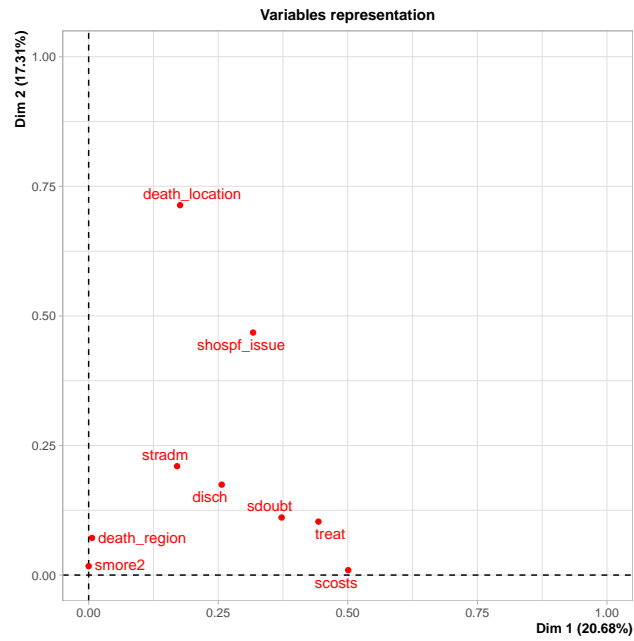


Figure 5: Quality of representation of the active variable

(a) Correlation of the variables with the 1st and 2nd dimensions



(b) Correlation of the variables with the 3rd and 4th dimensions

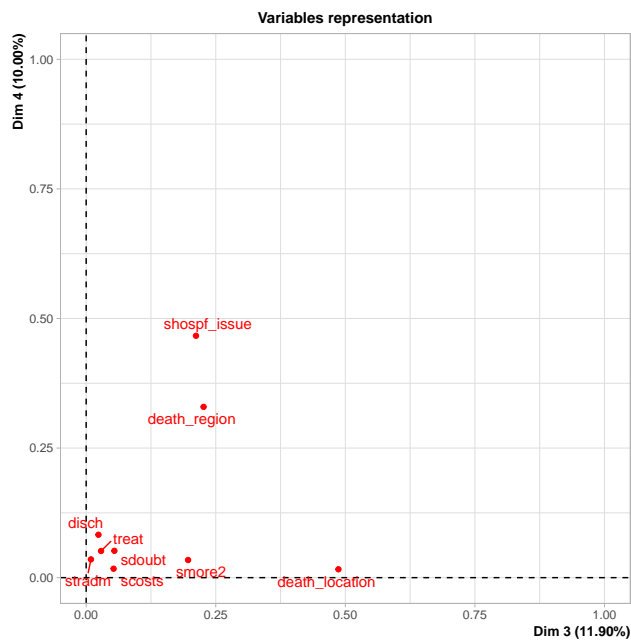


Table 9: Contribution of each variable to the construction of the dimensions

	Dim 1	Dim 2	Dim 3	Dim 4
treat_no	16.3	4.5	1.8	3.9
treat_yes	3.5	1.0	0.4	0.8
Other region or country	0.3	3.6	16.7	28.9
Ouagadougou/Centre	0.0	0.2	0.9	1.5
Other	7.3	3.2	22.8	1.4
Hospital or other health facilities	0.4	20.5	3.2	0.0
Home	0.1	14.3	11.7	0.1
sdoubt_no	4.5	1.6	1.1	1.3
sdoubt_yes	12.1	4.3	3.1	3.5
smore2_no	0.0	0.0	0.2	0.0
smore2_yes	0.0	0.9	15.0	3.1
stradm_no	2.8	4.1	0.3	1.2
stradm_yes	4.8	7.1	0.5	2.1
shopsf_issue	6.1	0.3	13.5	20.9
shopsf_no	7.5	16.0	1.1	3.7
shospf_yes	0.6	8.6	1.8	18.4
scosts_no	8.3	0.2	1.5	0.6
scosts_yes	14.0	0.3	2.6	1.0
disch_no	1.9	1.5	0.3	1.2
disch_yes	9.6	7.8	1.5	6.4

The contribution is expressed in percentages, all contributions in a given dimension add up to 100%.

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

5.5 Characterisation of the clusters with the active variables (chi2 tests)

Table 10: Quality of the representation of each category (cos2)

	Dim 1	Dim 2	Dim 3	Dim 4
treat_no	0.454	0.106	0.029	0.053
treat_yes	0.454	0.106	0.029	0.053
Other region or country	0.007	0.072	0.227	0.329
Ouagadougou/Centre	0.007	0.072	0.227	0.329
Other	0.175	0.064	0.313	0.016
Hospital or other health facilities	0.018	0.710	0.077	0.001
Home	0.004	0.519	0.292	0.001
sdoubt_no	0.379	0.113	0.055	0.053
sdoubt_yes	0.379	0.113	0.055	0.053
smore2_no	0.000	0.019	0.214	0.037
smore2_yes	0.000	0.019	0.214	0.037
stradm_no	0.174	0.214	0.009	0.036
stradm_yes	0.174	0.214	0.009	0.036
shopsf_issue	0.166	0.007	0.213	0.276
shopsf_no	0.251	0.449	0.021	0.060
shospf_yes	0.026	0.318	0.046	0.395
scosts_no	0.504	0.010	0.053	0.017
scosts_yes	0.504	0.010	0.053	0.017
disch_no	0.257	0.174	0.024	0.083
disch_yes	0.257	0.174	0.024	0.083

Generally, a $\cos^2 \geq 0.1$ is considered a good representation of the variable in the dimension.

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

5.6 Robustness checks

Table 11: Cluster 1 - Died elsewhere

	% Cat. in cluster	% of cluster with this Cat.	% Cat. for all deaths	p.value*	v.test*
death_location=Other	88.6	79.5	6.0	0.000	18.8
treat=treat_no	25.6	64.1	16.6	0.000	9.8
death_region=Other region or country	47.4	34.6	4.9	0.000	8.9
shospf_issue=shospf_no	14.6	71.8	32.7	0.000	7.3
smore2=smore2_yes	62.5	12.8	1.4	0.000	5.8
smore2=NA	42.3	14.1	2.2	0.000	5.2
treat=NA	37.0	12.8	2.3	0.000	4.6
scosts=scosts_no	9.2	84.6	61.4	0.000	4.6
scosts=NA	42.1	10.3	1.6	0.000	4.4
sdoubt=NA	27.3	11.5	2.8	0.000	3.7
shospf_issue=NA	66.7	5.1	0.5	0.000	3.7
stradm=NA	27.6	10.3	2.5	0.000	3.5
disch=disch_no	7.4	93.6	83.7	0.008	2.6
stradm=stradm_no	7.8	73.1	62.0	0.036	2.1
disch=disch_yes	2.6	6.4	16.3	0.008	-2.6
stradm=stradm_yes	3.1	16.7	35.5	0.000	-3.8
sdoubt=sdoubt_yes	2.2	9.0	26.6	0.000	-3.9
shospf_issue=shospf_issue	1.0	2.6	17.4	0.000	-4.1
shospf_issue=shospf_yes	2.8	20.5	49.4	0.000	-5.4
scosts=scosts_yes	0.9	5.1	37.0	0.000	-6.8
death_location=Home	1.8	12.8	48.3	0.000	-6.8
death_location=Hospital or other health facilities	1.1	7.7	45.7	0.000	-7.5
smore2=smore2_no	5.0	73.1	96.4	0.000	-7.9
death_region=Ouagadougou/Centre	46.6	65.4	95.1	0.000	-8.9
treat=treat_yes	1.9	23.1	81.1	0.000	-11.6

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

Reading: Among all deceased, 88.6% that died in an other location than their home or a health facility are part of the cluster 1. Among all deaths in cluster 1, 67.4% had died in another location, compared to 6% in the total population. Hence dying in another location is positively and significantly associated with belonging to cluster 1, with a v.test of 17%.

*Results from a chi2 test of independence. Only categories significantly associated with the cluster are shown ((abs(v.test) >=2))

Table 12: Cluster 2 - Died at home no care

	% Cat. in cluster	% of cluster with this Cat.	% Cat. for all deaths	p.value*	v.test*
shospf_issue=shospf_no	74.5	99.0	32.7	0.000	28.8
death_location=Home	48.8	95.8	48.3	0.000	20.1
disch=disch_no	29.4	100.0	83.7	0.000	10.7
treat=treat_no	56.4	38.1	16.6	0.000	10.6
scosts=scosts_no	31.5	78.5	61.4	0.000	7.1
death_region=Ouagadougou/Centre	75.8	99.7	95.1	0.000	4.8
sdoubt=sdoubt_no	26.3	75.4	70.6	0.038	2.1
stradm=stradm_yes	28.1	40.5	35.5	0.042	2.0
stradm=stradm_no	22.5	56.7	62.0	0.034	-2.1
sdoubt=sdoubt_yes	19.9	21.5	26.6	0.022	-2.3
smore2=smore2_yes	0.0	0.0	1.4	0.011	-2.6
death_region=Other region or country	1.8	0.3	4.9	0.000	-4.8
death_location=Other	0.0	0.0	6.0	0.000	-6.1
scosts=scosts_yes	12.9	19.4	37.0	0.000	-7.4
treat=treat_yes	17.9	59.2	81.1	0.000	-10.3
shospf_issue=shospf_issue	1.0	0.7	17.4	0.000	-10.4
disch=disch_yes	0.0	0.0	16.3	0.000	-10.7
death_location=Hospital or other health facilities	2.2	4.2	45.7	0.000	-17.9
shospf_issue=shospf_yes	0.2	0.3	49.4	0.000	-21.6

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

Reading: Among all deceased, 66.4% of those that died at home are part of the cluster 2.

Among cluster 2, 83.1% had died at home, compared to 32.7% in the total population.

Hence dying at home is positively and significantly associated with belonging to cluster 2, with a v.test of 21.8.

Results from a chi2 test of independence. Only categories significantly associated with the cluster are shown (abs(v.test) >=2)

Table 13: Cluster 3 - Died at hospital, no issue

	% Cat. in cluster	% of cluster with this Cat.	% Cat. for all deaths	p.value*	v.test*
shospf_issue=shospf_yes	71.0	98.8	49.4	0.000	27.7
death_location=Hospital or other health facilities	62.6	80.6	45.7	0.000	18.2
sdoubt=sdoubt_no	46.0	91.6	70.6	0.000	12.5
disch=disch_no	41.9	98.8	83.7	0.000	12.0
treat=treat_yes	40.2	91.8	81.1	0.000	7.3
scosts=scosts_no	42.9	74.1	61.4	0.000	6.7
stradm=stradm_no	41.0	71.7	62.0	0.000	5.1
smore2=smore2_no	36.4	98.8	96.4	0.001	3.4
smore2=smore2_yes	0.0	0.0	1.4	0.001	-3.3
stradm=stradm_yes	25.9	25.9	35.5	0.000	-5.1
scosts=scosts_yes	23.9	24.9	37.0	0.000	-6.4
treat=treat_no	14.4	6.7	16.6	0.000	-7.1
death_location=Other	0.0	0.0	6.0	0.000	-7.7
disch=disch_yes	2.6	1.2	16.3	0.000	-12.0
sdoubt=sdoubt_yes	7.4	5.5	26.6	0.000	-13.2
shospf_issue=shospf_issue	0.0	0.0	17.4	0.000	-14.0
death_location=Home	14.3	19.4	48.3	0.000	-15.1
shospf_issue=shospf_no	0.8	0.7	32.7	0.000	-19.9

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

Reading: Among all deceased, 67.4% of those that died in a health facility are part of the cluster 3.

Among cluster 3, 88.7% died in a healthfacility, compared to 45.7% in the total population.

Hence dying in a health facility is positively and significantly associated with belonging to cluster 3 with a v.test of 22.5.

Results from a chi2 test of independence. Only categories significantly associated with the cluster are shown (abs(v.test) >=2)

Table 14: Cluster 4 - Died at hospital, problems

	% Cat. in cluster	% of cluster with this Cat.	% Cat. for all deaths	p.value	v.test
shospf_issue=shospf_issue	76.1	79.6	17.4	0.000	22.3
death_location=Hospital or other health facilities	33.1	90.8	45.7	0.000	14.5
scosts=scosts_yes	31.5	69.9	37.0	0.000	10.3
sdoubt=sdoubt_yes	34.3	54.6	26.6	0.000	9.2
disch=disch_no	19.6	98.5	83.7	0.000	7.3
treat=treat_yes	19.5	94.9	81.1	0.000	6.0
death_region=Ouagadougou/Centre	17.7	99.0	95.1	0.002	3.1
stradm=stradm_no	18.9	70.4	62.0	0.008	2.7
stradm=NA	0.0	0.0	2.5	0.005	-2.8
death_region=Other region or country	3.5	1.0	4.9	0.002	-3.1
treat=treat_no	3.6	3.6	16.6	0.000	-6.1
disch=disch_yes	1.6	1.5	16.3	0.000	-7.3
sdoubt=sdoubt_no	10.5	44.4	70.6	0.000	-8.5
shospf_issue=shospf_yes	6.7	19.9	49.4	0.000	-9.3
scosts=scosts_no	8.0	29.6	61.4	0.000	-9.9
shospf_issue=shospf_no	0.3	0.5	32.7	0.000	-12.6
death_location=Home	2.1	6.1	48.3	0.000	-14.0

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

Reading: Among all deceased, 61.5% of those that visited a health facility and reported problems are part of the cluster 4.

Among cluster 4, 78.3% went to a health facility and reported problems, compared to 17.4% in the total population.

Hence reporting problems after having visited a health facility in the final days is positively and significantly

associated with belonging to cluster 4, with a v.test of 19.

Results from a chi2 test of independence. Only categories significantly associated with the cluster are shown (abs(v.test) >=2)

Table 15: Cluster 5 - Died at home with previous care

	% Cat. in cluster	% of cluster with this Cat.	% Cat. for all deaths	p.value*	v.test*
disch=disch_yes	93.2	91.8	16.3	0.000	28.1
death_location=Home	33.1	96.4	48.3	0.000	16.0
sdoubt=sdoubt_yes	36.2	57.9	26.6	0.000	10.3
scosts=scosts_yes	30.8	68.7	37.0	0.000	9.9
treat=treat_yes	20.5	100.0	81.1	0.000	9.2
stradm=stradm_yes	29.0	62.1	35.5	0.000	8.3
shospf_issue=shospf_yes	19.3	57.4	49.4	0.014	2.5
shospf_issue=shospf_issue	22.0	23.1	17.4	0.027	2.2
scosts=NA	0.0	0.0	1.6	0.031	-2.2
sdoubt=NA	3.0	0.5	2.8	0.020	-2.3
treat=NA	0.0	0.0	2.3	0.007	-2.7
death_location=Other	2.9	1.0	6.0	0.000	-3.6
shospf_issue=shospf_no	9.9	19.5	32.7	0.000	-4.4
stradm=stradm_no	9.7	36.4	62.0	0.000	-7.9
treat=treat_no	0.0	0.0	16.6	0.000	-8.6
scosts=scosts_no	8.5	31.3	61.4	0.000	-9.3
sdoubt=sdoubt_no	9.8	41.5	70.6	0.000	-9.3
death_location=Hospital or other health facilities	0.9	2.6	45.7	0.000	-14.8
disch=disch_no	1.6	8.2	83.7	0.000	-28.1

Source: Ouagadougou HDSS (2010-2019), 1,175 deceased 15 and older with a completed VA

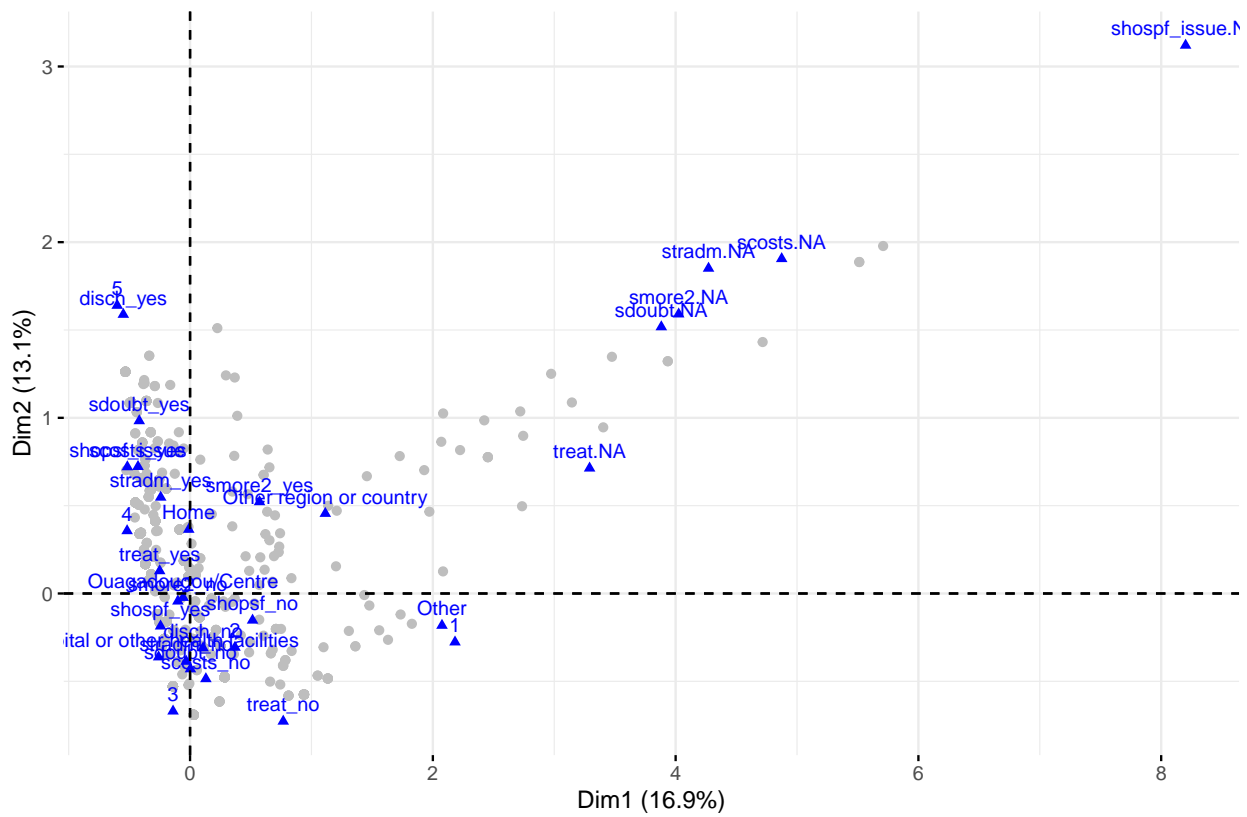
Reading: Among all deceased, 72.9% that were discharged from hospital very ill are part of the cluster 1.

Among all deaths in cluster 5, 67.6% were discharged from hospital, compared to 16.3% in the total population.

Hence dying in another location is positively and significantly associated with belonging to cluster 5, with a v.test of 19.5.

Results from a chi2 test of independence. Only categories significantly associated with the cluster are shown (abs(v.test) >=2)

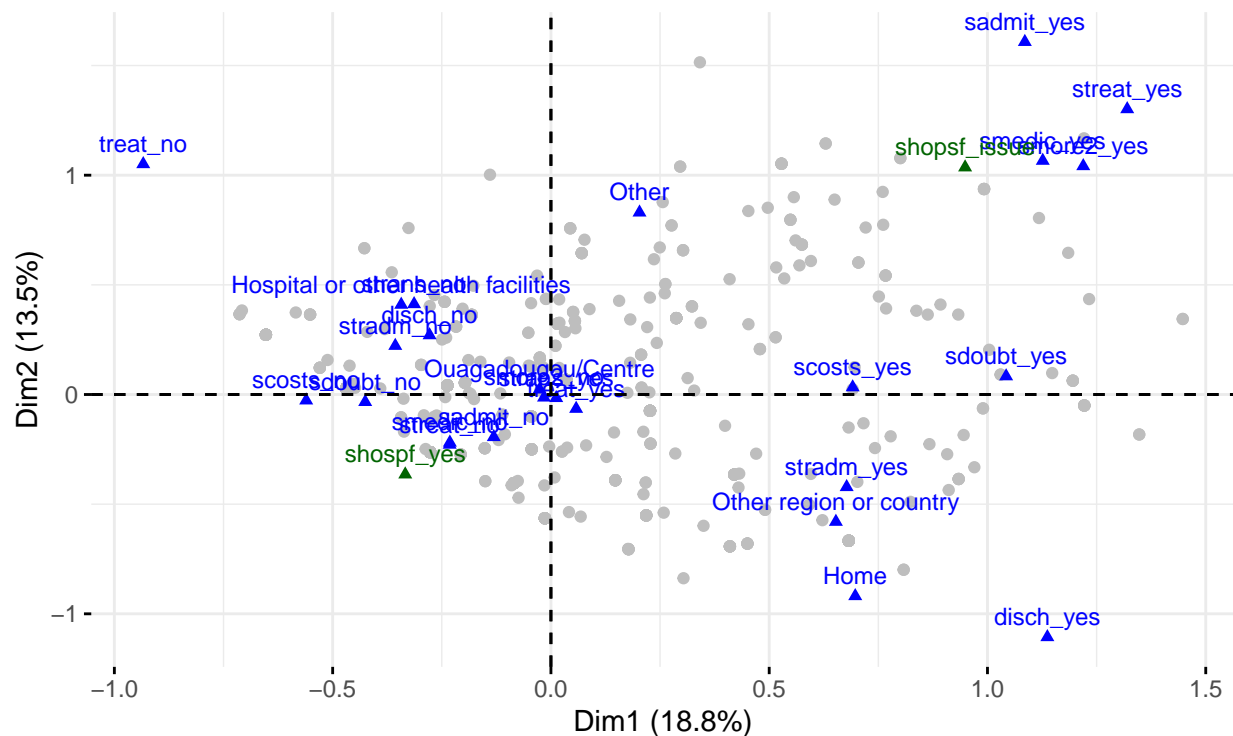
Figure 6: Graph of the 1st and 2nd dimension of an MCA without missing values imputation



Data : HDSS Ouagadougou (2010–2019).
 Population : 1,175 deceased older than 15 years old with a completed VA.
 Note: Unsurprisingly, all missing values seem to be highly correlated.

5.7 Separated MCA for those who visited a health facility and those who did not

Figure 7: Visited a health facility in the final days

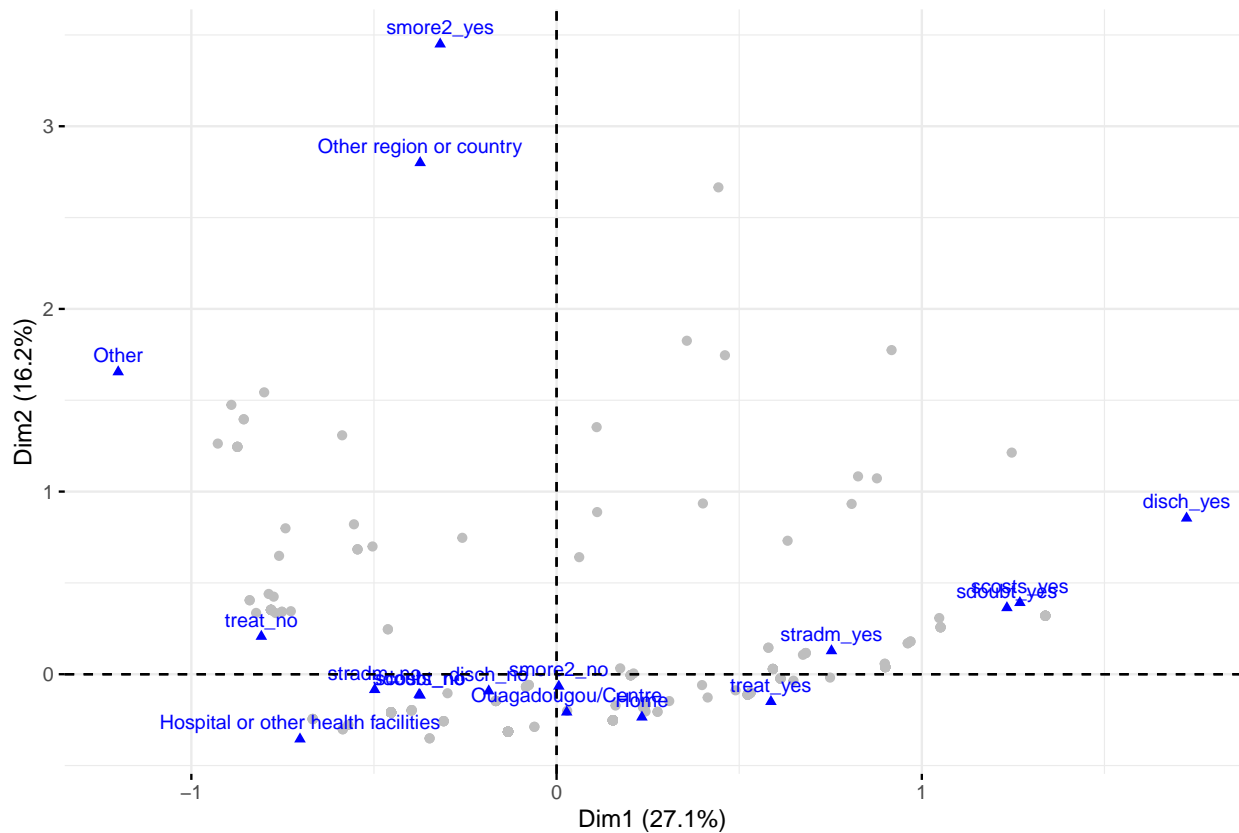


Data : HDSS Ouagadougou (2010–2019).
 Population : deceased with a VA more than 15 years old

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Figure 8: Did not visit a health facility in the final days



Data : HDSS Ouagadougou (2010–2019).
Population : deceased with a VA more than 15 years old

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