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# Mortality trends and access to care for cardiovascular diseases in Agincourt, rural South Africa: a mixed-methods analysis of verbal autopsy data

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## ABSTRACT

**Objectives** Cardiovascular diseases are the second leading cause of mortality behind HIV/AIDS in South Africa. This study investigates cardiovascular disease mortality trends in rural South Africa over 20+ years and the associated barriers to accessing care, using verbal autopsy data.

**Design** A mixed-methods approach was used, combining descriptive analysis of mortality rates over time, by condition, sex and age group, quantitative analysis of circumstances of mortality (CoM) indicators and free text narratives of the final illness, and qualitative analysis of free texts.

**Setting** This study was done using verbal autopsy data from the Health and Socio-Demographic Surveillance System site in Agincourt, rural South Africa.

**Participants** Deaths attributable to cardiovascular diseases (acute cardiac disease, stroke, renal failure and other unspecified cardiac disease) from 1993 to 2015 were extracted from verbal autopsy data.

**Results** Between 1993 and 2015, of 15 305 registered deaths over 1 851 449 person-years of follow-up, 1434 (9.4%) were attributable to cardiovascular disease, corresponding to a crude mortality rate of 0.77 per 1000 person-years. Cardiovascular disease mortality rate increased from 0.34 to 1.12 between 1993 and 2015. Stroke was the dominant cause of death, responsible for 41.0% (588/1434) of all cardiovascular deaths across all years. Cardiovascular disease mortality rate was significantly higher in women and increased with age. The main delays in access to care during the final illness were in seeking and receiving care. Qualitative free-text analysis highlighted delays not captured in the CoM, principally communication between the clinician and patient or family. Half of cases initially sought care outside a hospital setting (50.9%, 199/391).

**Conclusions** The temporal increase in deaths due to cardiovascular disease highlights the need for greater prevention and management strategies for these conditions, particularly for the women. Strategies to improve seeking and receiving care during the final illness are needed.

## INTRODUCTION

Non-communicable diseases (NCDs) are estimated to be responsible for two-thirds

### Strengths and limitations of this study

► This is the first known investigation combining both mortality trends and barriers to access to care for people who have died of cardiovascular diseases.

► In combining quantitative and qualitative analysis to develop a three delays model specific to cardiovascular disease in the Agincourt population, this study provides a basis for development and application to other settings to deal with care access and quality issues in the final stages of chronic illness.

► Using two components of verbal autopsy data provides complimentary information and a basis for refining circumstances of mortality indicators, but direct comparison is limited by methodological differences in data collection.

► The non-specificity of verbal autopsy cause of death categories, particularly 'other and unspecified cardiac diseases,' reduces the ability of this study to analyse trends in specific cardiovascular disease conditions.

► Other factors influencing equity in access to care, such as migratory status and socioeconomic status, cannot be included due to lack of available data within verbal autopsies.

of global mortality.[1] Cardiovascular diseases (CVDs) are the most prevalent NCD, both globally and in South Africa.[2 3] NCDs remain vastly undersupported; currently less than 0.1% of South Africa's national health budget is spent on NCDs.[4]

Access to care is a vital element of universal health coverage and a key challenge for South Africa; economic, geographical and racial inequalities together create vast disparities.[5–7] The South African government is now in its second phase of implementing National Health Insurance.[8] This second phase has come with an emphasis on strengthened and community-based primary care: a national programme, Re-Engineering Primary Health

Care, was initiated in 2010 with the aim of strengthening health promotion and prevention and early detection of disease.[9] As a response to South Africa's dual burden of HIV/AIDS and NCDs, the National Department of Health introduced an integrated chronic disease management model in 2011.[1]

Although other studies have quantitively examined gaps in care-access using a continuum or 'cascade' of care approach,[10 11] knowledge of where barriers in access to care for CVD occur and the identity of such barriers in rural South Africa, as well as who is less likely to seek care, is a key gap in the literature. This is a crucial area for research, as delays in accessing care are an important predictor of patient morbidity and mortality for CVD outcomes.[12]

Due to a lack of civil registration data and death certification systems in many low-income and middle-income countries (LMICs), existing data on trends in CVD deaths may vary in reliability.[13] There is a civil registration system in South Africa, with marked improvements in recent years, but evaluations have highlighted persisting quality issues that may which influence its reliability and validity .[14] Verbal autopsy (VA) is a method of ascertaining cause of death and the circumstances surrounding that death in situations—such as deaths in the community—where other methods are not available or reliable. VAs are done by trained fieldworkers who ask a standard set of questions to carers of the deceased. Either physician judgement or computer algorithm is used to assign cause of death based on these data,[15] which has been shown to be reliable and reproducible.[16] Since 2012, versions of the WHO VA tool have included questions on circumstances surrounding deaths.[17] There is also a free text section where fieldworkers record summaries about the death and its circumstances, which may include information not captured on the binary responses from the rest of the VA tool—including access to care. VA presents a unique opportunity to understand social exclusion from access to health systems within a population, as well as quantify causes of death. When conducted sequentially in the same community, VA enables an understanding of how patterns of access to health systems change over time. This research presents both substantive findings to this end and develops the VA methodological approach.

A three delays model can be used to examine barriers in accessing care. This approach categorises delays into three phases: seeking, reaching and receiving care (see online supplemental figure A1),[18] and draws attention to the multifactorial nature of access to care.[19] It facilitates an overview of access to care for a particular context by breaking down the care pathway into a series of steps, and suggests targets for health planning. Use of the three delays model has been used extensively for care in obstetric emergencies[18] with recent broader applications, for example to sepsis,[20] trauma[21 22] and time-critical conditions.[23] It has not yet been applied to CVDs.

This study aims to contribute to bridging the gap in the evidence needed to support prioritising and planning services for NCDs, which is especially important as South Africa works towards the goal of universal health coverage.[24] This study is the first known investigation combining both mortality trends and barriers to access to care for people who have died of CVD.

Using VA data, this study documented trends in CVD deaths that can be described as 'downstream' deaths; cardiac conditions, strokes, and renal disease, rather than 'upstream' CVD risk factors (eg, diabetes or hypertension). It aimed to understand differences over time, by condition, age and sex of those dying in a rural population in South Africa. This study also aimed to ascertain barriers to and patterns of access to care leading up to the death, using a three delays framework and examination of both CoM and free text components of VA data.[23] By combining quantitative and qualitative findings, this study aimed to develop a three delays model specific to CVD in the Agincourt population, providing a basis for development and application of the three delays model to the final stages of chronic illness in other settings.

## METHODS
### Study design
This study presents a mixed-methods analysis of VA data. Quantitative analysis comprised of descriptive analysis of CVD mortality rates and a three delays approach to analysis of circumstances of mortality (CoM) indicators and free-text narratives of the final illness. Free text narratives were also analysed qualitatively.

### Study setting and participants
This study was done in the Agincourt Health and Socio-Demographic Surveillance System (HDSS) site, in Mpumalanga province, rural North East South Africa. The HDSS covers an entire sub-district population of ~117 000 persons and has been stewarded by the MRC/Wits Rural Public Health and Health Transitions Research Unit since inception.[25] The population has been surveyed at least annually since 1992, with VA conducted on every death in the study population occurring in each preceding year. Previous studies have shown recall to be good up to a year after a death.[26] At the time of research, VA data from 1993 to 2015 was available.

### Quantitative analysis
#### Measures
Deidentified VA data were electronically stored and three elements extracted:

#### *Cause of death: derived using InterVA-5*[27]
InterVA-5 is the most recent probabilistic modelling approach developed to assign cause of death, using responses to VA interview questions. Detailed explanation of how cause of death is assigned is provided by Byass *et al*.[28] Two authors (JNLV and JD) reviewed VA cause of death categories to select deaths related to CVDs. Included categories were 'acute cardiac disease' (corresponding

to ischaemic heart diseases), 'stroke' (corresponding to cerebrovascular diseases), 'renal failure' (corresponding to acute and chronic renal failure) and 'other and unspecified cardiac disease' (corresponding to acute rheumatic fever; chronic rheumatic heart diseases; pulmonary heart disease and diseases of pulmonary circulation; other forms of heart disease; disease of arteries, arterioles and capillaries; diseases of veins, lymphatic vessel and lymph nodes not elsewhere classified; other and unspecified disorders of the circulatory system).[29] After discussion among the authors, renal failure was included in our analysis as a CVD outcome because the main causes of chronic kidney disease are CVD risk factors—hypertension and diabetes. These exceed other causes, such as chronic glomerulonephritis or HIV.[30] Chronic kidney disease is especially likely to be related to CVD in older adults in this population, where CVD risk factors are highly prevalent and under-treated.[31] To minimise capturing non-CVD causes, cases of renal failure deaths in people aged under 40 years old were excluded.[32] InterVA-5 gives a likelihood of a death being due to a given cause; greater than 50% was required for case inclusion. Each death appears once in the analysis.

### CoM indicators
The ten CoM indicators are closed questions (see online supplemental figure A1) added to the VA tool in 2012, which examine social and health systems determinants of death and social exclusion from access to care.[17] These indicators are based on a framework of proximate (biological processes preceding outcomes), intermediate (health systems factors), and distal (socioeconomic and cultural conditions) determinants of health outcomes.[17] An 11th indicator was included alongside the ten CoM indicators, which asks whether the deceased was discharged while still ill. While not part of the CoM indicators, this is thought to be important to include, especially for chronic conditions such as CVD, as these patients may experience multiple cycles of accessing care. It may suggest poor quality of care.

Delays in access to care were examined using the CoM indicators, including cases where death occurred between 2012 and 2015 (the years where CoM indicators were available). A person was classed as having experienced a delay if they had a positive response to the relevant indicator, with the exception of three (calling for help, travelling to a healthcare facility and using motorised transport to reach a facility), where a negative response was used to capture experiencing a delay.

### Free-text descriptions of the death and its circumstances
The free-text sections of each VA are recorded by a trained lay field worker at the time of interview. Based on discussions with the respondent, most often the primary care-giver, this enables more nuanced details about circumstances around the time of death to be captured.

### Analysis
All deaths recorded within the Agincourt population were included in the dataset. Systematic house-to-house visiting and detailed inquiry of every household member limits the risk of missing deaths. Descriptive data were generated using SPSS V.25.[33]

### Mortality trends
CVD deaths for each condition category, 5-year time period, sex and 10-year age group are described as age-sex-time-standardised mortality rates.

### Three delays quantitative analysis
To identify inclusion of cases in the three delays analysis, cases where free text and CoM data were not both available were first excluded. Free texts were examined to identify cases which were found dead at the scene or had died suddenly, with therefore no opportunity to seek care. These cases were also excluded. The remaining cases are referred to as those 'able to seek care.' Responses to CoM questions are described as total cases indicating they had experienced at least one delay across any of the CoM indicators, shown as a proportion of total cases able to seek care. Total cases for each specific delay are then shown as a proportion of cases that had experienced at least one delay across any of the CoM indicators.

In addition delays extracted from the free text are analysed quantitatively, in a similar manner for that done with the CoM indicators, using data on the three delay coding extracted during the qualitative analysis (see below). The free text was also examined to determine the first care-seeking act, where this information was available.

### Qualitative analysis
The free texts were analysed qualitatively to ascertain delays in access to care, using a combination of deductive and inductive approaches. A deductive approach enabled causes of delays to be extracted using a set of a priori codes based on the three delays framework of seeking, reaching and receiving care. An iterative process[23] enabled emerging codes to be incorporated until saturation was reached.

Initial coding was conducted by JNLV, with codes reviewed by JD and AF. This method has been previously applied to the same dataset.[23] NVivo V.12 software was used for the qualitative analysis.[25 34]

### Construction of a three delays model
Finally, a three delays model, specific to CVD in the Agincourt population, was developed through aggregating delays derived from the CoM and free-text analyses.

### Patient and public involvement
We did not directly include public involvement in this study. The database, from which this study derives data, is used to inform a public engagement programme at the Medical Research Council/Wits University Rural Public Health and Health Transitions Research Unit (Agincourt).

**Table 1** Age-sex-time-standardised mortality rates per 1000 person-years for a total 15 305 deaths over 1 851 449 person-years, between 1993 and 2015

| | Total CVD deaths | Acute cardiac disease | Stroke | Renal failure | Other and unspecified cardiac disease |
|---|---|---|---|---|---|
| Crude mortality rate | 0.77 | 0.13 | 0.32 | 0.04 | 0.29 |
| Sex | | | | | |
|   Female | 0.82 | 0.09 | 0.36 | 0.03 | 0.34 |
|   Male | 0.73 | 0.17 | 0.27 | 0.05 | 0.25 |
| Age group | | | | | |
|   0–10 | 0.02 | 0.00 | 0.01 | N/A | 0.00 |
|   11-20 | 0.07 | 0.00 | 0.04 | N/A | 0.03 |
|   21–30 | 0.28 | 0.04 | 0.10 | N/A | 0.14 |
|   31–40 | 0.67 | 0.11 | 0.30 | N/A | 0.26 |
|   41–50 | 1.55 | 0.33 | 0.49 | 0.13 | 0.60 |
|   51–60 | 4.01 | 0.77 | 1.48 | 0.22 | 1.54 |
|   61–70 | 7.18 | 1.05 | 2.76 | 0.44 | 2.93 |
|   71–80 | 13.68 | 1.66 | 5.99 | 0.69 | 5.34 |
|   81+ | 28.53 | 5.40 | 12.89 | 1.21 | 9.03 |
| Time period | | | | | |
|   1993–1997 | 0.41 | 0.04 | 0.17 | 0.02 | 0.19 |
|   1998–2003 | 0.52 | 0.05 | 0.24 | 0.02 | 0.22 |
|   2004–2009 | 0.83 | 0.07 | 0.39 | 0.03 | 0.34 |
|   2010–2015 | 1.10 | 0.27 | 0.40 | 0.06 | 0.37 |

Data standardised against Agincourt INDEPTH Core Dataset. [53]
CVD, cardiovascular disease.

## RESULTS

### Mortality trends

A total of 15 305 registered deaths occurred over 1 851 449 person-years between 1993 and 2015. Of these deaths, 9% (1434) were attributable to CVDs, corresponding to a crude CVD mortality rate of 0.77 per 1000 person-years. Standardised mortality rates by sex, age group and time period are displayed in table 1.

The CVD mortality rate increased from 0.34 in 1993 (7.0% of all deaths) to 1.12 in 2015 (15.8% of all deaths). Across all time periods, stroke was the dominant cause of CVD deaths and suggested a linear increase, responsible for 41.0% (588/1434) of all CVD deaths across all years (figure 1). Mortality contributions of acute cardiac disease (16.3%, 234/1434) and renal failure (4.8%, 69/1434) were low across all years, although 2010–2015 saw an increase in acute cardiac disease deaths.

Over the entire time period, the CVD mortality rate was higher in women (female:male mortality rate ratio 1.13, 95% CI 1.02 to 1.26; figure 1). Mortality was higher in women for stroke (female:male 1.36, 95% CI 1.15 to 1.61) and other and unspecified cardiac diseases (female:male 1.37, 95% CI 1.15 to 1.63). Mortality was higher in men for acute cardiac disease (female:male 0.52, 95% CI 0.40 to 0.69), there was no significant difference for renal failure (female:male 0.63, 95% CI 0.38 to 1.02). CVD mortality rate increased with age (figure 1).

### Access to care

Between 2012 and 2015, 495 CVD deaths occurred; of these 41 (8.3%) cases did not have both free text and CoM information available and were excluded from analyses.
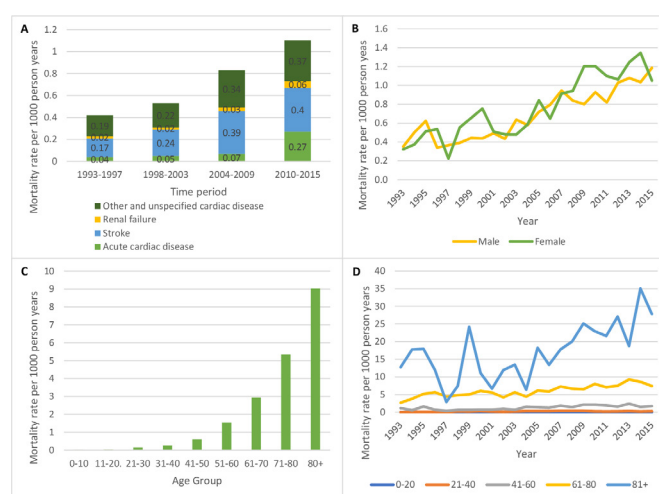


**Figure 1** Trends in CVD mortality 1993–2015. (A) CVD mortality rates for each 5-year time period disaggregated by condition. (B) Male and female CVD mortality rates over time. (C) Mortality rates due to cardiovascular disease for each 10-year age group. (D) CVD mortality rates for each 20-year age group over time. CVD, Cardiovascular disease.
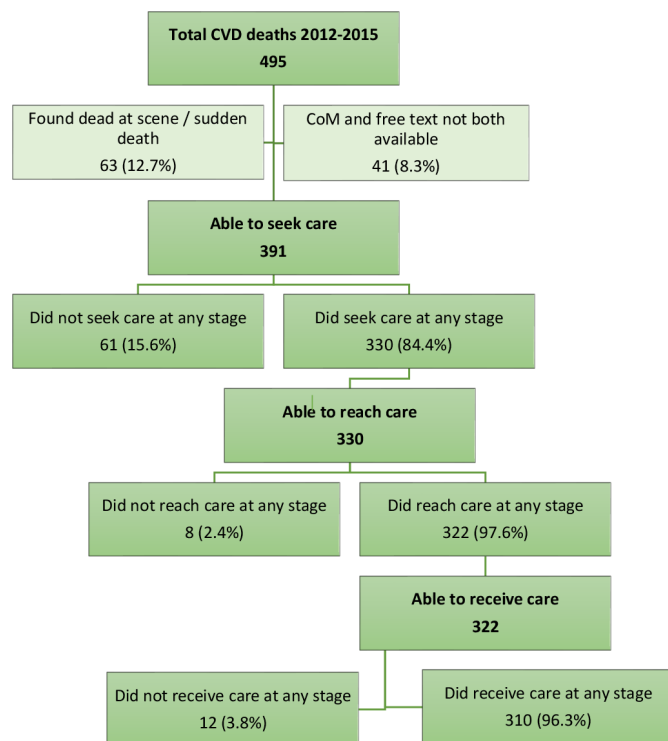
**Figure 2** Flow diagram showing access to care of all people who had CVD deaths between 2012 and 2015, analysed using the free text. Notes: number of cases at each stage of the care pathway are shown as a proportion of total cases which reached the previous step (shown in bold). CoM, circumstances of mortality; CVD, cardiovascular disease.

63 (13.9% of the 454 with data available) were found dead at the scene or suffered a sudden death, leaving 391 cases who were able to seek care. Of these, analysis of the free text showed 330 went on to seek care, 322 reached care and 310 received care (figure 2).

The CoM analysis showed 36.8% (151/391) of all cases which were able to seek care reported at least one delay. 82.1% (124/151) of these cases reported experiencing at least one delay in seeking care, 11.3% (17/151) in reaching care, and 32.5% (49/151) in receiving care. In 64.5% (252/391) of all cases who were able to seek care, the free text captured at least one delay. Of these, 46.0% (116/252) experienced at least one delay in seeking care, 4.4% (11/252) in reaching care and 59.9% (151/252) in receiving care (table 2).

When considering all delays, there was no significant difference in numbers experiencing any delay between sexes using the CoM indicators (88 female vs 63 male cases, $\chi^2=2.1$, p=0.148) or free text (142 female vs 110 male cases, $\chi^2=0.03$, p=0.856). No significant differences were seen in numbers experiencing a delay by age group on either CoM or free-text analyses.

Significant difference was seen by condition on CoM, with 18.1% acute cardiac diseases (13/72), 48.2% (67/139) stroke, 46.9% (15/32) renal failure and 37.8% (56/148) of other and unspecified cardiac disease cases reporting any delay ($\chi^2=19.1$, p<0.001). No equivalent significant difference was seen on the free text (see online

supplemental table A1 for delays shown by sex, age group and condition).

## Qualitative analysis

Themes identified in each delay category are summarised below, with a non-exhaustive selection of quotes which have been chosen to illustrate themes. Each quote has been given by the field worker recording each case.

### Delays in seeking care

Of the cases reporting any delay, almost half reported a delay in seeking care. However, specific reasons or explanations were rarely given, and lack of care-seeking was commonly expressed through phrases like 'nothing was done' or a refusal to seek care. Only one of the CoM indicators on seeking care—traditional medicine—was explicitly mentioned in the free text.

Traditional medicine was often sought either before or after having sought 'western' care. Care was sought from a traditional healer following perceived failure of treatment given at a 'western' facility and vice versa.

> The doctors didn't say what was wrong. Treatment was given but nothing changed… He was taken to the private doctor. The doctor didn't say what was wrong… He was taken to the traditional healer.

> He went to traditional healer who gave him traditional medicine… Nothing changed. He then went to private doctor.

Refusal to seek care was common among cases who did not travel to a facility. However, refusal appeared to be targeted towards hospitals rather than clinics.

> She was taken to the clinic… Treatment was given but nothing [changed]. After few days, she was worse. She refused to go to the hospital, she died at home.

### Delays in reaching care

Reaching care was very rarely discussed in the free text. Two explicit delays were mentioned, which related to ambulances and dying on the way to healthcare. Other cases indicated a delay occurred—such as in cases where the intention to seek care had been made—but further detail was not provided.

In cases where reaching care was discussed, this mostly centred around ambulance transport. Cases which mentioned calling directly for an ambulance themselves from home frequently experienced delays.

> An ambulance was called… It was late and when they arrive, they said that she is dead.

In several cases, there were suggestions of an intention to seek care but which were unfulfilled. While the free text did not provide further insight into the reasons for this delay, this suggests there may be additional delays following an intention to seek care which were not captured in the free text.

**Table 2** Delays in seeking, reaching and receiving care, as reported in CoM and free texts

| | Delay | Cases reporting each delay | | Cases reporting any delay | |
|---|---|---|---|---|---|
| | | n | %* | n | %† |
| **CoM** | | | | | |
| Any delay | | | | 151 | 38.6 |
| Seeking | Any delay in seeking care | 124 | 82.1 | | |
| | Costs of care and treatment prohibited other household payments | 113 | 74.8 | | |
| | Traditional medicine was used | 25 | 16.7 | | |
| | Telephone or cell phone was not used to call for help | 16 | 10.6 | | |
| | Doubts about whether medical care was needed | 9 | 6.0 | | |
| Reaching | Any delay in reaching care | 17 | 11.3 | | |
| | Did not travel to a facility (no reason given) | 16 | 10.6 | | |
| | Did not use motorised transport | 16 | 10.6 | | |
| | Took 2 hours or more to get to the nearest facility | 1 | 0.7 | | |
| Receiving | Any delay in receiving care | 49 | 32.5 | | |
| | Discharged while still ill | 40 | 26.5 | | |
| | Problems with way treated at facility | 7 | 4.6 | | |
| | Problems getting medications or diagnostic tests at facility | 5 | 3.3 | | |
| | Problems during admission to the facility | 2 | 1.3 | | |
| **Free text** | | | | | |
| Any delay | | | | 252 | 64.5 |
| Seeking | Any delay in seeking care | 116 | 46.0 | | |
| | At least one delay during seeking care‡ | 100 | 39.7 | | |
| | Traditional medicine was used | 18 | 7.1 | | |
| Reaching | Any delay in reaching care | 11 | 4.4 | | |
| | Death during travel | 8 | 3.2 | | |
| | Ambulance delay | 3 | 1.2 | | |
| Receiving | Any delay in receiving care | 151 | 59.9 | | |
| | Communication | 97 | 38.5 | | |
| | Discharged still ill | 35 | 13.9 | | |
| | Died on arrival/before being treated | 13 | 5.2 | | |
| | Family/self-forced discharge | 7 | 2.8 | | |
| | Problems with treatment | 6 | 2.4 | | |
| | Interhospital referral | 5 | 2.0 | | |
| | No diagnosis given | 2 | 0.8 | | |

Delays add up to >100% of cases as individuals could have experienced more than one delay within each delay category
*Denominator=who reported any delay (CoM: n=151, free text: n=252).
†Denominator=cases able to seek care (n=391).
‡The free-text categorisation of 'at least one delay during seeking care' combines cases who never sought care (corresponding to the 61 cases in figure 2) with those who refused to seek care or initially did not seek care but later did, and those who initially sought care and later refused in subsequent cycles of accessing care.
CoM, circumstances of mortality.

She collapsed at the gate… She died after an hour before they can take her to healthcare.

### Delays in receiving care

Delays in receiving care were reported in the free texts of most cases. This tended to focus on issues of communication between the clinician and patient or family, and being discharged while still ill.

A repeated and persistent theme on receiving care was that the patient, family or caregiver were not told by the clinician what the problem was.

At hospital he was admitted, oxygen, waterdrips and tablets was given but all the symptoms didn't change and the doctors didn't tell the family what was wrong.

In many cases, the patient was reported to have been discharged while still ill, frequently leading to re-entering the three delays cycle.

He was discharged at the hospital after six days and he was still sick. He was taken to another hospital after a day and he was admitted again… He was not getting better… He was discharged being sick.

Referral between hospitals presented an opportunity for delays, such as lack of admission at the second hospital, being admitted but reporting that nothing was done, and/or being referred back to the first hospital without any treatment or diagnostic tests being performed. This again highlights the non-linearity of accessing care for CVDs, as patients re-entered a process of making decisions, travel and readmission.

While she was at hospital she was taken to another hospital… To check her chest. She told them that they didn't do anything at the other hospital. They didn't admit her, she was sent back to the first hospital the same day.

Other cases indicated a lack of alignment between hospitals involved in inter-facility referral, particularly when patients were sent to another hospital for an operation. In several cases, such patients were taken to the referred hospital only to not receive the operation they had travelled for.

The doctor said she need to be operated [and] referred her to another hospital for operation, but she was not admitted and they said they are fully booked… She must wait until they have space.

Many cases referenced elements of patient decision making which negatively impacted the receipt of care, therefore, contributing to delays in receiving care. A key theme in patient decision making was self, or family, forced early discharge.

She was admitted and given treatment… The family asked doctors to discharge her but not given treatment as they promise to bring her back to hospital… She was not taken back to hospital… She died at home.

Refusal to be admitted to hospital also emerged as a patient-led delay in receiving care.

He was taken to the hospital. He refused to be admitted… He died at home after a day of consultation from the hospital.

### First care-seeking act

The first care-seeking acts identified from the free text are outlined in table 3. Cases were also categorised by hospital, non-hospital and delayed first care-seeking act. A total of 391 cases were able to seek care and therefore were included in the analysis. There were no significant differences in first care-seeking act by sex, age group or condition.

**Table 3** First care-seeking act, shown as number of cases and proportion of total applicable cases (n=391)

| Category | First care-seeking act | Cases | | Total cases in category | |
|---|---|---|---|---|---|
| | | n | % | n | % |
| **Hospital** | Hospital | 106 | 27.1 | 117 | 29.9 |
| | Ambulance | 11 | 2.8 | | |
| **Non-hospital** | Public clinics and health centres | 117 | 29.9 | 199 | 50.9 |
| | Private facility | 49 | 12.5 | | |
| | Traditional medicine | 12 | 3.1 | | |
| | Chemist | 5 | 1.3 | | |
| | Home treatment | 16 | 4.1 | | |
| **Delayed** | | | | 75 | 19.2 |

Base=total applicable cases (n=391).
'Delayed' includes cases where initially no care was sought but later was, and those who never sought care. This differs from table 2, where the free-text delay 'at least one delay during seeking care' also encompasses cases who later refused to seek care after having previously sought it.

### Three delays model

A three delays model for CVD outcomes, developed through combining qualitative analysis of the free text and the quantitative CoM analysis, is shown in online supplemental figure A2.

## DISCUSSION

While trends in deaths due to CVD have been the subject of previous studies,[35 36] this is the first known investigation combining both mortality trends and barriers to access to care for people who have died of CVD. In this low-income rural South African population, we found that CVD deaths are increasing over time, with an increase in mortality rate from 0.34 to 1.12 between 1993 and 2015. Most of these deaths were due to stroke, and women overall suffered significantly more CVD deaths than men. Women experienced fewer ischaemic heart disease events than men, contrasting with knowledge from other settings that women are as likely to have these conditions as men. However, the findings do fit with evidence from elsewhere that importance of CVD in women may be underestimated[37] and underdiagnosed.[38] This difference could also be due to differences in care seeking behaviours among men and women, although this analysis suggests there was no difference in reporting barriers to care in the final illness by sex.

To ensure validity of our findings, we used two methods to examine access to care for CVD in Agincourt, one using the CoM indicators and the other, free text. Care access was found to be generally good, with most cases seeking, reaching and receiving care. Nevertheless, many cases did report experiencing multiple and reinforcing delays in seeking and receiving care.

Both the CoM and free text highlighted seeking care as a key delay in accessing care. Although only 6% of respondents said that the deceased doubted the need for medical care when explicitly asked in the CoM, most cases did not present to hospital or call an ambulance as their first care act, suggesting that the urgent need for care was not recognised. Early hospital-based care is a critical determinant of most successful interventions for CVD outcomes;[39] that the first health-seeking act for people who died of acute cardiac disease was often prehospital rather than hospital is therefore troubling. Not seeking hospital care in the first instance can also lead to a re-entry into the three delays cycle, presenting opportunities for the patient to experience further delays. Health literacy campaigns around symptom recognition and presenting to facilities able to deal with these acute conditions could improve not only the current access to care cycle but also future iterations, and have worked well in other settings.[40] However, this study highlights multiple supply-side factors which also drive barriers to care seeking, which likely combine and converge with demand-side issues.

The South African public health system aims to provide healthcare that is free at the point of use for all.[41] Despite this, perceived costs were a major barrier to seeking care in most cases who experienced delays. Consistent reporting of prohibitive costs in Agincourt has also been shown elsewhere.[17] This may be due to poor information on availability of healthcare, or that non-medical direct (eg, transport costs, with longer distances to hospitals) and indirect costs (eg, fear of loss of earnings) are driving this barrier. Overall cost burdens of care have been shown to be low in Agincourt, but costs associated with transport and difficulty in obtaining income-related exemptions at hospitals limit the efficacy of state-provided protection.[42] Work must be done to further delineate the reasons for high reporting of prohibitive costs and institute appropriate solutions.

Reaching care appeared to be a fairly minimal delay. Although free text analysis highlighted a further delay not captured in the CoM indicators, ambulance delay, the number of cases reporting this was minimal. Shortages of ambulances has been a key challenge in this area, but the Department of Health has invested in Emergency Medical Services including increasing ambulance numbers.[43 44] Nevertheless, given that many patients who need this service are not using it due to prior barriers at the stage of seeking care, investment in ambulance services may need to be accompanied by measures to reduce these prior barriers.

Receiving care was a common barrier in both the CoM and free text analyses. Free texts highlighted many barriers not captured by the CoM; it is likely that the free text allows expansion on the barriers experienced in receipt of complex facility-based care that are not possible to capture in the smaller number of CoM fields for this delay, pointing to the complementarity of the two methods. Phrases like 'nothing was done,' and 'the doctor didn't say what was wrong' were ubiquitous. It could be that healthcare providers are not communicating effectively, or at all, with the patient and/or caregiver, and therefore this is an element of clinician–patient interaction which requires intervention. However, it could also be an indication that the clinician was not able to determine a diagnosis, potentially as a result of health system weaknesses (eg, availability of equipment, staff training, system capacity). Poor quality of care is now a greater barrier to reducing mortality in LMICs than insufficient access to care,[45] so understanding where these issues are is vital.

With either interpretation, these free text phrases suggest a wider issue of poor perception of care quality. Low expectations of care quality are prevalent in LMIC settings, including South Africa, which may reduce pressure on systems to deliver quality care.[46] Perceptions of care quality may also inform future care-seeking behaviours, as evidenced here by the frequent use of traditional healers after visiting a 'western' facility and feeling nothing changed or nothing was done, or by otherwise refusing to seek or delaying care-seeking. Refusal of care was common, and more so for hospitals than clinics. It could be hypothesised that care received in hospitals is perceived as poorer than in clinics; further supported by

the number of cases who sought non-hospital care in the first instance. Patient experience and perceived quality of care can impact utilisation of healthcare services.[47] Changing perceptions of hospitals as places to receive care and be treated, rather than places to die, requires both improvement in the health system to enable hospitals to provide quality care[48] and positive messaging to individuals and communities. Negative perceptions are particularly important to remedy in chronic conditions, which most CVDs are, where patients should have multiple opportunities to seek and receive care and are likely to accumulate experience and perceptions of care quality. Interpersonal skills, improving drug availability and technical care (eg, examination, explanation of treatment) have been identified as priority areas to improve perceived quality of care in the adjacent Limpopo province;[49] aligning with the free text analysis in this study. However, evidence on perceptions towards care in South Africa is limited and warrants further investigation.

This study explores application of the linear framework of the standard three delays model to CVD outcomes. However, several findings have highlighted the complexity in access to care for chronic conditions: delays in receiving care—such as being discharged while still ill—influence future care-seeking behaviours, and many cases enter multiple cycles. Delays may therefore multiply and reinforce each other over the course of multiple iterations of accessing care, even during the final illness as examined here. A linear model is oversimplistic for application to chronic conditions, which could be better represented as a cyclical model. This has been raised previously in applying the three delays framework to access to care in Burkina Faso and Indonesia.[50]

### Study limitations

The non-specificity of InterVA-5 categories was a key limitation, particularly 'other and unspecified cardiac diseases.' This reduces the ability to analyse trends in specific CVD conditions and means it cannot be determined exactly what is driving a large proportion of this CVD burden. Renal failure was included due CVD risk factors being major causes of chronic kidney disease, especially in older adults. While we have aimed to minimise the inclusion of non-CVD-related causes of renal failure, we acknowledge this analysis may capture deaths due to other causes. Other factors influencing equity, such as migratory status and socioeconomic status, cannot be included due to lack of available data within VAs. That this study could not capture these factors limits the utility of the study for health planning from an equity perspective. Delays in receiving care may be under-reported: respondents may have had more direct experience of issues in seeking and reaching care, and so be more likely to report these, and people who died outside of facilities are also less likely to have experienced issues with quality of care, but this does not mean the issues do not exist.[17]

Comparing proportions of cases experiencing each delay as calculated by the CoM versus the free text must be

given careful consideration given the differing methods of data collection, but they do provide complimentary information amenable to synthesis. In comparing the CoM and free text, this study raises the question of breadth vs depth. The CoM is an invaluable tool for gaining a broad overview of delays in accessing care and are feasible to perform at scale. The free text, while able to pick up delays not captured in the CoM, is time-consuming to analyse with challenges of scalability. However, it has been shown that extracted word frequency counts from free texts can be used by machine learning for automated classification.[51] Insight gained from the free text could inform expansion or refinement of the CoM to enable a greater level of detail to be captured, particularly for assessing delays in receiving care. The CoM is continually evolving[52] and this analysis provides an empirical basis for revisiting them.

### Future research

The three delays model developed here presents a basis for development and application to other settings to deal with access and quality issues in the final stages of chronic illness. This study also presents an opportunity to revisit and refine the CoM indicators. It also highlights several avenues for further research. First, the greater burden of CVD death among women requires further investigation in order to develop strategies to tackle this inequity. Prominent delays in accessing care also require further examination, particularly around high reporting of prohibitive costs, and on perceptions of care quality.

### CONCLUSION

This study is the first known investigation combining both mortality trends and barriers to access to care for people who have died of cardiovascular. It shows the increase in deaths due to CVD between 1993 and 2015 in a rural region of South Africa. Given CVD in South Africa is now the second greatest cause of mortality after HIV/AIDS in South Africa,[3] there is a vital need for prevention and management strategies for these conditions. As women suffer a significantly higher CVD mortality than men, they should be a key focus of such strategies.

While care pathways appear to be generally good for CVD, this study has highlighted issues around seeking care, including that many CVD cases first seek care outside a hospital setting during the final illness and receiving care. Strategies to improve access to care are therefore needed. This study highlights the complexity in accessing care for chronic conditions such as CVD; many cases enter multiple cycles and may experience multiple and reinforcing delays. While a three delays model provides a valuable framework, the potential need for a cyclical model for examining access to care for chronic conditions should be considered.

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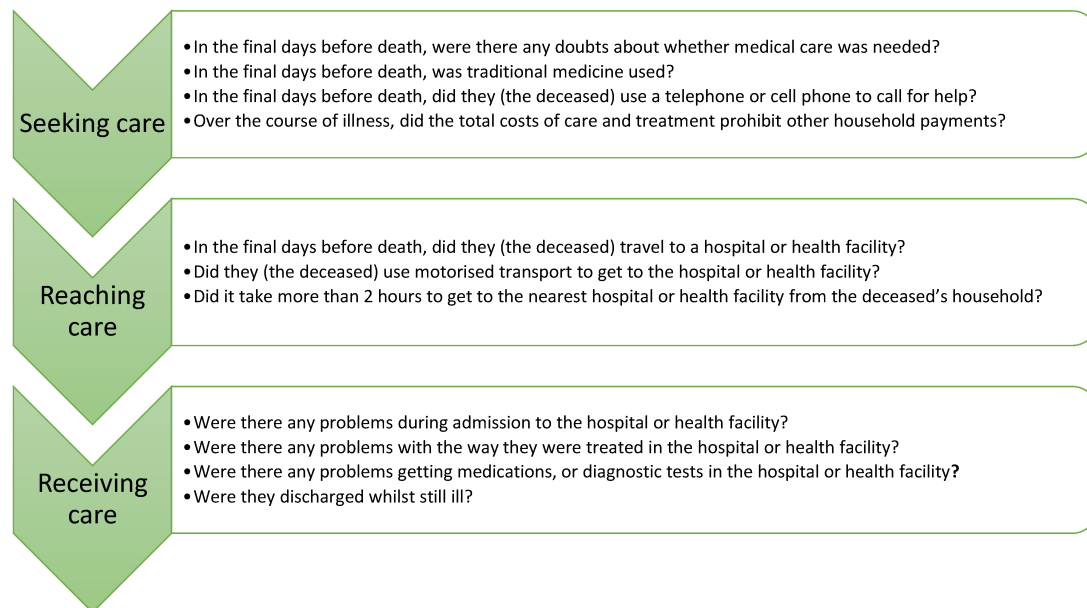Lucia D'Ambruoso http://orcid.org/0000-0002-8505-3368
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**Seeking care**

- In the final days before death, were there any doubts about whether medical care was needed?
- In the final days before death, was traditional medicine used?
- In the final days before death, did they (the deceased) use a telephone or cell phone to call for help?
- Over the course of illness, did the total costs of care and treatment prohibit other household payments?

**Reaching care**

- In the final days before death, did they (the deceased) travel to a hospital or health facility?
- Did they (the deceased) use motorised transport to get to the hospital or health facility?
- Did it take more than 2 hours to get to the nearest hospital or health facility from the deceased's household?

**Receiving care**

- Were there any problems during admission to the hospital or health facility?
- Were there any problems with the way they were treated in the hospital or health facility?
- Were there any problems getting medications, or diagnostic tests in the hospital or health facility**?**
- Were they discharged whilst still ill?

Supplementary Figure A1: Circumstances of Mortality and Verbal Autopsy indicators included for analysis of delays in accessing care

**Supplementary Table A1:**
**Cases reporting any delay, shown as a proportion of the total cases who were able to seek care**

| | | Results of the CoM analysis | Results of the free text analysis |
|---|---|---|---|
| | | Cases reporting any delay | Cases reporting any delay |
| **All cases** | | **38.6%** | **64.5% (252/391)** |
| **Sex** | **Male** | 36.6% (63/172) | 64.0% (110/172) |
| | **Female** | 40.2% (88/219) | 64.8% (142/219) |
| **Age Group** | **0-10** | 0.0% (0/1) | 100.0% (1/1) |
| | **11-20** | 33.3% (1/3) | 33.3% (1/3) |
| | **21-30** | 41.7% (5/12) | 58.3% (7/12) |
| | **31-40** | 30.0% (6/20) | 80.0% (16/20) |
| | **41-50** | 41.5% (17/41) | 58.5% (24/41) |
| | **51-60** | 43.5% (20/46) | 67.4% (31/46) |
| | **61-70** | 34.2% (25/73) | 63.0% (46/73) |
| | **71-80** | 39.0% (30/77) | 64.9% (50/77) |
| | **81+** | 39.8% (47/118) | 64.4% (76/118) |
| **CVD Condition** | **Acute cardiac disease** | 18.1% (13/72) | 75.0% (54/72) |
| | **Stroke** | 48.2% (67/139) | 58.3% (81/139) |
| | **Renal failure** | 46.9% (15/32) | 65.6% (21/32) |
| | **Other and unspecified cardiac disease** | 37.8% (56/148) | 64.9% (96/148) |
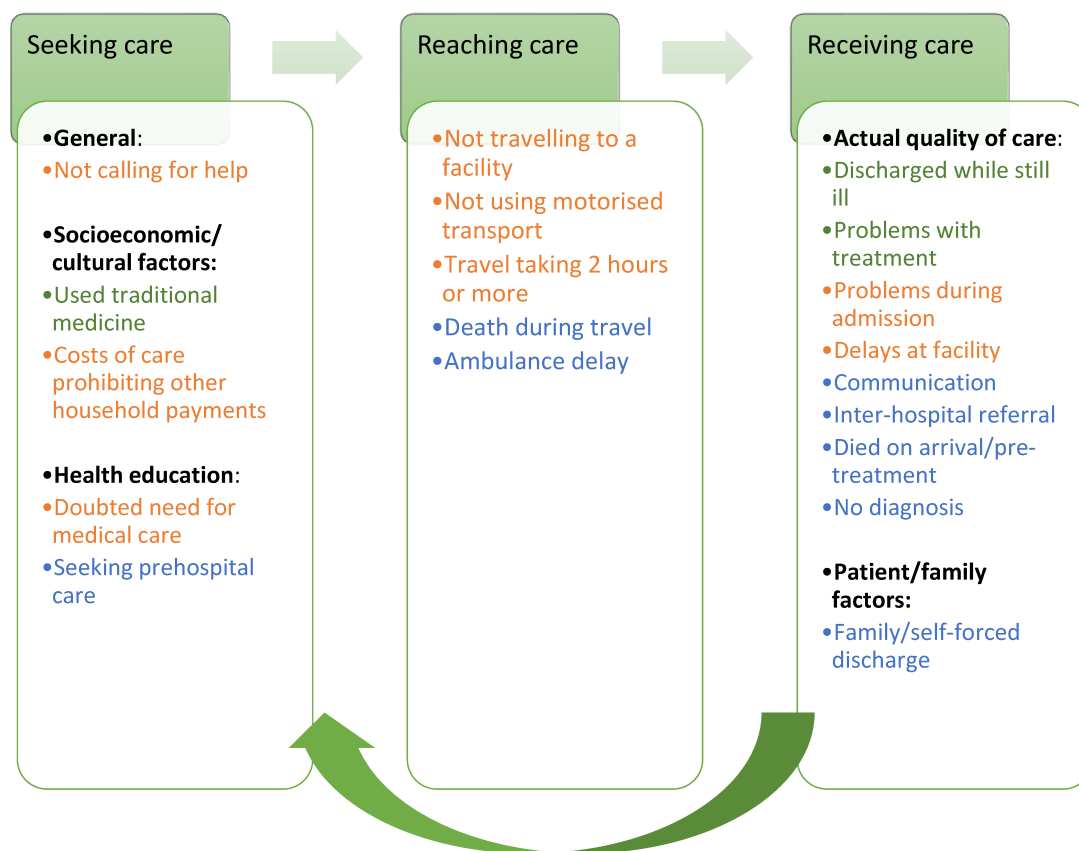
Supplementary Figure A2: Three delays model for access to care for cardiovascular diseases in Agincourt. Orange text indicates themes derived from the CoM, blue text indicates themes derived from the free text, and green text indicates themes which were derived from both the CoM and free text. Delays in receiving care impact future delays in seeking care by influencing future iterations of seeking care, as shown by the arrow.