DEPARTMENT OF HEALTH RESEARCH BRIEF

Verbal Autopsy with Participatory Action Research (VAPAR)
Expanding the knowledge base through partnerships for action on health equity

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Understanding non-communicable diseases (NCDs):

combining surveillance data with local knowledge

Predicted to be the leading cause of death in South Africa by 2030, NCDs form part of a complex and dynamic burden of avoidable mortality. Most NCD deaths are preventable and occur among people who are socially disadvantaged. We combined routine data on NCD mortality with local knowledge gained through community research for more complete bio-social understandings of NCDs.

Mortality data for 1,715 deaths from Agincourt HDSS (2014-15) was analysed and combined with community-based research in villages with varied characteristics focussing on epilepsy and stroke.

Causes/circumstances of deaths

- **NCDs accounted for 30% of total mortality burden,** of which, infectious diseases 32%, external 6%, neonatal 1% and maternal causes 1%. Neoplasms accounted for 30% of NCD deaths (n=156), cardiac conditions 15% (n=76), asthma 17% (n=86) and stroke 13% (n=65). All cancer deaths >15 years.
- All NCDs >65 years (51%), adult (24%) and mid-age (22%). 3.1% (n=16) of NCDs deaths <14 years.
- Similar patterns in circumstances between all deaths and NCD deaths.
- The following is for all deaths.
- **Access to care:** multiple problems identified. Specifically:
  - 37% reported not calling for help;
  - 27% reported not travelling to a facility at or around the time of death;

Community meeting

  - 27% reported prohibitive overall costs of care;
  - 3% reported not using motorised transport to travel to hospital;
  - >1% reported hospital or facility being >2 hours away.
- **Recognition of severity:** reported problems overall low:
  - 4% reported use of traditional medicine at or around the time of death;
  - 2% reported doubts about the need for care.
- **Quality of care,** problems reported were overall low (among individuals who travelled to a hospital/facility):
  - 3% reported problems related to interpersonal treatment;
  - 3% reported problems related to medication.
  - 2% reported problems related to difficulties with admission

Local knowledge

- **Detailed understandings of signs, symptoms and severity:** For stroke: loss of function/sensation, paralysis and memory loss. For epilepsy: uncontrollable movements, fainting, frothing at the mouth and incontinence. Physiological causes of stroke known as high salt intake, high BP, low levels of physical activity and poor diet.
- **Stress as a cause:** Stress frequently described as a result of poverty and significant risk factor contributing to the exacerbation e.g. poor diet contributing to risk - identified as a fundamental root cause.
- **Traditional beliefs:** 'Xifulana' traditional term for stroke and 'Ringhadi' referred to a snake in the abdomen thought to be causative for epilepsy. For stroke believed to be caused by curse, hospital treatment was perceived to be damaging. For epilepsy, traditional medicine was viewed as essential and babies should receive preventative traditional remedies.
- **Access to care limited:** Despite traditional medicine use, poverty described as directly impacting abilities to pay for travel to clinics/pharmacies, and to obtain medications. Transport to clinics and clinic opening hours described as unsatisfactory, and in clinics, long waiting times described.
- **Perceptions of low quality of care:** Interpersonal care in clinics, particularly confidentiality, recounted as problematic. Mistrust in clinic staff significantly deters individuals from attending clinics.

Combining the data

- **Poverty and unaffordable care:** Overall, care is unaffordable. This manifests in not calling for help and not travelling to facilities at time of death. Local knowledge detailed how lack of resources exposes individuals to risk generally and limits access at time of death.
- **Quality of care:** Low levels of problems with quality of care in statistical data, but local knowledge revealed major problems. We acknowledge: VA respondents reporting on causes of relatives' deaths may be better positioned to comment on access than quality; and respondents may be unwilling/unable to recognise problems with quality. Quality of care statistics may under-estimate scale.
- **Traditional medicine:** Low reports of traditional medicine in statistical data, but high reporting in community meetings. The statistical data focus at/around the time of death, while community discussions consider conditions more generally.

Interpretation

- **Multiple and reinforcing barriers to access in end-of-life care:** The community-based work revealed detailed understanding of signs, symptoms and severity. Causes (medical and traditional) were conceived of simultaneously in medical and traditional terms. Strong preferences for traditional therapies and strong views about perceived low quality of care in clinics, which constrained access.
- **Social factors exacerbate NCDs:** the results highlight the impact of social contexts on NCDs, and specifically on access to care. Despite good recognition of severity of epilepsy and stroke, the data strongly suggest substantial issues with accessing services at and around time of death.
- **Improve access:** reduction of financial burdens through National Health Insurance (NHI) is an important move. However, access is also influenced by indirect costs and interpersonal care processes.
- **Mobilise services towards communities:** expansion of CHWs and home-based carers under PHC re-engineering may be valuable for individuals with NCDs in rural settings. It may also serve to improve connections and exchanges of information, addressing perceptions of poor quality of care and the implications for care seeking.

Community meeting

Routine Surveillance Data 2014-15

Causes of all deaths

Non- communicable	516 (30%)
Infection	557 (32%)
Injury	106 (6%)
Children <1 month	21 (1%)
Maternal	16 (1%)
Unknown	499 (29%)
TOTAL	1715 (100%)

Top 10 NCDs (27% total burden)

Asthma	86
Digestive neoplams	67
Stroke	65
Acute abdomen	55
Acute cardiac disease	38
Respiratory neoplasms	34
Reproductive neoplasms	33
Diabetes mellitus	20
Liver cirrhosis	20
Renal failure	13
TOTAL	431

Top 3 circumstances of NCD mortality (% all problems)

ALL DEATHS (n=1715)	
No call for help	37%
No travel to facility	27%
Overall costs prohibitive	26%
NCD DEATHS (n=573)	
No call for help	37%
No travel to facility	27%
Overall costs prohibitive	27%

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