Assessment of Quality of Registration of Causes of Death at Home using Verbal Autopsy in Alexandria, Egypt

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Abstract:

Background: Accurate and comparable good-quality data on mortality and causes of death regarding completeness, accuracy and timeliness should be enhanced to support policy development and implementation. **Objective:** to assess the quality (completeness and correctness) of registration of cause-of-death at home in Alexandria Health offices using WHO Verbal Autopsy tool. **Method**: Descriptive approach was selected where a cross sectional survey was conducted. Records of home deaths, in 24 months, were obtained from all health offices. Then, verification of the data registered was done by visiting homes of those deaths and conducting re-interviews with family members using "Verbal Autopsy" approach. The collected data was submitted to the assigned team of three independent doctors trained by WHO staff to identify the immediate and underlying probable causes of death. The identified probable cause of death was compared with what was registered in the death certificate for any discrepancy. **Results**: On comparing health office records to VA diagnoses, only 35% of health office records causes of death were compliant with VA based diagnoses. The diseases with high sensitivity (>75%) were acute ischemic heart diseases (93%), cerebral infarction (83%), cerebral atherosclerosis (80%) and hepatic failure. Moreover, the percentage of ill-defined causes of diseases was reduced from 34.7% to 13.5%. **Conclusion**: The use of standard VA methods adapted to Egypt enabled a plausible assessment of cause-specific mortality patterns and a substantial reduction of ill-defined diagnoses

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Introduction

Accurate and comparable good-quality data on mortality and causes of death regarding completeness, accuracy and timeliness should be enhanced to support public health planning, resource allocation and measuring the impact of interventions. Where programs to improve health are in place, they need to be routinely monitored and evaluated to ensure they met their objectives and targets. The most commonly used data to satisfy these needs are information on deaths; rates, causes, and age and sex distribution.[1-2] Country decision-makers have drawn attention to the lack of information on causes of death in most developing countries and the urgent need for international health agencies to take a lead in redressing the situation.[1,3] In Egypt, registering deaths by the Ministry of Health works nearly perfectly for events that occurred in the hospital. However, registration of deaths that occur at homes or outside of the health centers and hospitals is incomplete. Although complete vital registration systems with accurate medical certification of the cause of death are the "gold" standard source for such data, they are difficult to establish and expensive to

maintain in large populations such as that of Egypt.[4-7] The next best option is to assess the reliability of cause of death reporting in the routine registration system by comparing registered diagnoses with diagnoses derived through an independent, standardized cause of death ascertainment strategy.

In these situations a retrospective technique may be the only suitable method for documenting and analyzing the distribution and significance of different causes of mortality through using verbal autopsy (VA).

The objective of present study was to assess the quality (completeness and correctness) of registration of cause-of-death at home in Alexandria health offices using VA.

Method

A descriptive cross sectional survey was conducted in Alexandria. The inclusion criteria deceased should bea resident of the areaof health office, the death should have occurred at home between January 2008 and December 2009, and the death should be registered in the health offices.

Records of home deaths in the target couple of years, were obtained from allhealth offices representing official regions of Alexandria.

Orientation meeting on data collection and acquisition from health offices and then homes and building rapport was conducted for the data collectors. Besides, they were provided with the needed forms of WHO VA questionnaires according to ages.

A pilot study was conducted prior to starting the fieldwork in two health offices to obtain information which would facilitate the planning and execution of the main survey. Feedback from those who conducted the pilot study and their notes were consideredMain notes covered how to access and approach health office stuff and the data there and how to manage resistance especially from the clerks and data

compilers, in addition to the time consumed and the quantity of anticipated data. Moreover, how they managed to enter homes despite unstable and insecure country conditions those days after the Egyptian revolution (2011) and commonly misunderstood or unacceptable questions in the VA sheet.

Fourteen data collectors were recruited to collect data from health offices and certify deaths; five were Public Health staff in the Faculty of Medicine and High institute of Public Health, Alexandria University, three were family medicine general practitioners, two nurses, two paramedical and two nonmedical undergraduate students. Each trained data collector was provided with the list of cases distributed over an area map for field investigation, and the interviews were conducted over two months. Senior research management staff visited field sites several times to solve any problems, provide onsite refresher training, supervision and feedback on interviewing skills and data recording.

Data collectors started their home visits at the health office were they were accompanied by a clerk to guide them for the addresses. They prepared rough maps for their catchment areas with target streets, where they brought together all geographically close addresses (in the same street for example) together to visit on the same day. This was extremely helpful and time saving.

Out of 27 health offices in Alexandria, 20 were included (including the 2 piloted ones). Data were collected in two phases; In phase 1, all home deaths that occurred between January 2008 and December 2009 were obtained from recordsof the health offices. Phase two included verification of
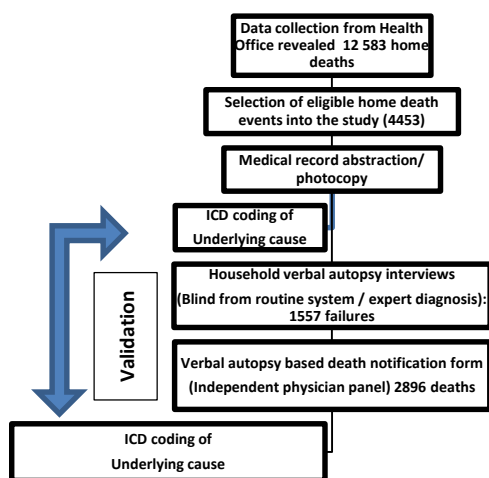
Figure 1: Flow chart showing study protocol and data collection of home deaths

Figure 2: Distribution of home deaths enrolled by the number of health office records compliant with VA diagnosis

the data registered by visiting homes of those deceased and conducting interviews with family members (usually primary caregiver who was with the deceased in the period leading to death) using translated WHO standard Verbal Autopsy questionnaire into Arabic [(7)].

In the present study, the WHO standardized 2012 verbal autopsy instrument[7] for the cause of death was used to derive independent diagnoses for each death in the study sample.

The collected data were submitted to the assigned panel of three independent doctors trained by WHO staff o identify the probable cause(s) of death (conference coding was done when the three physicians gave different final diagnosis). The identified probable cause of death was compared with what is registered in the registers for any discrepancy. (Figure 1)

Data were entered into SPSS system files, and all analyses were performed with SPSS version 20.

By definition, validation means comparing the underlying cause of death derived from the verbal autopsy with the true underlying cause recorded in the death notification form for the deceased, derived from either a pathological autopsy or clinical records.

Non availability of reference diagnosis for the underlying cause is an elementary

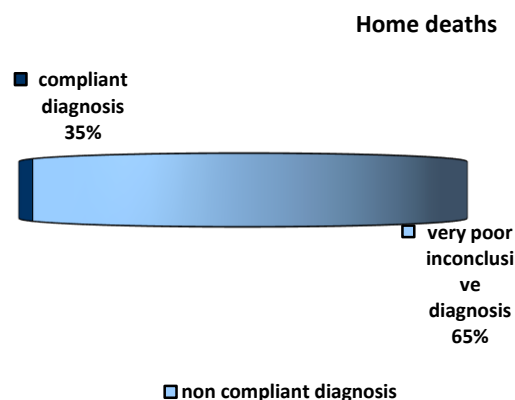constraint in measuring the validity of verbal autopsy procedures.

The parameters measured were sensitivity, specificity, and positive predictive value (PPV), using standard methods, each with 95% confidence intervals. Finally, misclassification was assessed from a matrix of cause attribution of deaths as assigned by the expert review and by verbal autopsy. Sensitivity and PPV convey give different messages about the ability of verbal autopsy to identify deaths owing to a particular cause.

Verbal autopsy might be considered to have a good validity for diseases or conditions for which sensitivity is 75% or more; tolerable validity for those with sensitivity 50– <75%; and poor validity at 50% or less.

Ethical obligations of the health information collection were considered, including the safeguarding of privacy and security of health information; disclosure of health information; development, use, and maintenance of health information systems and health information; and ensuring the accessibility and integrity of health information.

Results

Data availability and Acquisition: Table 1 shows that out of 27 health offices in

Table (1): Distribution of health offices in Alexandria by number of home deaths in 2008-9, conducted home visits, completed VA and failed visits.

No.	Health office	No. of home deaths	Total conducted visits	Total completed VA questionnaires	Total failures
1	Sidi Bechr	1518	320	200	120
2	Elmandara	1431	200	50	150
3	Elwardian	1338	1000	900	100
4	Fleming	959	161	55	106
5	Abouelnawateer Sidigaber	846	217	217	0
	Aboelnawateer Raml	830	145	145	0
6	Embroso	821	188	130	58
7	Sidi gaber	645	500	350	150
8	Bacous	555	56	8	48
9	Aboukeer	515	111	50	61
10	El-Attarin	406	55	53	2
11	El-Ibrahimeya	330	200	150	50
12	Manshia	322	211	100	111
13	Somuha	320	300	163	137
14	El Anfushi	317	317	77	240
15	El-Matar	281	53	52	1
16	El Gomrok	229	229	47	182
17	Gomhoria	200	51	51	0
18	El-Hadara	102	102	61	41
19	Karmouz	37	37	37	0
	Total	12583	4453	2896	1557
	Percent		100.0	65.03	34.97

Table (2): Distribution of enrolled home deaths by age and sex

Age group	Male	Female	Total No.	%
0-<4weeks	15	9	24	0.82
4 weeks-<15 years	6	5	11	0.37
15-44 years	54	36	90	3.10
45-59 years	519	400	919	31.73
60+ years	957	896	1853	63.98
Total	1551 (53.57%)	1345 (46.43%)	2896	100.00

Alexandria, 20 were included (including the two piloted offices). Whereas in the remaining 7 health offices, there were either no records of the target years due to moving the health office to a new building or due to being lost as mentioned by the directors of

the offices, or records did not differentiate between home deaths or hospital deaths.

Those health offices were Gheit Elenab, Elsoyouf, Alamreya, Meena

Table 3: Validation characteristics of verbal autopsy procedures for top most reported causes of death in Alexandria, Egypt

ICD	Cause	Medical Record*	Verbal Autopsy deaths	Sensitivity	Specificity	Accuracy
I10	Essential (primary) hypertension	146	144	0.50	0.27	0.50
I63	Cerebral infarction	29	6	**0.83**	0.34	0.82
I24	Acute ischemic heart diseases	13	1	**0.93**	0.00	0.93
I25	Chronic ischemic heart disease	16	27	0.37	0.00	0.38
B18	Chronic viral hepatitis C	3	21	0.13	1.00	0.12
C34	Malignant neoplasm of bronchus and lung	13	13	0.50	0.56	0.50
C50	Malignant neoplasm of breast	10	18	0.36	0.71	0.36
I70	Atherosclerosis	6	13	0.32	0.00	0.32
I11	Hypertensive heart disease	4	71	0.05	0.22	0.05
N19	Unspecified renal failure	25	2	0.50	0.56	0.50
I21	Acute myocardial infarction	19	8	0.70	0.13	0.71
C80	Malignant neoplasm without specification of site	9	7	0.56	0.14	0.58
J44	Other chronic obstructive pulmonary disease	7	8	0.47	0.00	0.49
K72	Hepatic failure, not elsewhere classified	7	2	**0.78**	0.17	0.78
C22	Malignant neoplasm of liver and intrahepatic bile ducts	7	5	0.58	0.43	0.58
N18	Chronic renal failure	6	11	0.35	0.19	0.38
C16	Malignant neoplasm of stomach	6	7	0.46	0.42	0.48
G30	Alzheimer disease	4	3	0.57	0.29	0.59
I64	Stroke, not specified as haemorrhage or infarction	4	4	0.50	0.00	0.54
I67	Cerebral atherosclerosis	4	1	**0.80**	0.38	0.76
C71	Malignant neoplasm of brain	3	4	0.43	0.00	0.39
C61	Malignant neoplasm of prostate	3	4	0.43	0.33	0.47

* Medical record: Available medical documents on the cases to revert to.

Elbasal Gherbal, Ellaban, and Moharam Beik.

So detailed records of **12,583** home deaths among residents of 20 health offices were reviewed. Out of the reviewed home deaths, only 4453 (35.38%) home deaths of 19 health offices were included for home visits.

First, there were many absent addresses despite being home deaths. In Hagar Elnawateya, for example there were 581 home deaths yet no addresses at all, so no cases were eligible for home visits. Second, difficulties with illegible and tiny unreadable handwriting, that in many cases data collectors were forced to make an educated guess as to what a particular word

was. The difficulty in reading made the copying a painfully slow process. In some cases the names or addresses were impossible to read even after considerable effort, so they were inevitably omitted from the sample. In many health offices, the majority of addresses were very unclear and very incomplete, with just a street name and no number, and sometimes completely absent. After starting home visits the team discovered that many of the addresses were fake and some were addresses of notifiers not the deceased.

Quality of registration of cause of death and related information in the health offices:

Correctness: Date of death: in 12 health offices the date of registration of death was the same as date of death for all cases. Place of death: When we started with the column of place of death to pick our

Table 4: Misclassification matrix for major diseases in Alexandria, Egypt

			Verbal autopsy												
		Causes	Chronic viral hepatitis C (B18)	Malignant of bronchus and lung (C34)	Malignant of breast (C50)	Essential hypertension (I10)	Hypertensive heart disease (I11)	acute ischaemic heart diseases (I24)	Chronic ischarmic heart disease (I25)	Cerebral infarction (I63)	Atherosclerosis (I70)	Chronic renal failure (N18)	ill defined	other causes	Total
HO Record	B18	Chronic viral hepatitis C	3	0	0	0	0	0	0	0	0	0	0	8	11
	C34	Malignant of bronchus and lung	0	13	0	0	0	0	0	0	0	0	0	36	49
	C50	Malignant of breast	0	0	10	0	0	0	0	0	0	0	0	27	37
	E14	Diabetes	4	0	0	0	0	0	0	0	0	0	7	236	247
	I10	Essential hypertension	0	0	4	67	45	0	11	0	4	0	11	150	292
	I11	Hypertensive heart disease	0	0	0	0	4	0	0	0	0	0	0	11	15
	I24	Acute ischaemic heart diseases	0	0	0	0	0	0	0	0	0	0	0	146	146
	I25	Chronic ischarmic heart disease	0	0	0	0	0	0	0	0	0	0	0	64	64
	I63	Cerebral infarction	0	0	0	41	7	0	0	6	0	0	4	51	109
	I70	Atherosclerosis	0	0	0	0	0	0	0	0	0	0	4	19	23
	N18	Chronic renal failure	0	0	0	0	0	0	0	0	0	6	4	12	22
	ill defined		22	7	15	124	67	0	30	4	26	4	293	412	1004
	Other		50	29	38	56	143	4	60	12	19	31	67	368	877
	Total		79	49	67	288	266	4	101	22	49	41	390	1540	2896

targets of home deaths and those recorded attorney cases (medico-legal cases), we were faced with a major problem in 5 health offices, that they were all registered with the name of the health office without any distinction at all. So we decided to omit those offices.

Cause of death registration:

Completeness: The register had three columns to analyze the cause of death and the contributing causes. Yet, in almost all records, the cause was written in big font to cover the 3 columns without any differentiation of direct or indirect cause or contributing factors, and in very few cases the three columns were completely filled but the information was incorrectly registered and unrelated to causes or contributing events.

In almost all health offices there were no registration at all of the section of deaths of women aged 15-49 years despite there were many cases of dead females in this age.

Data acquisition at homes using VA instrument:

More than 90% were adults more than 15 years (Questionnaire III).

Families who showed no objection to interviewing were very cooperative and very curious to find out the real cause of death of their deceased. Only few found it too late to explore this.

Regarding the respondents, in the majority of cases (84.80%), a relative who had taken care of the deceased during the final illness was sought. However, in many other cases interviews, friends or neighbors were more useful even in presence of the caretaker. This solved somehow the problem of long recall period. A female respondent was preferred for maternal mortality cases if possible. The vast majority of respondents were present at the death event (93.99%).

Out of the 4453 eligible home deaths to be interviewed, 2896 (65.03%) had completed verbal autopsy questionnaire, whereas 1557 (34.97%) failed due to problems of the address of the deceased as inaccuracy or moving or fake addresses (89.91 % of failed interviews), or non-response and refusal to let data collectors in (6.42% of failures).

In the present study, according to table 2, 98.% of the enrolled home deaths were adults (15+ years), and % were children. Regarding their gender, 53.57% were males.

On average an interview with the standard WHO VA instrument lasted 20-35 minutes excluding introduction and thanking.

Comments on the VA instrument and recommendations:

VA questionnaire in its present design was thought at the beginning of the study to be usable only by physicians and is difficult to move away from Physician review. However after data collection it was apparent that collection of information to determine cause of death is feasible "where there is no doctor", provided there are well-trained interviewers adapted to the local community.

Questions on sensitive or stigmatizing issues may not provide reliable answers. This was particularly true for suicide, induced abortion, and even some diseases which are normally not stigmatizing, yet families of the deceased were embarrassed to admit as hepatitis and tuberculosis.

The open narrative was in many cases a demand to attain information on culturally sensitive circumstances related to cause of death. It was essential for data collectors and physicians to provide insight into the sequence of events and symptoms review.

Questions on sensitive topics needed to be rephrased in a way that would not offend respondent.

Interviewers asked for supporting documents after each interview, as any prescriptions or drugs used by the deceased (they were copied on the filled questionnaire sheet to be interpreted by the assigned panel) and this was very useful for some cases as in hepatitis C and Tuberculosis.

The detailed outcomes of the group reviews and feedback where consolidated in a 1 day workshop following the data collection.

Validation of VA: The list of causes chosen for validation is portrayed in Table 3 (Figure 2). Certain high frequency causes of death such as acute ischaemic heart disease (IHD), and cerebral infarction were collected.

On comparing health office records to VA diagnoses, only 35% of health office records causes of death were compliant with VA based diagnoses.

Table 3 portrays validation characteristics of verbal autopsy procedures for most prevalent causes of death in Alexandria..

Table 4 shows the misclassification matrix for leading causes with 'low' or 'tolerable' sensitivity scores. For each disease, the Columns of the matrix indicate the total number of deaths identified as being due to that cause from the verbal autopsy.

Limitations

Despite the approval letters provided, directors of several health offices refused to allow data acquisition and uncovering, and

needed to have further personal communication and letters appointed and provided to each data collector with the target health office s/he was supposed to collect data from. Another problem was the unavailable records for those two years and the team had to wait for few days to get them from data warehouse. Yet still not all were available, for example for Gheit Elenab we found incomplete records of 2008 only. When registers were available, they had some torn pages, and in Elmansheya data from April through December 2008 were missing and were never recorded.

The recall period was too long and the majority of households had some information as to the cause of death from contact with health services, and of them, about half could produce some medical documents at interview

Discussion

Quality of registration of cause of deaths in Alexandria health offices is poor indeed. The use of standard VA methods adapted to Egypt enabled a plausible assessment of cause-specific mortality patterns and a substantial reduction of ill-defined diagnoses. The present study attempted to ascertain the validity of a standard set of verbal autopsy procedures developed by the WHO to identify leading causes of deaths, and to identify patterns of misclassification error for different causes, and the reasons for such misclassification. Knowledge of such misclassification patterns can be used to correct data from routine death reporting systems to more reliably estimate overall cause-specific mortality patterns. Not only will this better inform national disease prevention and control strategies, but it is also of obvious interest for assessing national mortality patterns and burden of disease report findings to develop, test, and validate the use of verbal autopsy (VA) methods.

In the present study, the interview with the standard WHO VA instrument lasted 20-35 minutes excluding introduction and thanking. This was too long for many families and few even quit before the interview was finished. All data collectors recommended reduction of the tool while taking into account relevance of the cause of death to be ascertained in the instrument. Shortened VA instrument, considering keeping the balance between the desirable time of interview and performance of the instrument can widen the scope of its use, enable its use in routine death registration systems and can increase response rates by cutting down respondent load.

Verbal autopsy tool proved to have an acceptable level of accuracy in diagnosing leading causes of home deaths. Our results were consistent with other studies in Thailand, Pakistan, India and Philippines that used the WHO verbal autopsy tool to ascertain causes of deaths outside the hospital[8,12] and the reported sensitivity were above the acceptable range for accurately diagnosing the cause of death.[13]

The present study had several strengths. It was one of the largest well-designed validation study for home death in Egypt. It included expert physicians with more than 15 years of clinical experience to review the available information and assign a reference standard primary cause of neonatal death in the light of ICD-10. The two verbal autopsy reviewers had received extensive training by WHO expert trainer in assigning the cause of death and following case definitions. They worked independently and were blinded to each other in determining the cause of death.

Conclusion

In the present study the quality of registration of cause deaths in Alexandria health offices was poor and suggests that the WHO revised verbal autopsy tool has reasonable validity in determining causes of

home deaths in Egypt. The WHO verbal autopsy tools can be used in resource limited community-based settings where home deaths are high and death certificates specifying cause of death from hospital are not available.

Recommendations

It is not possible to establish an effective system overnight, it requires a political will, stewardship by national authorities and the collaboration of different concerned agencies, households, civil society and medical professionals. This could be accomplished by the following:

Legislations and regulations

Enforcement of legislation that require the notifier to have the ID of the deceased when notifying any case of death, and to determine the exact time of death, especially if occurring outside the hospital, because the ID has full address of the deceased.

Issue a decree or legislation for using the standard VA methods adapted to Egypt for all cases of deaths that occurred outside the hospital

Record linkage is a vital demand for improvement of quality of causes of death registration between health offices affiliated to MoHP, Ministry of Justice represented in the Forensic Medicine agency and higher levels of data management. So, issuing sovereign and political decisions to activate and improve record linkage and transparency and eliminate the bureaucracy and complications is recommended.

Issuing ministerial decree to employ graduates of Institute of Health, in registration and statistics department, in health offices as coders.

Integration of ICD in the undergraduate curriculum in Medical and Nursing colleges.

Training: Identify a lead team (TOT) that can support, plan and monitor ongoing training over all governorates on ICD and verbal autopsy; Training of clerks and health officers on accurate registration in records with strict monitoring and evaluation, to improve medical records in all aspects.

Interventions: Automation of all health offices to replace paper files with all its incompleteness and to keep on-shelf quality over time and to simplify retrieval of data.

Linking birth and death registers with the family folder using ACME program in health offices to improve quality.

Development of a standard unified electronic format for different agencies (MoHP, CAPMAS, Ministry of Justice….). Careful continuous monitoring and assessment.

Verbal Autopsy instrument: Shortened VA instrument is a demand. Questions on sensitive topics need to be rephrased in a way that would not offend respondent. Standard translation to local language is mandatory

Conflicts of interest: none declared

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