Reasons for Not Reporting Deaths: A Qualitative Study in Rural Vietnam

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Abstract

This qualitative study explores socio-cultural and health systems factors that may impact on death reporting by lay people to registry systems at the commune level. Information on local perceptions of death and factors influencing death reporting were gathered through nine focus group discussions with people of different religions and ethnic affiliations in a rural district of northern Vietnam. Participants classified deaths as "elderly deaths," "young deaths," and "child deaths." Child deaths, including newborn deaths, used to be considered punishment for sins committed by ancestors, but this is no longer the case. Concepts of the human soul and afterlife differ between the Catholic and Buddhist groups, influencing funeral rituals and reporting, especially of infant deaths. Participants regarded elderly deaths as "natural" and "deserved," while young deaths were seen as either "good deaths" or "bad deaths." "Bad deaths" were defined as deaths of "dishonourable" persons who had led a "bad life" involving activities such as gambling, drinking or stealing. The causes of "bad deaths" and deaths due to stigmatized diseases (e.g., HIV/AIDS, tuberculosis and leprosy) were often concealed by the family. The study suggests that the risk of under-reporting deaths seems to be largest for deaths

of infants and "bad deaths." Little awareness of regulations and lack of incentives for reporting or lack of sanctions for not reporting deaths also result in under-reporting of deaths. Therefore, education programs and enforcement of legal regulations on death notification should be emphasized. The risk of misreporting the real causes of "bad deaths" and deaths due to stigmatized diseases should be considered in verbal autopsy interviews. Using different sources of information (triangulation) is useful in order to minimize both under-registration and misreporting causes of death.

Background and Rationale

Mortality rate is an important aggregate indicator for the health status of a population. Valid mortality data are obtained only when deaths are reported and registered properly. However, it is estimated that about two thirds of the world's population, mostly in low-income countries, remain outside any kind of systematic health surveillance (Beaglehole and Bonita 2001) and a significant proportion of global deaths pass unrecorded (Byass 2001). Therefore, data used to estimate mortality in many countries are questionable (Lumbiganon et al. 1990; Becker et al. 1996; Cleland 1996). Vietnam is no exception in this respect, even though it has a relatively good healthcare system (Phuong 2000; Hoanh 2000).

At the commune level in Vietnam, two main systems are responsible for recording demographic data including deaths, namely, the legal system, called the Juridical system (Household Registration System in the past) and the Communal Population Register System (CPRS). In addition, commune health centres also collect and register births and deaths in the community, especially those occurring at the centres. Despite the existence of these registration systems, the limited quality of the data has complicated efforts to present reliable estimates of mortality levels in Vietnam (Merli 1998). A recent study (Huy et al. 2003) in a rural district of Vietnam showed that at least 19% of all deaths were not registered by the CPRS; most of these were deaths of infants and elderly women.

Different factors may contribute to this situation. As in any other registry system, in the death registration system there are two equally important actors: the informers (community people) and the registrars (persons in charge within the system). The quality of data depends on both. Various factors can be assumed to interfere with the quality of reporting, such as cultural values and perceptions associated with different categories of deaths, the social status of the deceased and the perceived benefits and disadvantages of reporting a death.

The aim of the present study was to explore socio-cultural and health systems factors that may influence the completeness and quality of death reporting at the community level. Findings will help us improve the routine death reporting system as well as design community-based mortality surveys.

One important cultural concept orienting this study is that of the human soul as expressed in local culture, because we assume that this may influence perceptions and, thus, the reporting of deaths. Other concepts relevant to the analysis are stigma and shame, known in the literature to be strongly associated with various kinds of diseases, categories of death and death reporting (Long 2000; Johansson 2000).

The Concept of the Human Soul in Vietnamese Culture

In Vietnam, Confucianism, Buddhism and Taoism, known as the "triple religions" (tam giao), have coexisted for many centuries and have pervaded the culture and all aspects of Vietnamese life. Over time, these religions have blended and constitute what can be labelled a Vietnamese "folk religion," with Buddhism as the core (Jamieson 1993). Other religions, including Christianity (Catholicism and Protestantism), Islam, Cao Dai and Hoa Hao, coexist with the triple religions, but of these only Catholicism is practised in northern Vietnam to any sizeable degree. In Vietnamese culture the concepts of soul and spirit are fundamental to everyday religious practice (Chanh 1993; Rydström 1998). People believe that their ancestors' souls powerfully protect their offspring. Through ancestral worship the links between the realms of the living and the dead are maintained, and descendents receive protection from ancestors. Births are not merely part of biological reproduction but are seen as direct reproductions of the souls and bodies of the ancestors. "Life and death are thus conceived to

be a dialectical process that links two realms together into one biological and spiritual world" (Chanh 1993). Death is considered a passage from the natural to the supernatural realm, expressed in the Vietnamese saying "Life is a temporary stay; death is a return" (*song gui, thac ve*). Death ends the transience of one's biological life and makes possible the return to the spiritual realm of one's ancestors.

There are numerous rituals at the time of death and afterwards. It is thought that if these rituals are not carefully performed, the soul of the dead person will become a "wandering soul" and will harm his or her own offspring instead of protecting them (Chanh 1993). Rituals at birth are equally important and are held at different times within the first year after birth. Among Buddhists, the most important one is the "Rite of One Full Year of Age" (*le day tuoi*). This rite is held to express thanks to the family's ancestors and also to mark the child's "personhood" (Chanh 1993). Only after the performance of this rite is the child regarded as a "human being."

Birth and death rituals and numerous other religious ceremonies and rituals have been profoundly influenced by the socio-economic and political changes occurring over the last 50 years in Vietnam. Socialist ideology and modernization have acted to reduce the strength of religious practices and rituals (Kingsley 1996). Today's modern Vietnamese are taught to acknowledge their own influence on their daily lives and to not see their failures or successes as the consequences of otherworldly powers. Therefore, some rituals, which were regarded as Confucian, feudal and "backward," have disappeared (Rydström 1998). Moreover, in wartime, when economic resources were stunted, many rituals were set aside spontaneously. In recent decades a return to traditional rituals has been noted. For example, the ancestor cult is sustained and generally accepted in Vietnamese society today. Some funeral rituals have disappeared while others still remain, with modifications (Kingsley 1996; Rydström 1998).

Method

The study was carried out in Ba Vi district, Ha Tay province, in northern Vietnam. Ba Vi's population is around 250,000 people, belonging mainly to the Kinh (91%) and other minority ethnic groups such as the Muong, Dao, Tay, Hoa and Khme. Geographically, the district is divided into lowland, highland and mountainous areas, with 32 communes, each with 6,000 to 10,000 inhabitants. Each commune is divided into a number of hamlets. Most people in Ba Vi are farmers (81%), with agricultural production and livestock breeding as the main economic activities (Chuc and Diwan 2003).

We were aware that exploring perceptions of death and how these might influence death reporting could be sensitive and complex issues, and they were little known to us. We therefore adopted a qualitative approach using focus group discussions (FGDs), which are considered appropriate for identifying and exploring values, perceptions and attitudes of people, especially related to topics of which pre-understanding is limited (Morgan 1997). FGDs reflect and elucidate the personal experiences and opinions of those participating, as well as the perceptions in the community that they represent (Krueger 1988; Long 2000).

In this study, we conducted nine FGDs with local people from nine hamlets located in different parts of the district. These hamlets were purposively selected in terms of geographic location, religion and ethnicity, including five groups in lowland areas and four groups in highland areas. Most FGD participants belonged to the Kinh majority ethnic group, except one group in the mountainous area, which was composed of the Muong ethnic group. In six FGDs, participants were predominantly Buddhists, and two groups' participants were Catholics. The Muong minority group in the mountainous areas adheres to Vietnamese folk religion. Each discussion group consisted of 6 to 11 participants, male and female, who were all farmers having lived in the selected hamlets for at least five years. The discussions, held in Vietnamese, took place in common public settings such as the village common house. They were conducted by a moderator (the first author) and lasted for about 1½ to 2 hours. Prior to the FGDs, the research team developed a discussion guide that included perceptions about different kinds of deaths, descriptions of related rituals, and reasons for possible under-reporting and/or hiding the real causes of death. The moderator encouraged participants to

freely exchange views on these issues while keeping the basic focus of the discussion. He probed into new and interesting leads coming up and verified that he had correctly understood what emerged from the discussions.

All group discussions were tape-recorded and transcribed by the moderator and note taker immediately afterwards. Transcriptions were translated into English by a professional translator. In order to check the quality of translations, two transcripts were translated into English by two independent translators. No major differences between the translations were identified. Qualitative content analysis was used to analyze data (Morse and Field 1984; Graneheim and Lundman 2004). Analysis started when all data had been collected. Individual research team members carefully read all translated transcripts to acquire an overall sense and understanding of the whole text. Open codes were applied by two of the researchers independently and similar codes were grouped into categories and subcategories. These were compared, modified and expanded by the researchers during the analysis. Two main categories were defined: (1) types of death and related rituals with the subcategories according to age and perceived causes and (2) reasons for under-reporting and misreporting deaths. An attempt was made to identify emerging themes and discuss their underlying meaning in a socio-cultural and health systems context (Berg 2001).

The study was conducted within the FilaBavi, with ethical approval by the Research Ethics Committee at Umeå University. Permission to conduct the study was also obtained from the district authorities. Informed consent was sought from participants prior to each discussion.

Findings

Participants in Buddhist groups described life as a circular movement starting from birth, through aging and illness, and ending with death (*sinh*, *lao*, *benh*, *tu*). In all groups, the human soul was thought to continue its existence after biological death, either in the paradise of the Catholics, the heaven of the Divine Buddha or, for a "bad" person, in hell.

Types of Deaths and Related Rituals

All groups differentiated between three categories of deaths: elderly deaths (*chet gia*), young deaths, (*chet tre*) and child deaths (*chet tre em*). Perceptions of elderly deaths were similar between religious and ethnic groups. The death of an old person was seen as a natural process as described here:

The death of an elder is like an old tree, which cannot produce glue to maintain its life. When a person gets old, all organs in the body – heart, lung, digestive tract – become exhausted, deteriorated. The organs cannot work any more, and the person dies.

The funeral ceremonies for deaths of elderly persons, called *mo hoi*, were described by participants as lengthy and with many formal rituals. The children of the deceased should arrange a farewell party to celebrate his or her parent's entry into "the other world." The *mo hoi* was held with a music performance and a meal offered to all attending the funeral. Usually, many people came to say farewell and to present sacred offerings to the deceased. Among the Buddhists, the funeral for an elderly person used to be held with a drama performance in which people rowed a boat to symbolize the journey of the deceased to the other world.

Participants defined "young death" (*chet tre*) as deaths of working-age adults. Such deaths were said to be caused by severe diseases, by not getting appropriate healthcare in time, by leading a "bad life," or by suicide or accident. Young deaths were divided into "good death" (*chet vinh*) and "bad death" (*chet nhuc*). Good death or "honourable death" was associated with sadness and grief for the relatives and the community. Bad death was the death of a "dishonourable" person who had led a "bad life" involving activities such as gambling, drinking, fighting, stealing or causing trouble for others. Such deaths usually left a bad reputation and shame for the relatives. The funeral ceremony for young deaths, called *lam ma*, was said to be arranged in a much simpler way than the *mo hoi* ceremony for elderly deaths. There was neither a music performance not a reading of prayers at the

lam ma ceremony, and it never lasted long since people did not want to prolong the misery of a "good death" or the shamefulness of a "bad death" for the family.

In group discussions the notion of "child deaths" (*chet tre em*) varied from the death of an infant to the death of a child up to school-leaving age. Such deaths were always considered a great tragedy. Participants often attributed causes of infant deaths to mothers' carelessness or to the exposure of the parents to toxic substances such as pesticides or herbicides, including Agent Orange, the dioxincontaining chemical sprayed during the war. Participants in all groups explained that there are many old proverbs and sayings reflecting the traditional belief that an infant death is a punishment for ancestral sins, for example, "Doi cha an man, doi con khat nuoc" (when the father eats too salty food, his children will be thirsty). Some participants, particularly older men, were also eager to point out that today a newborn death is not considered a punishment, but the sayings remain in the common language:

In the past, people said that a child died because its parents or grandparents had committed some bad deed. Nowadays people do not think so any longer, but they still keep that in mind, reminding them not to behave badly towards others. Our older generations used this saying to educate themselves and their children.

A major difference emerging between the groups was in the definition of personhood, that is, when a child became a "full human being." The Buddhists considered a newborn as "not grown enough to be a person" and consequently did not arrange funeral ceremonies for a newborn death. The burial was carried out immediately, even at night, with only family members attending. The simple way Buddhists arrange burial for newborn deaths was remarked on in the Catholic group:

In Buddhism, if a newborn dies, they just wrap the dead child with a mat for burial. However, we Christians should always have a wooden coffin for the deceased regardless of whether it is only five or six months or a newborn. We think that even though it is still small it is a human being, so we should do every thing the same as for adults.

Among the Catholics, if an infant or a child died, the funeral would be held with the same rituals as for an elderly or adult death, except for the prayers, as the infant is thought to become a saint immediately and prayers are not needed.

Views differed on how long an infant or child remained too young to be considered "fully human." Among the Kinh people in the lowlands, the first year of life was considered infancy, while among the Muong ethnic minority, people considered a child up to the age of 12 years an infant, (so sinh, meaning newly born, fragile). Only after that age would the child not be able to reincarnate: "After the age of twelve the child will not reincarnate because it has finished the period of 'God's care' – het cua mu" (meaning that before age 12 the child still belongs to God).

Reasons for Under-reporting or Misreporting Causes of Death

Most participants agreed that it was very difficult to hide deaths in their setting, where relationships were very close between community members. However, it was also said that certain deaths might not be reported due to a combination of factors.

Participants in Buddhist and minority groups stated that newborn deaths were often not reported and registered because the child was seen as "not grown enough to be a person" and had no relationships with other people in the community. The newborn death was seen as a great sadness for the family, and they did not want to talk about it. Therefore, even people living in the same village might not know about a newborn death. In contrast, Catholic participants agreed that all deaths were known by people in the village because when any death occurred, including a newborn one, the church bell rang to inform people of the sad news.

It emerged in discussions that adult deaths that might not be reported were those seen as "bad

deaths," such as deaths due to HIV/AIDS or suicide. Generally, the family would not want to inform others of a death that might leave a bad reputation or bring shame on the family. In deaths due to so-called social diseases such as tuberculosis and leprosy, there was a tendency to hide the cause of death because of the fear of stigma for family members, especially for younger generations. Such deaths would be reported but given different causes:

If someone asks the cause of death, they will say that the person died of some illness. They hide some social diseases such as tuberculosis or leprosy because they think that these diseases are hereditary so their children will have inherited these diseases and then people will not maintain relationships with them.

Another factor impinging on death reporting was local birth registration practices. All groups stated that in rural areas births were often not registered for several years, even delayed until the child started schooling, as some participants in the minority group mentioned. In such a case, if a child dies, its death would not be reported either: "No birth registration, no need for death registration.... If a child dies and it has not been registered in the household registration book then there is no need to register its death."

Lack of knowledge of the duty to report deaths was also a cause of under-registration. Several participants in different groups stated that they did not know of the legal regulation to report deaths to the local authority, or they did not know where and to whom they should report the death. Others said that they knew a death should be reported, but because the families were too busy with the funeral, they paid no attention to reporting it and no one reminded them or requested them to do so. Therefore, families reported only specific deaths to get a death certificate in order to receive a death benefit, or for insurance claims or other bureaucratic transactions that need a death certificate. A number of participants mentioned that some people were not willing to report deaths because they feared that their cultivated land would be reduced, while several others knew that this regulation had been changed with the new land law promulgated in 1993. Some participants added that the termination of pension payments for retired government employees was also a reason why people might delay or neglect to report deaths.

The most common statement in all FGDs was that people did not report deaths because there was no legal sanction for not reporting, and they received no benefit from it. A male participant stated in a loud voice:

No one is punished [for] not reporting the new birth. It is the same with death reporting. If we go for death registration, we will lose some time from our farming work. To speak frankly, people here do not report deaths because they get no benefits from that.... Why should we report death if we only lose time?"

It was also said that deaths of people not registered as residents in the community (e.g., migrants) were commonly under-reported. At the death of a community resident, local authorities normally presented flowers and sacred offerings to the family. This was not the case for non-residents. One participant told the group, "My sister came here to work on a short-term contract for a State Farm. We got nothing for her death; therefore we did not report it."

Discussion

In this study from a rural area in Vietnam, we have explored socio-cultural and health systems factors that may impinge on the quality and completeness of death reporting by lay people to registry systems at the commune level. Generally, perceptions of death and rituals at death described by participants in our study are similar to those reported in previous studies from Vietnam (Chanh 1993; Rydström 1998; Minh 2002) and can also be found in other cultures (Castle 1994; Jewkes and Wood 1998; Marrone 1999; Einarsdotter 2000; Yang and Chen 2002). However, few of these studies

have explored the effects of death-related perceptions and classifications on death reporting.

Our study has demonstrated how perceptions of the human soul and personhood seem to have an important bearing on how infant deaths are reported or not reported, particularly among Buddhist groups. The considerable under-reporting of infant deaths found in the commune registry system (Huy et al. 2003) is given many supporting explanations in our study. Even though many participants pointed out that they did not consider an infant death as punishment for ancestral sins, as was common in the past, such beliefs may still influence how people perceive and deal with an infant death. The burial for a newborn death was described as being so fast and secret that many people in the same village did not know about the death. In this case, the death may obviously be easily missed by the person in charge of the death registry. Buddhist participants regarded a newborn as "not grown enough to be a person." Chanh (1993) also noted this perception. He described that the child less than one year old was not considered old enough to possess an authentic human soul (*linh hon*). Therefore, if the child dies before the age of one, it will become not a human soul, but a "little demon" (*ranh*) that is believed to have the capacity to reincarnate itself (Chanh 1993).

In findings similar to ours, Jewkes and Wood (1998) noted in their study conducted in rural South Africa that infant deaths were not ritually mourned by the family and the community because the child was considered "not yet a human being" or "an angel taken by God." The burial for a very young infant death was described as "urgent" and "rapid." The view of infants as "not yet fully human" together with little awareness of why registration was necessary had contributed to the low rate of death registration in the South African study (Jewkes and Wood 1998). At the core of this practice in both settings lies the cultural construction of personhood as a process rather than as a stage achieved through a live birth, as is implied in discourses of the vital registration system. We suggest that the discrepancy between local definitions of personhood and those implied in vital registration systems helps explain the under-reporting of both births and deaths found in many countries.

Further, it emerged in our findings that certain causes of death, notably HIV/AIDS, leprosy, tuberculosis and suicides, were closely associated with concepts of stigma and shame for the deceased's family. This was seen as having a potentially large impact on misreporting causes of death, although hiding such deaths was thought to be difficult. Misreporting of the real causes of death that are stigmatizing and considered shameful has been demonstrated in several other studies in Vietnam and other low-income countries (Hieu et al. 1999; Bramley 2001; Songane and Bergström 2002). For example, studies of tuberculosis in Vietnam (Long 2000; Johansson 2000) have shown how people hide the real causes of the disease for fear of being stigmatized. Today HIV/AIDS seems the most severely stigmatizing disease, not only for the sick person but for the whole family (Ngamvithayapong-Yanai et al. 2005; Varas-Diaz et al. 2005). In our study, a death due to HIV/AIDS was seen as a bad death caused by a bad lifestyle, which is in line with public opinion in Vietnam, which classifies HIV/AIDS as one of the "social evils" (Mensch et al. 2003).

Among the three types of death defined by our FGD participants, elderly deaths were described as "natural" and "deserved" and the funeral as a ceremony of remembrance and wishing the deceased a safe journey to the other world. However, reporting of such deaths may be easily neglected. From a social point of view, elderly farmers in Vietnam have little material relationship with society. They are exempted from social contributions (men and women under 60 and 55 respectively have to contribute 15 days of work annually) and they do not receive a pension from the State. Therefore, administratively, it is not necessary to report or register their deaths. The lower reporting of female deaths found in our previous study (Huy et al. 2003) as compared to male deaths could be partly explained by the fact that women generally live longer and more often live alone. Thus, as noted also by Merli (1998), there may be no one around to report their deaths.

Health systems factors that contribute to possible under-reporting of deaths are the absence of both benefits for reporting and legal sanctions for not reporting a death. In our study, several participants did not know of the legal regulations to report deaths, while others knew but did not practice it because "no one reminds [them] or requests it." The same situation has been described in a study from rural Thailand (Lumbiganon et al. 1990), where 45 % of infant deaths were not

reported. Mothers of children who had died explained that as they had not registered the birth of the child, they saw no need to register the death, and there were neither sanctions nor benefits linked to the registration. This may be even more common in Vietnam, where it is not compulsory to have a death certificate to bury a dead person.

Demographic information, including data about deaths, collected by the routine registry systems are necessary for planning purposes, provided they are complete and of high quality. Information collected at the commune level is obviously important because misconceptions at this level will create inaccuracies throughout the system. However, various studies have pointed out severe underregistration and misrepresentation in the current system in Vietnam. For instance, a study conducted in three provinces in Vietnam by Hieu (1999) added 16% of deaths after extensive research from different registry systems. A relatively large discrepancy of maternal deaths between the healthcare system and the population system, as well as numerous misreported maternal deaths, was also found in the study by Bramley (2001). The findings of this study therefore have practical implications that should be disseminated to people working for the registry systems as well as to the communities. All stakeholders must be made aware of factors that could obstruct the process of reporting death and consequently impinge on the quality of data collected by existing systems. Local leaders such as village heads and registrars dealing with death registration at the grassroots level should work in a more active manner and be aware of the passive attitude and ignorance in the community with respect to death registration. They must request and remind community members to report deaths in an appropriate time interval. In addition, and in order to increase the active involvement of people, it is important to introduce education programs to make people understand the importance of death surveillance and their legal obligation to report deaths, as well as other lawful documents such as the new land law passed in 1993 that provides for the inheritance of allocated land. Moreover, law enforcement in parallel with motivation should be considered as a way of increasing people's active participation in registering deaths.

There are certain limitations in our study. First, FGD participants were not homogeneous in terms of sex and age. Therefore, following traditional Vietnamese hierarchical structures, in some groups male and/or older participants talked more than the others, and younger participants tended to repeat the views of older ones. In other groups, it was difficult to get a good discussion going as some participants were rather passive and responded to the moderator's questions but did not continue the discussion among themselves. This could be because they were not familiar with such group discussions and felt shy. We acknowledge that this could have impinged somewhat on the richness and diversity of the findings, which may have been enhanced with more homogeneous groups. For example, a group with only women might have yielded more in-depth understanding of how infant deaths are perceived and dealt with. Second, we are aware that translating the FGD transcriptions from Vietnamese into English is a delicate task. We took measures to double-check the appropriateness of the translation, but nuances could have been lost. This may apply especially to concepts of personhood and the human soul. With these limitations in mind, we consider our findings trustworthy and relevant, enabling a deeper understanding of the causes of under-reporting deaths.

Conclusions

Our study indicates that under-reporting of deaths is likely to occur in the study setting, especially infant deaths, deaths due to tuberculosis, leprosy, HIV/AIDS, and other "social diseases," and deaths among migrants who are not registered as residents in the community. Reasons for not reporting deaths include perceptions that newborns and infants are not considered "fully human," fear of social isolation and stigma of family members and low enforcement of death-reporting regulations. These factors should be taken into account by those in charge of death registration in order to minimize under-registration of deaths. Under-reporting of infant deaths represents a big challenge for the collection of trustworthy indicators of infant mortality in Vietnam from routine reporting systems and from surveys. Both the cultural context and influence of policy on infant death registration need to be considered. That stigma and shame seem to be strongly associated with certain causes of

death provides a warning signal for researchers using the verbal autopsy technique as a method of identifying causes of deaths. Using different sources of information (triangulation) is useful in order to minimize both under-registration and misreporting.

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