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MORTALITY IN RURAL VIETNAM

**Validity of routine reporting and
experiences from a surveillance system**

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ABSTRACT

Background: Findings from many low-income countries, Vietnam included, show that mortality estimates based on death data collected in routine systems have low validity.

Aims: The overall aim of this thesis is to examine and discuss the validity of mortality estimates based on data collected in different systems in a rural setting in Northern Vietnam and to identify factors that can influence the reporting and registration of deaths, all in order to make recommendations for improvement of death registration.

Methods: The studies were conducted in a rural district where a Demographic Surveillance System (DSS), called FilaBavi, started in 1999. Four studies were undertaken. One study (paper I) used a quantitative approach to examine and compare validity of mortality estimates collected in the FilaBavi and in the existing routine systems. Focus Group Discussions (FGD) were held with community members (paper II) and with persons responsible for the routine death reporting systems (paper III) to gain in-depth understanding of perceptions of death and to identify obstacles that impeded death reporting and registration in the official systems. FGDs and qualitative interviews were used to learn about experiences of surveyors and bereaved persons involved in death inquiries (paper IV).

Main findings: Out of 471 deaths detected by all methods in 1999 and 2000, the FilaBavi quarterly household follow-ups detected 470 deaths (99.8%). The Commune Population Registry System missed 89 cases (19%), the majority being infants and elderly people's deaths. The FilaBavi, re-census survey missed 19 deaths (4%), and the neighbourhood survey, where groups of local people listed deaths, over-reported (paper I).

Community members regarded 'elderly deaths' as 'natural' and 'deserved', and consequently such deaths might not be notified. Infants were not considered as 'fully human', therefore infant deaths were not necessarily reported. 'Young deaths' were seen as either 'good deaths' or 'bad deaths'. The latter, considered due to stigmatised diseases (e.g. HIV/AIDS, tuberculosis and leprosy) and suicide, were often concealed by the family. Other reasons for not reporting deaths were poor knowledge of the legal obligation to report deaths, lack of incentive to report and the absence of legal sanction in case of not reporting (paper II). Registrars also identified the inadequate functioning of administrative structures with respect to supervision, training and collaboration between systems as a reason for the low quality of death data in the routine system (paper III).

There was a mutual reluctance between the surveyors at FilaBavi, for conducting death inquiries, and bereaved respondents, for receiving surveyors for such inquiries, especially in the case of child or untimely deaths, but both parties felt a sense of duty to do so. The choice of visiting time, the venue and the respondent, as well as the need for creating good rapport with the family were considered as important to facilitate the death inquiry and to minimise distress among the bereaved (paper IV).

Conclusions: Mortality estimates based on information from routine systems at the commune level have low validity. FilaBavi performed better than any of these official systems. Several reasons for poor reporting and registration, which were possible to improve, were identified. Further, minimising discomfort and compassion stress is an important ethical issue in death inquiries. The experiences of death inquiry from the FilaBavi can also be useful in other DSS with similarities in cultural and administrative context.

Key words: Death surveillance; mortality validity; sensitive research; surveyor's experiences; vital registration; Vietnam.

LIST OF PUBLICATIONS

This thesis is based on the following papers:

- I. Huy TQ, Long NH, Hoa DP, Byass P, Eriksson B. Validity and completeness of death reporting and registration in a rural district of Vietnam. *Scandinavian Journal of Public Health*, 2003; 31 (Suppl. 62): 12 – 18
- II. Huy TQ, Johansson A, Long NH. Reasons for not reporting deaths – A qualitative study in a rural setting, Vietnam. *Journal of World Health & Population*. Epub February 2007.
- III. Huy TQ, Johansson A, Long NH. Obstacles for death registration in a rural district in northern Vietnam – Views from people working for commune registry systems (submitted).
- IV. Huy TQ, Long NH, Eriksson B, Johansson A. Experiences learned from FilaBavi – A Demographic Surveillance System, Vietnam (submitted).

The papers will be referred to by their Roman numerals I – IV.

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LIST OF ABBREVIATIONS

CDR	Crude Death Rate
DHS	Demographic Health Survey
DSS	Demographic Surveillance System
FILA BAVI	Epidemiological Field Laboratory in Ba Vi District, Vietnam
FGD	Focus Group Discussion
GSO	General Statistic Office
IMR	Infant Mortality Rate
MOH	Ministry of Health
CPFC	Committee of Population, Family and Children
SAREC	Department for Research Cooperation Agency
SIDA	Swedish International Development Cooperation Agency
UN	United Nations
U5MR	Under five Mortality Rate
UNICEF	United Nations Children's Fund
WHO	World Health Organization
VHW	Village Health Worker

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DEFINITIONS OF TERMS

Census	A complete enumeration of a population in a specified area.
Surveillance	The systematic collection, analysis, interpretation, and dissemination of health data to assist in the planning, implementation, and evaluation of public health interventions and programmes.
Follow-up	Observation over a period of time of an individual, group or a defined population, whose selected specific characteristics have been assessed in order to observe changes in health status or health related variables.
Crude Death Rate	Number of deaths in a given population during a given time period per 1000 population.
Infant Mortality Rate	Number of deaths during first year of life per 1000 live-born children.
Maternal death	A death of a woman during pregnancy or within 42 days after termination of pregnancy, irrespective of the duration and location of the pregnancy, and due to any cause related to or aggravated by pregnancy or its management, but not by accidental or incidental causes (WHO/FIGO).

PREFACE

In 1980, I was recruited to work as a nurse at the Intensive Care Unit in the Vietnam-Sweden Uong Bi General Hospital (UBGH), in Quang Ninh, Vietnam. In 1982, I was sent to Kristianstad, Sweden, for special practical training in intensive care management. On my return to Vietnam, I was posted in the Army for four years and in 1988, I came back to UBGH to work as a nursing manager for the hospital.

Uong Bi General Hospital was established in 1980 and financially supported by the Swedish Government through Sida during the first years (1980-1999). During these years several Swedish doctors, nurses, and midwives worked at UBGH. Following this phase several initiatives and activities have taken place and UBGH is now a hospital prepared and willing to receive undergraduate students both from Vietnam and international students from several countries, Sweden included. Through the collaboration with Sweden in the Health Systems Research Programme, I was inspired to pursue a Masters degree in Public Health (MPH) in 2000 at the Division of International Health (IHCAR), Department of Public Health Sciences, Karolinska Institutet, Stockholm, Sweden. In 2004, I was registered a PhD student at IHCAR, Karolinska Institutet. During my doctoral training I have been supervised by Professor Bo Eriksson from the Nordic School of Public Health, Gothenburg, Sweden, Dr. Annika Johansson from IHCAR, Karolinska Institutet, Stockholm, Sweden, and Dr. Nguyen Hoang Long from the Planning and Finance Department, Ministry of Health, Vietnam.

During my research training I have continued to work in Uong Bi General Hospital and I have also been invited as a lecturer in different nursing and medical schools in Vietnam. The research training that I have gone through during these years has further increased my interest in systematic search for knowledge as related to people's needs and how it can be used to improve the quality of care in a broad sense. For this, basic technical information and the views of various stakeholders are equally important. This view is reflected in this thesis.

BACKGROUND

The importance of death registration

Vital Events Registration has become routine in many countries. According to the United Nations (UN, 2003), a good registration system should be continuous, complete, permanent and compulsory as vital registration is concerned with the recording of key life cycle or vital events, inclusive of live births, deaths, foetal deaths, marriages, divorces, adoptions, legitimation of births, recognition of parenthood, annulment of marriages, or legal separations. Additionally, 'first priority' topics should include the date and place of occurrence, the date of registration, and the place of residence. Unlike censuses that describe the state of the population at a fixed point in time, vital statistics are collected on a continuous basis, and are therefore important for the study of population change.

There are various priority items for specific types of registration. Death registration, for example, should include cause of death, age, sex and marital status of the deceased, as well as the name of the certifier. From these data mortality rates can be compiled. These are important because they are aggregate indicators of health status of a population since they are related to the quality of health care services and other factors influencing health. They have an important relationship with socio-economic conditions in a society and provide essential information for health planners, as well as politicians, for making health care and socio-economic development plans (Hill, 2006; Reidpath and Allotey, 2003). Understanding mortality patterns is thus useful and considered as a crucial prerequisite for guiding public health action and for supporting the development of evidence based policy. Mortality statistics are used to (i) study patterns and trends in cause-specific mortality over time; (ii) judge the public health importance of different causes of death; (iii) help in identifying priorities and appropriate interventions for avoidable causes of deaths; (iv) make a comparison of age, sex and cause-specific mortality between populations (in regions and countries); and (v) evaluate the effect of interventions on cause-specific mortality (MoH, 1997).

Policy makers are currently paying specific attention to mortality measures because they are used to formulate two targets included in the UN Millennium Development Goals and are one out of three components of the UN Human Development Index (Hill, 2006; Lindstrand et al., 2006). The World Health Organization (WHO) recently published a special, thematic issue of the WHO Bulletin (WHO, 2006) on mortality surveillance that focussed on the importance of mortality in measuring the health status of people all over the world, as well as on different endeavours in collecting data and making effective use of them for policy making.

Death registration in low-income countries

Despite its importance, the validity of mortality information in many countries is low. In low income countries, where most deaths occur at home without the presence of health professionals, certification and registration of deaths are still incomplete. It has been estimated that only one-third of global deaths are registered with information on age, sex, and causes of death, and that the vast majority of unregistered deaths occur in low income countries (Lopez et al., 2000). The coverage of death registrations varies between countries, ranging from almost 100% in high income countries to less than 10% in low income countries (Huong, 2006; Mathers et al., 2005). A study undertaken in Kenya reported that more than 80% of childhood deaths occurred at home and were not registered in any routine monitoring system (Mungala and Snow, 1994). Reviewing death registration among 115 member countries of the WHO, only 23 countries, mostly in Europe and North America, have data that are more than 90% complete (Mathers et al., 2005).

Different countries use different methods for death registration according to resources and capacity in the country. Health facility-based systems, censuses, Demographic and Health Survey (DHS), National Health Survey (NHS), Sample Vital Registration (Sentinel Site Systems) and Demographic Surveillance Systems (DSS) are used (Lindstrand et al., 2006). Some examples are:

- Vital Event Registration (civil event registration): The purposes of the system are to meet legal requirements to establish civil status and protect individual rights. It could also serve as a source of data for informing policy and planning provided it is working well.
- Health Facility Based Systems: data from hospitals and health centres provide the main source of health statistics in many low income countries. The information available is then restricted to selected groups, that is, to those with health care contact.
- Demographic and Health Surveys: many countries use national representative sample surveys to measure key health indicators, including mortality, and are often focused mainly on childhood and maternal deaths. These surveys have the limitation that sample sizes are often not enough to sufficiently identify many cases for stratified analysis (Korenromp et al., 2004).
- Periodic Censuses: are considered as an important source of data on deaths as they shall cover entire populations. They are highly resource consuming and need a great deal of technical support. In many countries, census is therefore only undertaken every tenth year.
- Sample Registration System (Demographic and Health Sentinel Site): is defined as a community-based system implemented as a nationally representative sample with functions for continuous enumeration of demographic data, such as births, deaths, migration (Wells and Agrawal, 1967; Bhat, 2002; Yang et al., 2005).
- Demographic Surveillance Systems (DSS): have been developed in many low in-come countries. DSS functions are to define risk and the corresponding dynamics in rates of birth, death, and migration in a population over time (Indepthnetwork, 2002; Tollman and Zwi, 2000). FilaBavi, which will be further discussed below, is an example (Chuc and Diwan, 2003).

Sentinel Site and DSS are specific systems that can provide information on both numbers and causes of deaths and are good options for countries with a weak routine for registering vital events. Timely and high quality data can be

obtained for planning and management and can also provide a proper forum for research and training (Chuc and Diwan, 2003; Berhane et al., 1999).

In some countries e.g., China and Vietnam, another type of system was implemented, termed the Household and Vital Events Register (Merli, 1988; Lavelly, 1982). With this system, every household has a 'household registration book' [so ho khau]. This book is kept either by the head of the household (in cities) or by the commune accountant or police (in the countryside). The household and vital events registers cover the four demographic changes, i.e. births, deaths, in-migration, and out-migration.

Research methods in public health

The debate concerning the philosophical issues and relative virtues of quantitative and qualitative research has been going on for a long time (Gray and Densten, 1998). Many health professionals are not familiar with qualitative research methods which have a long history in the social science research (Pope, 1995). The nature of quantitative and qualitative research designs differ from each other.

Quantitative research refers to the counts and measures of things in order to seek scientific explanation. The researcher's interests are to find law, systematic relation, and explanation of phenomena (Polit and Hungler, 1991). The results of quantitative research are always statistical.

Qualitative research uses words predominantly or exclusively as data. It tries to look for the meanings behind words, and to seek deeper understanding of the underlying social phenomena. Qualitative researchers always study things in their natural setting, attempting to interpret or make sense of phenomena as understood by the study subjects, and they try to retain fidelity to the real world. Qualitative research applies holistic perspectives and often uses more than one data collection method (Greenhalgh and Taylo, 1997), among which Focus Group Discussions (FGD) and qualitative interviews are the most common.

Focus Group Discussion is a method that uses group interaction to explore how the views of participants on a particular topic are constructed and expressed in relation to a specific culture and context, involving opinions, attitudes and social norms (Dahlgren et al., 2004; Asbury, 1995). FGD has become a popular method in public health research as it can provide insight into potentially sensitive and little known issues which are not easily covered by surveys or individual interviews (Morgan, 1997; Barbour and Kitzinger, 1999).

Qualitative interviews aim at describing and understanding the subjects' own perceptions and experiences of the issues being explored (Kvale, 1996). The interview dialogue allows the researcher to capture not only what is communicated by words but also by tone of voice, facial expression and gestures in the communication flow. This method is often used for studies of sensitive issues that need more privacy and confidentiality than other methods can offer.

The choice of research methodology is driven by the research questions. Nowadays most people agree that using both qualitative and quantitative research methods will help researchers deepen their insights and perspectives in order to achieve a more comprehensive picture and to expand the scope of their study fields. The methods complement each other as each has its merits and utility depending on their power to bear upon the research question asked (Polit and Hungler, 1991; Kvale, 1996; Dahlgren et al., 2004).

Vietnam

Geography, demography and economy

Vietnam borders China in the north, Laos in the northwest and centre, and Cambodia in the southwest. Its 3,444 kilometres of coastline run from its border with Cambodia on the Gulf of Thailand along the South China Sea to its border with China. Vietnam contains a variety of agro-economic zones. The river deltas of Vietnam's two great rivers, the Red River in the north and the Mekong in the south, dominate those two regions. The country is largely lush and tropical, though the temperature in the northern mountains can become near freezing in the winter and the central regions often experience droughts.

According to the Vietnamese Ministry of Health (MoH), the current population is approximately 83 million with almost exclusively indigenous peoples. The largest group is the ethnic Vietnamese (Kinh), who comprise over 85 percent of the population. Other significant ethnic groups include the Hmong, Thai, Muong, Khmer, Cham, and Chinese, though none of these has a population over one million. The country's two largest population centers are Hanoi and Ho Chi Minh City, but 75 percent of the population lives in rural areas. The country's birth rate, estimated to increase 1.32 percent per year, has led to rapid population growth since the 1980s with approximately 34 percent of the population under 14 years of age. In order to limit population growth, a stringent population policy was introduced in the 1980s, advocating a limit on family size to one or two children. A rapid fertility decline has taken place in recent decades, from a total fertility rate of six children per woman to an average of 2.11 in 2005 (GSO, 2005).

When the war against America ended in 1975, the North and the South of Vietnam were reunited under a socialist government. In 1986 a new economic policy was introduced - 'doi moi' (renovation) - changing from the 'subsidised' socialist economy to a market oriented economy. Since the initiation of 'doi moi', Vietnam has made substantial progress in improving economic conditions. For example the number of poor households (income insufficient to provide meals of 2,100 calories/person/day) fell from 58 to 29 percent between 1993 and 2000 and Gross Domestic Product (GDP) growth rate increased 7.5% annually (Huong, 2006; Khe, 2004). However, Vietnam is still considered a low-income country (Bondurant et al., 2003). Some basic data and health indicators are presented in Table 1.

Table 1. *Basic data about Vietnam*

Indicators	
Area (km ²)	329 314
Population (million)	83.110
Female (million)	42.275
Population density (person/ km ²)	252.4
Life expectancy (year)	71.3
Infant mortality rate	17.8/1,000 live births
Under 5 mortality ratio	27.5/1,000 live births
Maternal mortality rate	80.0/100 000 live births
Low birth weight (<2500 grs, percent)	5.1
Under 5 malnutrition rate (percent)	25.2

Source: MoH, Vietnam, 2005

Culture and religions

In Vietnam, Confucianism, Buddhism and Taoism have coexisted for many centuries (Anh, 1998). They are known as “triple religion” (*tam giao*) and have pervaded all aspects of Vietnamese life. In a poetic metaphor, this blend of elements in East Asian cultures has been likened to a ‘grand tapestry’ with Confucianism as the ‘warp’, providing morality, and practical norms for human relation, Taoism as the ‘woof’ that defines human relations with the universe and the cyclical changes of nature, while Buddhism, with its notions of compassion and the afterlife, is the ‘golden thread’ in the tapestry (Saso, 1990; Johansson, 1998). Other religions, including Christianity (Catholicism and Protestantism), Islam, Cao Dai and Hoa Hao also coexist.

Within the diversity of cultural influences in Vietnam, the concept of family is deeply influenced by traditional Confucian doctrine. In the family, men are regarded as the heads and have the last word in making decisions on production, business and investment of household resources (Que et al., 1999). Traditionally, Vietnamese women should follow ‘the three obediences’ (*tam tong*), i.e. obey their father as daughters, their husband as wives and their eldest son if the

husband has died (Bich, 1999; Tuyet and Thu, 1978). The power sphere of women is mainly within the household with chores such as child rearing, responsibility for household work and expenses while they have little influence in other important issues, for example on buying expensive property, attending weddings, funerals or death anniversaries (Anh, 1991; Liljestrom, 1991; Long, 2000). Over the years, there have been important changes in Vietnamese society and improvements in women's status and education. The reduction in fertility has led to a decrease in household size and increased numbers of women in salaried employment. Despite this, the traditional Vietnamese family seems fundamentally unchanged, especially in rural areas, and son preference is still strong, as exemplified by the Vietnamese proverb, 'having ten daughters but no son is the same as having no children' (Dong, 1991; Rydström, 1998; Bélanger, 2002). The deep cultural value of sons in combination with the strong Government policies advocating a small family has created conflicts and dilemmas for Vietnamese families if no son is born, especially for the women (Johansson 1998). An expression of this is the recent indication that sex ratios may be rising in some provinces of Vietnam (Bélanger et al., 2002).

Perception of death and the rituals of death in Vietnam

Phan Ke Binh, who lived 1875-1921, is considered as a great scholar in Vietnam. One of his famous books, written in Vietnamese and first published in 1915, is called 'Vietnamese Customs' (*Phong tục Viet Nam*, reprinted in 1992). In the book he describes most popular beliefs and cultural customs such as worship, wedding rites, rituals of birth, death and after death etc. Phan Cong Chanh has also written extensively on the topic of Vietnamese traditions surrounding religion, births and deaths (Chanh, 1993). The following account is mainly derived from these two sources.

The ontological essence of Vietnamese culture has had a large influence on the everyday practice of people. The concepts of 'soul' and 'spirit' are fundamental to religious practice and the worship of the Divine Ancestral Souls is widespread. People believe that their ancestral souls provide a powerful protection for their offspring. It is the ancestral worship that links the realm of the living to the spiritual realm of death.

Within the diversity of cultural influences in Vietnam, birth and death represent a cycle. Birth is not only biological reproduction but also a complex spiritual phenomenon. This means that offspring are seen as direct reproductions of the souls and bodies of the previous generations. Traditionally, each person is thought to be born with a 'destiny number' (*so menh*), which determines the path and character of one's life from birth to death, length of life, health and illness, richness and poverty. One's 'destiny' is related to the cosmological belief that each human being is defined by a specific star. In Heaven, it is believed that there is one God in charge of keeping the 'Birth Records - *so sinh*' (the God of the South Star-*Nam Tao*) and another God in charge of keeping the 'Death Records-*so tu*' (the God of the North Star-*Bac Dau*). The life of a person is believed being decided by the God of the North Star. Life and death are thus conceived to be a dialectical process that links two realms together into one biological and spiritual world. Therefore, death is considered as a pass from the natural realm to the supernatural realm, as expressed in the Vietnamese saying: 'Life is temporary stay, death is a return' (*song gui, thac ve*).

Births and deaths are associated with numerous rituals. After birth, three rites are held at different times within the first year after birth. The most important is the 'Rite of One Year Full Year of Age' (*Le Day Tuoi Toi*), which is held to express thanks to the ancestors of the family and also to mark the child's humanity. Only after the performance of this rite is the child officially regarded a 'human being'. Thus, the child less than one year old is not considered to possess an authentic human soul and if the child dies before completion of one year, it will not become a human soul (*linh hon*) but a little demon (*ranh*) believed to have the capacity to reincarnate itself.

Many Vietnamese believe that a person's soul lives on after death. One of the most important moral obligations of the living, especially the deceased's children, is to conduct a proper funeral that will facilitate the soul's movement from the world of the living to 'the other world'. This transfer is vital because a soul that does not move to the other world is condemned to become a malevolent wandering ghost, while the soul that does move can become a benevolent family ancestor. The rituals at death and afterwards are more complicated. The most

important and popular practices are the Rite of Welcome the White Souls (*Le nhap hon bach*); the Rite of Funeral Procession (*Le an tang*); the rites held at 49 days and 100 days after death (Observance of the 49 and 100 day period) and the annual memorial rite. The rite of reburial (*Le cai tang*) is often held three to five years after the burial. Rituals at death and afterwards are performed differently from region to region and also depend on religion. Catholic people do not practise most of the rituals of death mentioned above.

Religious practices and rituals have been influenced by the socio-economic and political changes that occurred in the Vietnamese society over the second half of the 20th century. With materialist ideology and the expansion of education people were taught a 'scientific' view and to acknowledge their own influences on daily life. Many rituals, which were regarded as Confucian, feudal and backward, have now disappeared (Rydström, 1998; Malarney, 1996). During wartime and when economic resources were stunted, many rituals were set aside. However, many death rituals have re-emerged in present day Vietnam. The ancestor cult is sustained and is today generally accepted in the Vietnamese society.

Health Care System

The official health care system in Vietnam has four levels and has been developed since the August Revolution in 1945. The central level, the Ministry of Health, with 16 administrative and specialist departments, is responsible for formulating and executing health policies and programmes in the health sector for the entire country. Within the MoH, there is a Health Statistics and Information Division in charge of gathering health information from the provincial level and for compiling the annual health statistics book.

The Provincial Health Bureau directed by the MoH and the Province People Committee, is responsible for health activities in the province. The Department of Planning at the Provincial Health Bureau is responsible for health information from the district level used for health planning and for reporting to the MoH.

The health organisation at the district level has been changed over time but there is always a person in charge of health data of the district and reporting

to the provincial level. At the commune level, there is a Commune Health Station (CHS) with a health staff of 3-5 people headed by a medical officer. They mainly provide prevention, but also primary curative health care. The village health worker network collapsed during the 1980s, but has been restored and strengthened in recent years. Besides preventive and primary curative activities the village health worker is responsible for collection and reporting health information, including births and deaths, to the CHS.

Death registration systems in Vietnam

In Vietnam, at the moment there are three systems responsible for demographic surveillance (Figure 1). The first system is the classical, *de jure* system, called the 'births, deaths and marriages system' or 'juridical system' in short. A justice clerk is responsible for this system in each commune. The juridical system is considered as a bureaucratic system. By law, when a death occurs the next of kin of the deceased is legally obliged to notify the death to the communal justice clerk. The death certificate will be issued to the family of the deceased. During the period of subsidised economy, the system functioned well. All deaths were reported because the relatives of the deceased received some contribution for the funeral. Nowadays, there are no incentives for death reporting and many people do not actively report deaths. In order to correct for such shortcoming, it is regulated that the village head should also be responsible to record births and death in the village and to report these to the commune at the monthly meeting.

The second system is considered as a *de facto* system and was established by the National Committee for Population and Family Planning of Vietnam (now called National Committee for Population, Family and Children-NCPFC) after the government issued the two-child policy in 1988 (Hull and Duong, 1992). This system at the communal level is called 'Communal Population Register System' (CPRS). The CPRS is an active system with a network at the village/hamlet level, where one person, usually a woman, is nominated as a population counsellor (a part-time job with small monthly allowance paid by the NCPFC). Besides her/his tasks as an advisor in family planning matters, she/he is also in charge of recording all births, deaths and migration in her/his village. This

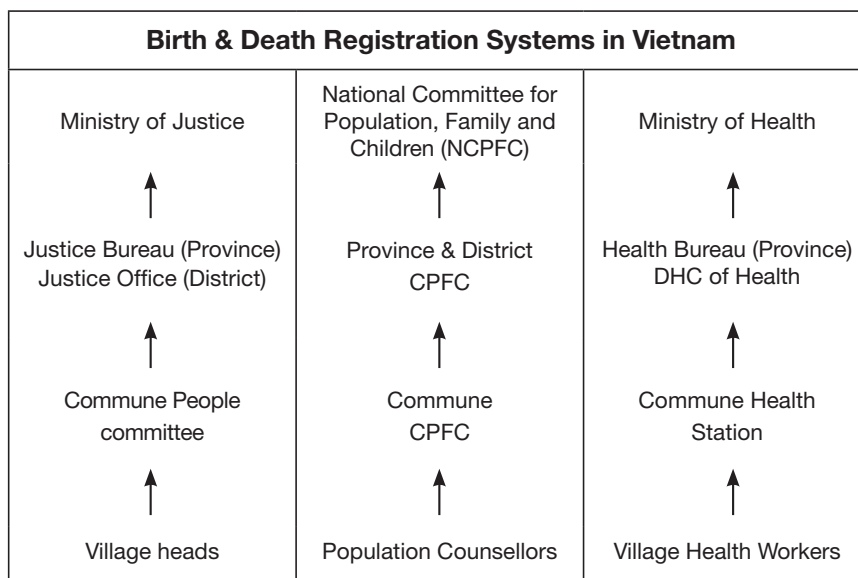


Figure 1. *Organisation of birth and death registration systems in Vietnam*

information is reported monthly to the person in charge of the system in the commune (population officer).

The third system is the communal health care system, which is also responsible to register deaths in the community. This system is mainly interested in causes of death and deaths that take place at the health care facilities, but it does not have a strong network as the CPRS. Therefore, it often collects demographic information, including deaths, via the CPRS. The demographic data in general and mortality information in particular collected by the CPRS system is considered the best among three routine systems.

Mortality development

The health situation in Vietnam as described through mortality and life expectancy is comparatively favourable for a low income country. Broadly, the mortality rates have declined considerably in the last few decades partly owing to governmental policies and programmes on education and basic health care for all. Both Infant Mortality Rate (IMR) and Under-five-mortality-rate (U5MR) based on data from different sources show decline over time. Results

from the General Statistic Office (GSO, 2001) show a decline of IMR from about 55 per thousand at the end of 1970s to about 40 per thousand by the end of the twentieth century. The U5MR went from 82.1 per 1000 live births in the period 1973-83 to 55.4 in 1989-93. According to reports provided by the World Bank (WB; 2001), this mortality rate has put Vietnam among countries in the Asian-Pacific region with low infant mortality rate, comparable to countries that have substantially higher levels of income per capita. The CDR at the end of the 1980s was just over 7 per thousand and had declined to about 6 per thousand by the end of the twentieth century (Table 2).

Table 2: *Crude Death Rate and Infant Mortality Rate. Vietnam, 1979–1999*

	IMR, death before one year of age per 1000 live born children	CDR, deaths per 1000 population
1979–1983	54.8	-
1984–1988	46.0	-
1988–1989	42.0	7.3
<i>Urban</i>	31.5	5.1
<i>Rural</i>	45.0	7.9
1998–1999	36.7	
<i>Urban</i>	18.3	4.2
<i>Rural</i>	41.0	6.0

Source: Vietnam Population Census 1989; GSO, Vietnam 2001; Vietnam ICDS 1994.

Despite the fast economic growth and steep decline of CDR and IMR in the whole country, there is still a remarkable difference in infant mortality between urban and rural areas as seen in the 1999 census. The IMR in the rural area was more than twice that in urban areas. The CDR in rural areas was about 50 percent higher than in urban areas (GSO, 2001). Vietnam National Health Survey conducted in 2001 (VNHS, 2003) showed a four-fold excess in infant mortality rate in the northern mountains as compared to the southeast (40.9 vs. 11.3 deaths per thousand), as well as between children where the mother had no education compared with those where mothers had completed high school (58.6 vs. 13.2 deaths per thousand).

Estimates of mortality of both infant and under-five children collected from different sources showed a large sex disparity. The IMR and U5MR by sex estimated by the DHS in 1993 and by the Inter-Census Demographic Survey (ICDS) in 1996 are presented in Table 3. The IMR and U5MR are substantially lower among females than among males, especially in the ICDS estimates.

Table 3. *IMR and U5MR estimated by ICDS (1984-93) and DHS (1992-96)*

Infant and under five mortality by sex, 1984-93 and 1992-96		
Sex	Infant mortality rate	Under five mortality rate
Male, 1984-93	50.3	66.7
Female, 1984-93	39.1	56.2
Male, 1992-96	35.6	42.1
Female, 1992-96	19.2	29.2

Source: GS0, 1995; NCPFC, 2001.

The quality of mortality estimates in Vietnam is largely unknown and likely to be much varied. Estimates based on data collected by different demographic surveys in recent years are sometimes much diverging. The validity of earlier results is extremely difficult to assess. For instance, the IMR reported by the MoH, Vietnam, was 33.5 per 1000 live births in 1983 while the State Planning Commission and UNICEF estimated it at 68.8 and 75.0, respectively, for the same year (WB, 2001). Some studies using quantitative and qualitative approaches have revealed low validity and incompleteness of death registration. The exhaustive study on maternal death carried-out in Vietnam (Hieu et al., 1999) showed that 16 % of total deaths of women in reproductive age, and 22% of all maternal deaths, were not registered by the health care facilities and the CPRS. Misreported deaths have been identified by another study (Bramley, 2001).

OBJECTIVES OF THE STUDY

General objective

The general objective of this thesis is to examine the validity of mortality estimates based on death data from different sources, as well as to identify factors that can influence reporting and registration of deaths and information about death at the commune level, in order to make recommendations for improvement of death surveillance in a rural setting in northern Vietnam.

Specific objectives

- 1 To compare mortality information collected by different methods in a rural setting and to discuss the validity of such information (**I**).
- 2 To identify obstacles possibly influencing death reporting and registration in the community register systems (**II, III**).
- 3 To describe local people's and surveyors' experiences on death inquiry through household surveys (**IV**).
- 4 To suggest actions to improve reporting and registration of deaths as well as death inquiry in order to attain better quality of death data and mortality estimates (**I-IV**).

SUBJECTS AND METHODS

Study setting

All studies included in the thesis were conducted in Ba Vi District, Ha Tay Province, north Vietnam where a field laboratory (called FilaBavi) was established 1999 (Chuc and Diwan, 2003). The FilaBavi was developed within the Health Systems Research Project supported by Sida/SAREC, Sweden, with the overall aim to implement a longitudinal epidemiological surveillance system in Ba Vi District of Vietnam that could generate basic health and health care data, supply information for health planning, serve as a background and sampling frame for specific studies, and constitute a setting for epidemiological training of research students.

Ba Vi is a district of Ha Tay Province in the Red River Delta Region, northern Vietnam. The district is 60 km west of Hanoi, the capital of Vietnam, and covers an area of 410 km², including lowland, highland, and mountainous areas, and ranges in altitude from 20 to 1297 meters above sea level. The District contains approximately 240,000 people, belonging to the Kinh ethnic group (91%), with Muong (8%) and minorities of Dao, Tay, Hoa, and Khme. Children under one year of age comprise 1.5% of the overall population, children under 5 years of age 7.9%, and women aged 15 to 49 years 27.1%. The District consists of 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. The average income per capita in the district is approximately USD 300 (FilaBavi annual report 2005).

Sixty-nine clusters in the district were selected randomly to constitute the sample for FilaBavi. These had 11,089 households with 51,024 inhabitants for surveillance. A cluster was defined as an administrative unit, usually a village, although if the village was too large it could be divided into two clusters. On average, there are about 600 – 700 inhabitants in each cluster.

The organisation of the FilaBavi includes steering committees, project leaders, research students, field manager, field supervisors, surveyors and computer staff. The central steering committee is mainly responsible for policy and technical guidance and consists of members representing the MoH, Hanoi Medical University and Ba Vi District People's committee. The local steering committee is in charge of supporting practical management and implementation of the field laboratory activities. Members of the committee come from Ba Vi District People's Committee, Ba Vi District Health Centre, Hanoi Medical University and research students. A field manager and three keyers are working in the FilaBavi office located at the district hospital. The field manager is responsible for administration and coordination fieldwork activities.

The computer staffs (keyers) have a high school education and relevant training on basic computer skills and office work. The scientific committee of FilaBavi deals with research and research training issues from a scientific point of view and has representatives from Hanoi Medical University, Karolinska Institutet and Umeå University. Figure 2 shows a map of the field laboratory.

There are 42 female surveyors divided into six groups, each led by a field surveyor. The criteria for selection of surveyors are that they should be living in the district

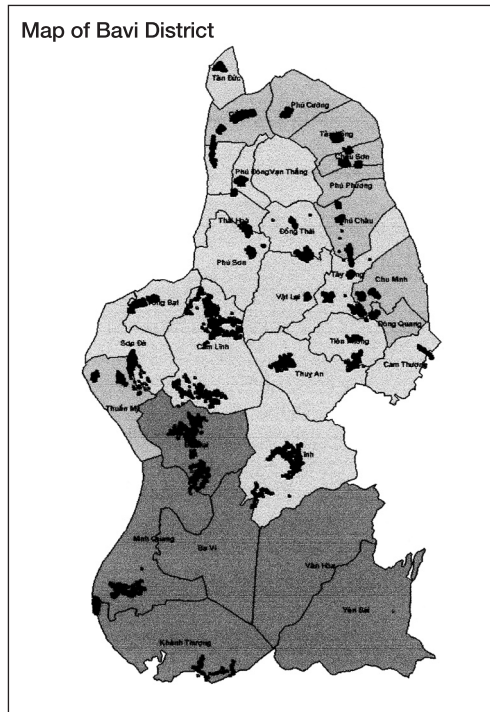


Figure 2. Structure of the study setting (FilaBavi). The lightly shaded areas in the north and north-east are the riverside areas. The darker areas in the south are mountainous areas. The black spots show the sampled clusters.

and have completed high school education. All surveyors are trained before starting their fieldwork and frequently updated in order to ensure the quality of data collection. Field supervisors are persons with a medical background, such as assistant doctors or nurses. Each supervisor is in charge of a group of 6-8 surveyors. The main tasks of a field supervisor are to check manually all survey forms filled by the surveyors in the group.

She or he is also responsible for conducting re-interviews on approximately five percent of the home visits in the quarterly follow-up surveys. Feedback is given to the surveyors in weekly meetings.

An initial baseline survey was carried out in early 1999. Since then household follow-up surveys have been conducted quarterly. A re-census with basically the same scope as the baseline survey has been conducted every second year, 2001, 2003, 2005, and 2007. At baseline and re-census, socio-economic information at household level and characteristics of household members is collected.

At follow-up surveys, demographic and household information is updated. Particularly vital events, birth, death and migration are recorded. Up to June 2007, 30 follow-up surveys have been conducted. At the visit, the surveyor asks if any death has occurred in the household since the last survey. If so, the surveyor has to undertake an additional interview and fill a death registration form. Once a death is reported to the supervisor, he or she is responsible to go to the deceased family to assess the cause of death by using verbal autopsy techniques (Huong et al., 2003).

Study designs and data collection methods

Both quantitative and qualitative approaches were applied in the studies presented in this thesis. The study design and study populations and data collection techniques used in the studies are summarised in Table 4.

Quantitative research

The quantitative data (paper I) were obtained from the household quarterly follow-up surveys from 1999-2000, the first re-census, and the neighbourhood

Table 4. *Summary of study design, population and data collection methods*

STUDY AND STUDY TYPE	SOURCE OF INFORMATION	METHOD AND COLLECTED DATA
<p>Study 1 (paper I) Validity and completeness of death registrations May–June 2001 Quantitative study</p>	<ul style="list-style-type: none"> - Households and persons in FilaBavi sample. - FilaBavi data base - Neighbourhood survey - Lay people who were local residents. 	<ul style="list-style-type: none"> * Death cases detected in quarterly follow-up and re-census. * Review of death lists recorded by CPRS of 29 communes, where FilaBavi was sampled. * Death cases listed by local people, who have lived in the selected village for at least 5 years [44 men and 24 women].
<p>Study 2 (paper II) Perception of death and reasons for not reporting deaths May – December 2001 Qualitative study</p>	<p>[83 participants, including 52 men and 31 women were recruited for FGDs].</p>	<ul style="list-style-type: none"> * Nine FGDs: - Religion: 6 Buddhist groups, 2 Catholic groups and one folk religion. - Ethnicity: 7 Kinh ethnic groups, one group of mixed ethnicities and one group of Muong ethnic. - Geography: 5 groups in lowland, 3 groups in highland and one group in mountainous. (mixed sexes and ages)
<p>Study 3 (paper III) Obstacles for death registration June – August 2005 Qualitative study</p>	<ul style="list-style-type: none"> - People working for commune registry system, i.e. justice clerk, health officer and population motivators 	<ul style="list-style-type: none"> * Fourteen FGDs: - 7 groups with village population motivators. 51 persons, all women - One group with 6 commune population officers (5 women, one man). - 3 groups with commune justice clerks. 14 persons, all men. - 3 groups with commune health officers. 14 persons, mainly men.
<p>Study 4 (paper IV) Survivors/superiors and bereaved persons view on death inquiry March – July 2006 Qualitative study</p>	<ul style="list-style-type: none"> - FilaBavi field supervisors and surveyors [6 supervisors (4 women, two men); 33 surveyors (all women)] - Bereaved family members of deceased (experienced reporting deaths to the surveyors and supervisors in the past year) 	<ul style="list-style-type: none"> * Five FGDs were conducted including: four FGDs with surveyors and one FGD with supervisors. * 15 in-depth interviews were undertaken with bereaved family members, selected to include an equal number of those who had experiences of reporting child death, adult death and elderly death

survey and from the death data registered by the CPRS. The surveyors are normally assigned fixed groups of households. In order to minimise surveyor bias, in the first re-census they were temporarily reassigned to other clusters where they had not had the responsibility during quarterly follow-ups. The first re-census was a cross-sectional survey where surveyors also asked the heads of households if any deaths had occurred within the household from the 1st January 1999 to the 31st December 2000. Surveyors had no information about the names or number of persons who had died and been reported in the quarterly follow-ups. If any death had occurred, a structured form was filled-in.

To compare deaths registered by the FilaBavi with the official data, twenty-nine female primary school teachers were recruited, one in each of the 29 communes where FilaBavi clusters are located. Their task was to copy all information of deaths registered during 1999 – 2000 in the death book of each commune CPFC using a structured form. Those surveyors were trained by the research team before the fieldwork was carried out and completed in April 2001. Out of the 29 lists, three were double-checked. Only minor differences were found.

For the neighbourhood survey the research team contacted the head of villages with few deaths registered by FilaBavi, implying possible underreporting. The participants in the survey were selected among people supposed to know about deaths in the community and they were asked to make a list of all known deaths during 1999-2000 in the village. After comparison and discussion of the lists, an agreed upon list was constructed for the village.

Qualitative approach

FOCUS GROUP DISCUSSION (PAPER II-IV)

FGDs were chosen in the studies on local people's and registrars' opinions on death reporting as we expected that this method would be able to capture consensus and diverging views of the participants. Altogether, nine FGD sessions were conducted in study II, fourteen and five sessions in study III and IV, respectively. The group participants were selected purposively. The thesis author conducted all FGDs with the assistance of a note taker in each session and an observer in several sessions. All sessions were tape recorded with full

consent of the participants. The discussions, which took between one and a half to two hours, were held in Vietnamese in a common public setting, such as the commune meeting hall or meeting room of District Health Centre. The venues for the discussions were chosen carefully in an effort to obtain both convenience and an open, relaxed atmosphere for participants. Thematic discussion guides were developed by the research team prior to the FGDs. The moderator encouraged the participants to freely exchange views on the issues raised in each session while keeping the basic focus of the discussion. He probed into new and interesting issues coming up and verified that he had understood rightly what emerged from the discussions.

QUALITATIVE INTERVIEW (PAPER IV)

Open-ended qualitative interviews were undertaken with 15 family members who were the next of kin of the deceased and had experienced death reporting to the FilaBavi surveyors during death inquiry in the past year. They were selected to include an equal number of those who had experiences of reporting child death, adult (untimely) death or elderly death. The interviews were conducted by the thesis author with assistance from a note taker in the interviewees' houses to maximise privacy and convenience for interviewees. An interview guide prepared by the research team was used. The interviews were usually started with questions about their health status, their work and other general aspects of life before coming to their experiences of the death inquiry. The length of interviews ranged from one to one and a half hours but the interviewer and the note taker usually spent longer time with interviewees, especially with bereaved mothers. Time was always left for questions, expressions of feelings, as well as providing consolation and showing sympathy. Tape recording was used with consent of all interviewees, and notes were taken to represent both summary of interview and the non-verbal language.

Data analysis

QUANTITATIVE DATA ANALYSIS

The deaths in the lists generated from the quarterly follow-ups for the period from the 1st January 1999 to the 31st December 2000, the re-census, and the CPRS were matched, manually by first name and surname, as well as by other variables such as sex, age and date of death. The deaths listed by the

neighbourhood survey were compared separately with those in the lists of deaths generated from quarterly follow-ups in the respective clusters. Computations were made using SPSS software version 10.8 (Norusis, 1999).

QUALITATIVE DATA ANALYSIS

All group discussions and qualitative interviews (paper II-IV) were transcribed by the note taker immediately afterwards. The transcripts were translated into English by professional translators. As the language structure of Vietnamese and English are very different, word-by-word translation is impossible, and thus, it may be difficult even for an experienced translator to capture the full meaning of the original text. Therefore several transcripts were translated into English by two independent translators in order to check the quality of the translations. No major differences between the translations were identified. However, limits of budget prevented us from doing many such quality checks and there were certainly nuances missed in the translation. For example, in the meanings of concepts related to human soul, personhood, different rituals related to death, particularly in paper II, a more careful semantic analysis would strengthen our understanding of the issues. To compensate for this, the research group spent considerable time comparing the translated transcripts with the original text and discussing their meaning.

Qualitative content analysis was used to analyse data (Graneheim and Lundman, 2004; Morse and Field, 1984). All translated transcripts were read carefully by research members individually to acquire an overarching sense and understanding of the whole text. Open codes were usually applied independently by two researchers and similar codes were grouped into sub-categories and categories. These were then compared, modified and expanded by the researchers during the analysis. Attempts were made to identify emerging themes and to discuss their underlying meaning in a socio-cultural and health systems context (Berg, 2001). Member checks were applied; several transcribed data and initial findings were referred back to the group participants in order to seek their opinions on the interpretation of their words. Peer debriefing was undertaken to receive comments from colleagues on the interpretation of the analysis and the findings.

Ethical consideration

Ethical approval to undertake the project was granted by Hanoi Medical University, Vietnam (Approval No20 IRB, 2005). The Research Ethics Committee at Umeå University gave ethical approval for the FilaBavi household surveillance system, including data collection on vital statistics (Reference number 2002-420). Permission to conduct the study was also obtained from the appropriate district authorities.

The studies were implemented in compliance with the ethical principles for Medical Research Involving Human Subjects (Beauchamp and Childress, 1983; Dahlgren et al., 2004). Informed consent was sought from participants prior to each discussion and qualitative interview. All participants were assured of anonymity, confidentiality and their right to withdraw from the study at any time. In all studies except study I, the name of each subject was coded. The lists of codes were kept separately so no names of any subjects appeared on transcripts. All research documents were well-kept and only research team members had access.

Special ethical consideration was paid to study IV, as a part of the research subjects in this study were bereaved people who experienced death reporting by the FilaBavi surveyors/supervisors. The researchers were aware of the vulnerability of the study subjects (Johnson and Clarke, 2003; Rosenblatt, 1995; Nelson et al., 2006), especially those bereaved of a child or in the case of an untimely death. The research team contacted the bereaved families several days prior to the date set for the interviews in order to ask for their consent to participate in the study (Nelson et al., 2006). The interviews were conducted with due respect for the pain and grief experienced by the respondents. For example in an interview with a bereaved mother who had lost a child, she was too grief-stricken to continue to talk and the interview was therefore ended.

MAIN FINDINGS

Local perception, classification of death and related rituals

In discussing perceptions of death, the focus group participants described life as a circular movement, starting at birth, through aging and illness and ending with death (*sinh, lao, benh, tu*). This was seen as the normal process with death as the ultimate end of life in this world. The tendency was to describe this process in 'scientific' terms, as a biological process. However, in all groups, the human soul was thought to continue its existence after biological death, either in the Paradise of the Catholics, in the heaven of the Divine Buddha or, for a 'bad' person, in hell.

The participants categorised deaths into three main types, i.e. 'elderly death' (*chet gia*), 'young death' (*chet tre*) and 'child death' (*chet tre em*). The 'elderly death' was described as a natural phenomenon, illustrated by the metaphor of an old tree: "Death of an elderly is like an old tree, which cannot produce glue to maintain life. When a person gets old, all organs in the body - heart, lung, digestive tract - become exhausted, deteriorated. The organs cannot work anymore, and the person dies".

As the death of an old person is seen as 'natural' and 'deserved', the relatives and others feel at ease. The mourning ceremony (*hoi*) for deaths of elderly persons is commonly held with many formal rituals and lasts a long time. The children of the deceased should arrange a farewell party to celebrate his or her entry into 'the other world'. The *hoi* is held with music performances and a meal offered to all attending the funeral. Usually many people come to say farewell, and to present sacred offerings to the deceased. Among the Buddhists, the funeral for an elderly person often includes a drama performance with people rowing a boat to symbolise the journey of the deceased to the other world.

The 'young death' of adults in working age, was said to be caused by severe diseases, by not getting appropriate health care in time, by leading a 'bad life', or by suicide or accidents. The 'young deaths' were either said to be 'good deaths' or 'bad deaths'. The 'good death' or 'honourable death' was associated

with sadness and grief of the relatives and the community. The ‘bad death’ was regarded as the death of a ‘dishonourable’ person who had led a ‘bad life’ with drinking, fighting, stealing or causing troubles for others. Such deaths usually leave bad reputation and shame for the relatives, but not sadness. The mourning ceremony for ‘young deaths’, called *lam ma*, was often arranged in a very much simpler way than the ceremony *hoi* for elderly deaths. At the *lam ma* ceremony, there was neither music performance nor reading of prayers and it never lasted long because people did not want to prolong the misery of a ‘good death’ or the shamefulfulness of a ‘bad death’ for the family.

The death of a child or a newborn baby was considered as a great misfortune. The causes of such deaths were often attributed to parents’ carelessness or to toxic exposure of the parents, for example pesticides or Agent Orange, the dioxin-containing chemical sprayed during the war. Participants explained that there are many old proverbs and sayings reflecting the traditional belief that an infant death was 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’]. They were eager to point out that nowadays a newborn death was not considered a ‘punishment’ but the sayings remain in 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 keep that in mind, reminding them not to behave badly towards others. Our older generation used this saying to educate themselves and their children”*.

The perceptions of infant deaths were quite different between the Buddhist and Catholic groups. The Buddhist considered a newborn as ‘still too small’ or ‘not grown enough to be a person’, and consequently they did not arrange funeral ceremonies. The burial was carried out immediately, even at night, and only few people in the family attended the burial. The views differed as to how long an infant or child remained ‘not grown enough to be a person’. Among the Kinh in the lowlands, the first year of life was considered ‘infancy’, while among the Muong ethnic minority in the mountainous area, some people considered a child up to the age of 12 years as an ‘infant’. Only after that age the child would not be able to reincarnate: *“After the age of 12 the child will not reincarnate*

because it has finished the period of 'God's care' - bet cua mu [According to the local people's explanation, a lunar century consists of 60 years and divided into five sub-cycles (twelve years each). A child within the first sub-cycle of its life is considered 'an infant', still under the God's care (*cua mu*)].

The simple way to arrange burial for newborn deaths by the Buddhists was remarked upon 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 even 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 died, the funeral would be held with the same rituals as for an elderly or an adult death, except for the prayers because, "A newborn or infant who dies becomes a Saint immediately, so there is no need to pray for it. The funeral for a child is often not so crowded as for an adult death, but the same rituals are performed".

Validity and completeness of death registration

Figure 3 is a diagram showing how the deaths 1999-2000 were detected. Totally 471 deaths were found and the quarterly household follow-up system detected 470 (99.8%), while the CPRS missed 89 cases (18.9%), and the re-census, missed 19 cases (4.0%). Of these 89 missed deaths by the CPRS, 21 were infants, accounting for 58.3% of total deaths in this age group. Out of 19 deaths missed in the re-census, eight were infants, accounting for 22.0% of total deaths in this age group.

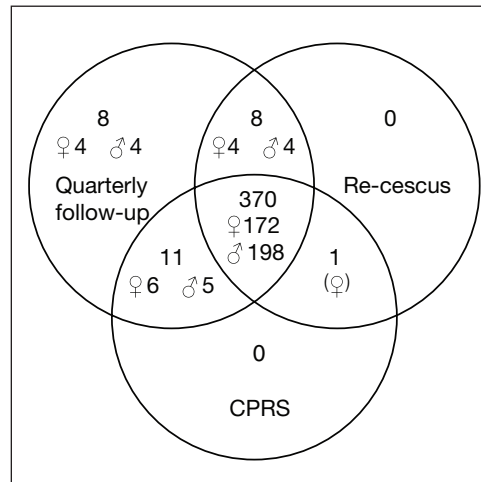


Figure 3. Comparison of deaths collected by three methods

In the CPRS, the number of unregistered deaths did not vary between the two years (43 cases in 1999 vs. 46 cases in 2000) but in the re-census the number of missed deaths in 1999 was more than double of that in 2000 (13 cases vs. 6 cases).

It was noticed that 89 deaths missed in the CPRS were scattered in 44 clusters among a total of 69 sampled clusters with the range from 1 up to 7 cases in each.

Fifty-one deaths found by the CPRS, were recorded with different surnames or given names, compared with official names registered by the FilaBavi, and in 4 cases the gender was not compatible. In addition, there were 55 cases where registered age deviated 2-6 years from actual age. Exhaustive searches (on spot check) were conducted to confirm such cases. The final findings asserted that they were the same deceased in the list of the FilaBavi but the personal information was recorded incorrectly by the local registrars.

Table 5 shows the detailed comparison of missing deaths stratified by sex and ages in the CPRS and the re-census. The table shows that deaths of infant girls were more likely to be missed in both systems. Further, deaths of women over 60 were more likely to be missed than deaths of men over 60 in the CPRS system.

Table 5. Comparison of undetected deaths stratified by sex and age group, by the re-census and commune approaches, in Ba Vi, Vietnam. Missing means not found among the total 471 deaths.

Age (year)	Sex	Total deaths Observed	Approaches			
			Re-census		CPRS	
			Deaths missed	% missing	Deaths missed	% missing
< 1	Male	23	4	17.0	13	57.0
	Female	13	4	31.0	8	62.0
1-4	Male	4	0	0.0	0	0.0
	Female	3	0	0.0	0	0.0
5-14	Male	9	0	0.0	1	11.0
	Female	5	0	0.0	0	0.0
15-49	Male	51	1	2.0	9	18.0
	Female	19	0	0.0	2	11.0
50-59	Male	12	0	0.0	2	17.0
	Female	11	0	0.0	2	18.0
> 60	Male	148	4	3.0	19	13.0
	Female	173	6	3.0	33	19.0
Total	Male	247	9	4.0	44	18.0
	Female	224	10	4.0	45	20.0
Grand total		471	19	4.0	89	19.0

Factors influencing death registrations

The qualitative research of this thesis was used to explore views and experiences about death registration of the key players, i.e. local people and people in charge of registering deaths. The aim was to understand why some deaths, especially infant deaths, are not registered in the commune registry systems. The findings indicated several possible reasons for incomplete registration of deaths.

“Why should we report death if we only lose time?”- Local people’s opinion

In general, participants in the local people’s FGDs agreed that it was difficult to hide deaths in their setting, where relationships were very close between

community members. However, certain deaths might not be reported due to economic, socio-cultural and health systems factors.

From a socio-cultural perspective, a death might not be notified for registration if it was a death of an old or very young person. As the 'elderly deaths' were regarded 'natural' and the burial did not require a death certificate, people were likely to neglect reporting them. Buddhist and ethnic minority participants 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 relationship with other people in the community. The funeral for a newborn death was often arranged immediately after death, even at night, and people living in the same village might not know about it. Although Catholic people had other perceptions of a child death and performed the same funeral rituals as for an adult death, the possibility of not reporting such deaths was still there. People might not notify a child death since the child had already become a saint.

The adult deaths that might not be reported were those seen as 'bad deaths', such as deaths due to HIV/AIDS or suicide. The family would not want to inform others of a death that might leave a bad reputation or bring shame on the family. Tuberculosis and leprosy were called 'social diseases', thus people tended to hide the causes of such deaths because of the fear of stigma for the family members, especially for younger generations. Such deaths would probably be reported but with incorrect causes.

Some people did not know of the legal regulation to notify deaths to the local authority, or where and to whom they should report the death case. Others who knew this said that they were too busy to do so and that no one reminded them. Thus, in reality, only specific deaths were notified in order to get death certificates necessary to receive death gratuity or for insurance claims or other bureaucratic transactions. Most FGD participants knew that notifying deaths did not result in loss of cultivated land but some mentioned this as a reason for not reporting death.

It was agreed that in rural areas, births were often not registered until after several years, even until the child started school. In such a case, *“No birth registration, no need for the registration of its death... If a child dies and it has not been registered in the household registration book then there is no need to register its death”*.

The most common opinion in the FGDs with local people was that deaths were not reported, as they received no benefit: *“No one is punished from not reporting the new birth. It is the same with death reporting. If we go for death registration, we will lose 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?”*

Deaths of people who were not registered as residents in the community (e.g. temporal migrants) were commonly not reported. Their families did not receive anything from the authorities. At the death of an adult resident, the local authorities normally presented flowers and sacred offerings to the family.

Neither incentives nor legal sanction - the registrar views

Participants from all groups of persons involved in death registration, i.e. commune justice clerks, health officers, population officers and population motivators, agreed that there was a considerable incompleteness in the registration of deaths, especially of infant deaths, in the juridical system. In the past, under the subsidised system, deaths were registered adequately in this system as at that time the deceased's family got tickets or coupons for buying coffin and materials used for the burial at a cheap price. Nowadays there is no benefit from death registration and the families of the deceased only notify the death when a death certificate is needed for death gratuity, insurance claims or for exemption of tax.

The powerlessness of law enforcement was regarded as another reason why deaths were not notified. It was difficult to impose any measures of sanctions if the family of the deceased did not conform to the regulations. A death was a great sorrow for the family, so no one wanted to force or fine the family of the deceased. The rigidity of the regulation was also recognised as a reason for

under-registration of deaths, especially of newborn deaths. From a legal point of view, a death cannot be registered if the birth has not been registered.

In addition to the incomplete registration of deaths, several other factors that could influence the quality of mortality information were revealed. For example, in the juridical system, justice clerks often recorded deaths based on information from the local radio or from village heads or sometimes from chatting with other people. Recording wrong information of deaths also happened in the other two systems because of the village health worker's (VHW's) or population motivator's incorrect recording of names and ages of the deceased.

Too many reports and too much paper work were considered as an impediment to the quality of death registration and reporting in the health care system. Most medical officers complained that they were requested to make reports on many different National Health Programmes (i.e. tuberculosis, leprosy, mental health, malnutrition, breast feeding, diarrhoea control, acute respiratory infection, and expanded programme of immunisation). Reporting death was just a small part of their work and did not receive much attention.

Further, FGD participants stressed that there was insufficient inter-systems collaboration with no link between the juridical system and the other two systems. In order to enhance the cooperation between the health care system and the population system in family planning activities, the head of the CHS was appointed as a co-vice chief of the commune population committee in some communes. Despite this, there still seemed to be little active cooperation in terms of sharing and comparing death data collected by each system: *"We invite people from the health care system to attend our meeting only if we have a plan related to the implementation of family planning"* (population officer group).

Many population motivators and health officers voiced the same complaints. Their superiors did not care about or discuss issues of mortality information. They only paid attention to the report of family planning activities and the number of births, especially the number of the third pregnancies or births. There seemed to be very little supervision of death registration in all systems. The biased attitude of the superiors also resulted in an imbalance in training

for staff working in the health care system and population system. None of the FGD population motivators, regardless of length of working experience, had ever been involved in any training on death registration. Many of them stated that it was the first time for them to have a chance to discuss and share information related to death registration.

Death inquiry – views of surveyors, supervisors and respondents

Several striking experiences were reported by FilaBavi surveyors and family members in certain situations of death inquiries such as child deaths, deaths due to stigmatised diseases or to other sensitive reasons, for example suicide.

The surveyors' experiences - stressful and delicate

Technically, the surveyors did not find death inquiry difficult but they all expressed reluctance to conduct such inquiries. They were often faced with the question: *“death is the end, why should you ask about it?”*. They frequently suffered emotional distress and tension in the inquiries. While a death inquiry was relatively easy for an elderly death or a person who had been sick for a long time, it could be very different in cases of an infant or child death: *“When I made an inquiry on an infant death... the respondent often cried very much. That made me feel very sad, too. The inquiry had to be interrupted now and then because the respondent could not answer my questions and I often felt too moved to ask further information”* (a female surveyor).

Many surveyors shared the experience that they were blamed if the family thought that their next of kin died because of the mistakes of health staff, if they were not satisfied with the attitude of hospital staff or when they had some other complaints with local authorities. In such cases the surveyors felt that the respondents poured all their anger on them.

A special difficulty encountered by the surveyors was the reluctance of some respondents to reveal what the surveyors suspected was the ‘true’ causes of death. FGD participants and interviewees shared the same experience that people usually tried to conceal information of the causes of death considered

shameful and creating bad reputation for the family, as explained by one of the field supervisors: *“I knew for sure that he had tuberculosis, so I tried to ask her about his disease process, where he went for examination and what drugs he received. Finally, she admitted that her husband had died of tuberculosis”*.

Suicide was considered as one of the most problematic cause of death. Even though there were clear evidences of the suicide, the family member kept talking about other causes of death and tried to divert the talk.

Bereaved respondents’ experiences - reluctant to talk

Two diverging views were identified from the interviews with family members. Often, the bereaved respondents expressed their thanks to the surveyors for their concerns. They recognised the surveyors’ sympathy with their families, and felt that their loss and grief were shared by the surveyors though their visit also recalled the sadness. All interviewees who had reported elderly deaths appreciated surveyors’ visits to their families.

Family members who had experienced a child death inquiry indicated that they did not want to recall their sadness but that they felt obliged to receive the surveyors and talk with them out of politeness and a wish to help them fulfil their task. Bereaved mothers often felt that they were disturbed by the surveyors’ visits. In an interview with a bereaved mother, whose son had died of burn due to boiling water, the thesis author got a first hand experience of this: *“I do not want anyone to recall my child’s death. I have tried to forget my misery, now you come and talk about it. You make me remember him very much”*, she burst out crying and ran out of the room and the interview had to be stopped (the interview was undertaken nine months after her child’s death).

However, some bereaved mothers and young spouses also indicated that they accepted the inquiries because they did not want to displease the surveyors and they thought they should help them fulfil their tasks. Cases were also told when surveyors almost had to squeeze out the ‘truth’ of tuberculosis, a suicide death or an HIV/AIDS death, which were felt to bring shame on the family and might have negative repercussions for children’s marriage prospects.

Special concerns when conducting death inquiry

A part of our research interest was to get opinions from surveyors about under-reporting in the re-census. Most surveyors attributed the missing deaths to the reallocation of all the FilaBavi surveyors to new cluster(s). Thus, households became new to them and they became 'strangers' to the family members, who were less willing to talk openly with the surveyors. In contrast, when the surveyor had established a close relation with the families, they would be very open and if some information was not reported or the respondent provided wrong information, the surveyor could notice this more easily.

There were several other practical issues that contributed to missing deaths in the first re-census. A main reason, mentioned by most group participants, was the heavy workload of having to collect excessive information, which exhausted both surveyor and respondent. A consequence could be that respondents got 'tired' and gave wrong information.

Longer recall periods could also be the reason for missing deaths in such surveys. Many participants mentioned that in the first re-census, people did not remember death events correctly up to two years back. For example, a death occurring at the beginning of the year might be remembered as having happened at the end of the previous year and was not reported. It was also pointed out that the use of the lunar calendar (about 1-1.5 month later than the western calendar) for important events such as weddings, building houses, births and deaths was also a reason for missing deaths. If a death occurred at the beginning of the western calendar year, it could be reported as having occurred at the end of the last lunar year by the respondent.

To explain the considerable number of missing infant deaths, a common view in all FGDs was related to the cultural perception of not considering an infant as 'fully human' if it died during the first days of life. As explained by one surveyor: *"For lay people if a child died very soon after delivery... the family did not consider it as an infant death, so when we posed the question [if there were any deaths]), they would say no"*.

Improving validity of death reporting and registration in the routine system

Participants in all groups involved in death registration in the routine systems discussed very actively on how to improve death surveillance.

Raising awareness and incentives in the communities

All stressed the vital need for information and education in the communities about this issue to encourage a high sense of responsibility for voluntary death notification. Providing incentives for death notification was another suggestion. An example was given from one commune where the local authorities had decided that if a death (of a commune resident) was notified in due time to the person in charge (justice clerk), the commune committee would send a delegation to visit the family of the deceased and offer a wreath for the death. This policy has encouraged people to notify deaths, however the policy was not valid for the death of a child who has no birth certificate. Another suggestion was to include the notification of death as one criterion for the family to be rewarded the title '*cultural family*'.

Strengthening cooperation between systems and individual competence

Most participants in the groups of medical officers and justice clerks urged for the cooperation between three systems, e.g. by holding a common meeting at least every quarter to exchange and validate information collected by each system. They also suggested the merging of the duties of the village health worker and the population motivator as this would improve the quality of death data.

A majority of participants expressed that the local authorities and superiors ought to pay more attention to death registration through training and active supervision. Based on previous experience of family planning training in large groups, a population motivator suggested that training should be conducted in smaller groups to allow for interaction and questions. Strengthening of organisational structure and activities within each system were also discussed intensively. While the medical officers raised the requirement for the completion of the health care network (i.e. to have a VHW for every village), the justice clerks focused on the need to improve routine to notify deaths at village level.

Limiting the number of death reports within each system and making them comparable between the systems were other suggestions. All participants agreed that the present economic incentive for the population motivator is too small and should be increased to value their work properly and to stimulate them to work better.

Measures to facilitate and improve quality of death inquiry in FilaBavi

The discussions about death inquiry in FilaBavi could be summarised as (i) establishing a good relationship with families; (ii) the surveyor should be well prepared and contact the right person, at the right time and place; (iii) paying attention to cultural observances; (iv) combining death registration inquiry with verbal autopsy interview; (v) strengthening information and motivation for local people; and (vi) providing further training for surveyors.

Establish relationships with families and be well prepared

A trusting and close relationship with bereaved families was regarded as a crucial factor, as this would facilitate the inquiry process and ensure the quality of information. Many surveyors explained that once the surveyor was considered as a friend or 'relative-like' by the families, the surveys in general and death inquiry in particular were easy and open.

Death inquiry was described as very special by the surveyors. Conducting other surveys, they could be quite casual, smile and joke with respondents, but death inquiry was different. They must be serious. In order to reduce distress of the inquiry the surveyors should be well prepared. Many surveyors suggested that if they knew the death prior to visiting the family they could prepare themselves better in how to talk to the bereaved and how to console them. To know of a death in advance is also helpful in deciding the best time for the inquiry visit. For elderly deaths it was thought that the inquiry could be conducted at any time even if the best time was within the first months. However, the first 10 days after death when the family members were 'very occupied and tired' should be avoided.

In case of child or untimely death, most group participants and interviewees thought that the inquiry should not be conducted early because then the families were shocked and felt distressed. The inquiry could take place when the bereaved had settled in mind, generally within the second or third month after death. An inquiry conducted 3 months or later after such a death was regarded as 'too late' as it could open a 'healed wound' of the bereaved. However, some bereaved mothers expressed that it would take them longer time, at least a year, to be in a calmer state of mind and able to meet surveyors.

All participants and interviewees agreed that the person who took care of the deceased most was the best respondent, as she or he would know most details about the death. For a child death, the majority recommended asking both parents in order to lessen the distress of the inquiry. Bereaved mothers thought it would be better if the father was asked because he could keep calm and provide more information. The grandparents of the deceased children were also suggested to be interviewed if they were involved in taking care of the child.

Combination of death inquiries

The combination of the death registration inquiry with verbal autopsy interview was recommended by most surveyors and field supervisors. In the routine set up by the FilaBavi (i.e. for each death, first a surveyor and then her supervisor should go to the family for death registration and verbal autopsy interview, respectively), the family was disturbed twice and had to recall their sadness unnecessarily. Another reason for combining inquiries was that the family of the deceased would appreciate their visit more if seeing two persons from the project coming to pay a condolence visit to the family. All interviewees supported the idea of integration of the two inquiries because they did not like to receive surveyors or supervisors twice.

Strengthening information and motivation for local people

Cooperation of local people was perceived as important for any surveys including death inquiry but it was also claimed that local people did not understand well the purposes of the FilaBavi. A common question posed by interviewees to the research team was, "*What benefit will we get from the project?*" and most surveyors

and supervisors reported that they were often faced with similar questions during the course of their work. All surveyors stated that the motive given to local people that the project aimed to improve health information was not enough. The FilaBavi should provide direct motivation for local people, such as having more sub-studies on health problems and health care intervention. Such studies should be larger so people can recognise the contributions of the project.

DISCUSSION

This thesis is concerned with the validity and completeness of death registration in a rural area in Vietnam and factors that may impinge death reporting and registration. To explore this I have studied the perceptions, attitudes and reported practices of both community members and officials responsible for registration. An additional view is obtained from the FilaBavi surveyors and field supervisors and from bereaved family members in death inquiries.

Extent and reasons of incomplete registration of deaths

During the period from 1999 to 2000, 471 deaths were detected by all methods. The FilaBavi quarterly follow-ups missed only one of these while the CPRS did not record approximately 19% of the identified deaths. To the author's understanding, in Vietnam, there are no studies using the same methods as ours to evaluate the validity and completeness of all kinds of deaths registered in routine systems. Some work has been done on maternal deaths (Hieu et al., 1999; Bramley, 2001). The problem of incomplete registration of death has been found in many low income countries (Lopez et al., 2000; Mathers et al., 2005; Jewkes and Wood, 1998). The completeness of death registration in Thailand has been improved since the computerised vital event registration started in 1995. However, a study conducted recently showed that 12.5% of total deaths were not registered (Prasarkul and Vapattznawong, 2006).

The estimates of IMR in Vietnam vary substantially between sources. The IMR estimates of several international agencies as well as of the State Planning Commission of Vietnam were two to three times as large as the MoH estimates (WB, 2001). In our study about 60% of the infant deaths reported in FilaBavi, were not registered in the routine system. Missing infant deaths have also been commonly reported in other countries. A study in Thailand reported that all perinatal deaths and 45% of infant deaths were not registered (Lumbiganon et al., 1990). In Egypt, where death registration is legally compulsory, only 57% of infant deaths were reported and nearly one-third of those was not found in the register (Becker and Weng, 1998).

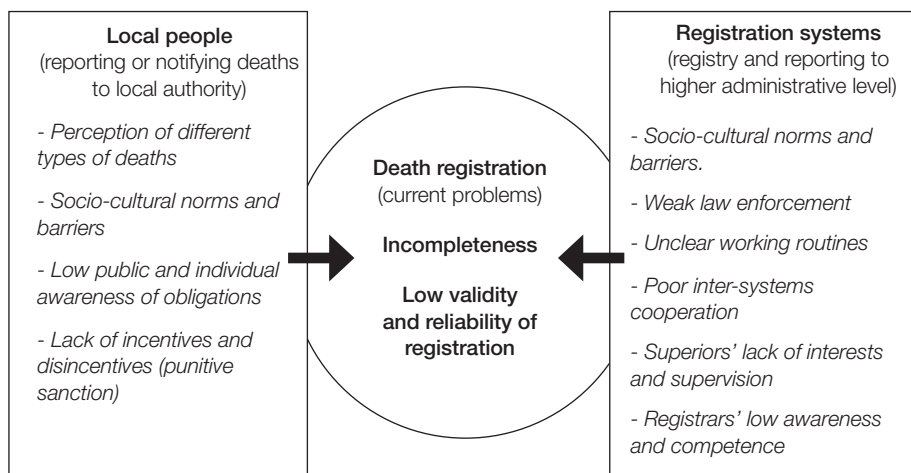


Figure 4. Factors influencing registration of death

Sex difference of infant deaths in my study (paper I), i.e., 33.3 per 1000 live births for male and 19.5 for female, was quite similar to those in DHS (1992-96). It is noteworthy that the rate of unreported female infant deaths in the CPRS and also in the re-census was higher than that for male infant deaths. One possible explanation to this could be that the births of girls are underreported to a higher extent than births of boys and consequently also their deaths, as deaths cannot be reported without a birth certificate. The strong son preference in Vietnam in combination with the strict one or two child policy could be one reason why parents tend to underreport the births of girls, thus avoiding the penalties for 'over-quota' births. A study conducted in 30 provinces of mainland China (Yi, 1996), estimated that about one quarter of all births were not registered and that girls were twice as likely to be missed. Similarly, Merli (1988) and Kane (1999) found under-registration of female births and suggested that this could be a consequence of the strict one-child policy in China.

In my study, the deaths of infant girls were more likely to be unrecorded in both re-census and the CPRS systems, and a tendency towards more unregistered elderly female deaths compared to males was shown in the CPRS (Table 5). The difference is not statistically significant as the number of deaths is small. However it should still be observed as it coincides with results of other studies. The registration of deaths in the 1979 and 1989 national censuses in Vietnam,

where a recall period of one year was used, also showed incompleteness for elderly deaths, especially for elderly women (Merli, 1998). As women live longer on average than men, relatively more old women live alone during their last years of life, which could explain why the death reporting is sometimes neglected. Further studies are needed in Vietnam to clarify the potentially gender selective underreporting of births and deaths of infants and of elderly women's deaths.

Local people's views

To understand the reasons of non-reporting and non-registration of deaths, we conducted the three qualitative studies. Figure 4 summarises possible influencing factors in local people (who report deaths) and the registry systems (which register deaths).

The findings clearly showed that perceptions of human soul and personhood had an important bearing on how infant deaths are reported, particularly in Buddhist groups. The perception among the Buddhist participants of a newborn as 'not grown enough to be a person' was also noted by Chanh (1993) who found that the child less than one year old was not considered old enough to possess an authentic human soul (*linh hon*). The burial of a dead newborn in my study was described as so 'fast' and 'secret' that many people in the same village did not come to know about the death. It was also found that the Catholics believed that a dead child would become a saint and therefore was no need to read prayers and to register its death. In these cases, the infant deaths can obviously be easily missed by the person in charge of the death registry. Even though many participants pointed out that they did not consider an infant death as a 'punishment' for ancestral sins, as was common in the past, such beliefs may still have a bearing on people's reporting or not reporting such death.

Similar to my findings, Jewkes and Wood (1998), in a study from rural South Africa, concluded that infant deaths were not ritually mourned by the family and the community because the child was considered 'an angel taken by God'. The burial for a very young infant death was also described as 'urgent' and 'rapid', contributing to the low rate of death registration in the South African study.

For local people, incentives and disincentives seem certainly to influence on death reporting. A possible reason for under-reporting was the absence of benefits for reporting and legal sanctions if not reporting a death. The same situation has been described in a study from rural Thailand (Lumbiganon et al., 1990) where mothers of children who died explained that they had not registered the birth of the child so they saw no need to register the death, and that there were neither sanctions nor benefits linked to the registration. This may be even more common in rural Vietnam, where it is not compulsory to have a death certificate to bury a deceased person. Another issue that could impinge the registration of infant and child deaths is the local birth registration practice. In rural areas, births are often not registered until after several years, even as late as when the child starts schooling. In such a case, if a child dies, its death would probably not be reported either. The rigidity of the law does not allow registering such a death. This might have resulted in a certain number of unregistered infant and child deaths.

The neglect to report elderly deaths could be due to the elaborate and time-consuming funeral ceremonies when an old person has died. Furthermore, from a social point of view, elderly farmers in Vietnam have little 'material relationship' with society. They are exempted from social contributions and they do not receive a pension from the State. Therefore, administratively, it is not necessary to report or register their deaths.

The findings in my study also revealed that certain causes of death, notably HIV/AIDS, leprosy, tuberculosis and suicides were closely associated with concepts of stigma and shame for the family of the deceased. The incorrect reporting of causes of death that are stigmatising 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, 1998) have shown how people hid the real cause for fear of being stigmatised because they regarded the tuberculosis a 'dirty' and 'hereditary' disease. Today HIV/AIDS seems to be the most severely stigmatising disease not only for the sick person but for the whole family (Ngamvithayapong-Yanai et al., 2005; Varas-Diaz et al., 2005). A death due to HIV/AIDS was seen as a 'bad death' caused by

'bad life style', which is in line with the public opinion in Vietnam, classifying HIV/AIDS as one of the 'social evils' (Mensch et al., 2003).

Registrars' point of views

Lack of awareness of regulations, lack of incentives and powerlessness of law enforcement together seemed to create a 'don't care' attitude of local people. Similar problems were found in other studies in Vietnam (Hieu et al., 1999; Bramley, 2001) as well as in other countries (Becker and Weng, 1998; Cleland, 1996; Lumbiganon et al., 1990; Songane and Bergström, 2002; Jewkes and Wood, 1998). A fear of losing land formerly allocated to the deceased was also uncovered as a reason inhibiting people from notification of death. Such misunderstanding is quite common in rural areas in Vietnam (Bramley, 2001).

Several measures to increase people's awareness and participation in registration of deaths were suggested in my study, mainly through information, education and communication. Special importance was to explain in detail about the new land law passed in 1993, which provides for the inheritance of allocated land. Another suggestion from the registrars was to include notification of death as a criterion for the family to be rewarded the title 'cultural family', which has already been implemented with good results in several areas.

The strong emphasis in Vietnam on fertility reduction and implementation of the two-child policy had apparently made local authorities and superiors neglect death reporting. When mortality reports were submitted, they did not check them as they did for reports on births. The leaders of registration systems might also have the idea of 'death is the end', resulting in a 'let it be' attitude towards death registration. Consequently, shortcomings were probably not identified, justified and corrected. This attitude also resulted in an imbalance in supervision of the staff's work within the system and in provision of training. It was commonly reported by the registrars that they had never gotten any training on death monitoring and registration, and many of them did not understand basic concepts such as perinatal, neonatal or maternal death. This could result in incorrect registration of death. Results from other studies (Bramley, 2001; Hieu et al., 1999) supported my observations. Population motivators often recorded

information of deceased by their memory. So called 'mentally recording' easily leads to incorrect registration of deaths such as wrong names, ages and even incorrect sex.

Why did the re-census miss deaths?

In the re-census, surveyors were changed between clusters to avoid 'surveyor bias' (Cleland, 1996). This meant that households were new to the surveyors. The re-census was conducted from April to June 2001 and deaths that occurred in 1999 and 2000 should be recorded. Thus the recall period varied from 4 months to 30 months. Compared to the quarterly follow-ups, the re-census missed 19 deaths, of which more than two-thirds (13 cases) had occurred in 1999 suggesting a substantial recall bias. Notably, out of these 19 deaths, eight cases were neonatal. Besides the earlier mentioned cultural reason of not counting newborn deaths, the surveyors considered the longer recall period a reason of missing deaths in the re-census. They also mentioned local people's habit of using the lunar calendar for important events as a possible reason for missing deaths.

It appears that death inquiry included in a multiple purpose survey, which means excessive information collected, could make both surveyor and respondent tired, increasing the risk that questions are not properly answered or neglected altogether. Cleland (1996) has also claimed that collecting too much information in a Demographic Health Survey can result in surveyors omitting some births or deaths or shifting their dates backward outside the recall period to shorten interviews. My impression is that using a cross sectional survey for collecting death data is questionable, especially when it uses a long recall period and by unfamiliar surveyors.

Death inquiry: a sensitive laden research and an ethical issue

Death inquiries have been conducted in FilaBavi since 1999. The findings derived from my study have raised important issues related to ethical and emotional aspects of conducting research with bereaved, vulnerable persons and

to the challenges of achieving an ethically and scientifically sound outcome. While most surveyors seemed to handle the delicate death inquiry in a culturally competent way, the study has also borne witness of bereaved mothers and spouses who found the inquiry intrusive and distressing, and of surveyors who apparently went too far in getting the 'truth' out of the interviewees. The findings highlight the real dilemmas of the surveyors in trying to comply with their job requirements in emotionally charged situations when they themselves feel moved and sad.

Bachelor and Briggs (1994) address ethical issues which may arise for social and medical researchers when exploring issues that may be stressful or painful for participants. They stress the need to consider equally the needs, expectations, responsibilities and power of all 'actors' in a research project, including surveyors and respondents, and to strive for an equitable balance, while respecting the integrity of all. A number of other authors have addressed the investigators' experiences in bereavement studies, emphasising the need to be open and transparent in how ethical and emotional dilemmas are handled in the research process (Sque, 2000; Rager, 2005). They highlight the 'compassion stress' which investigators may experience and discuss ways to handle this, e.g., through counselling and peer debriefing among the investigators. The death inquiry at the Ba Vi site is limited in scope compared to most bereavement studies and the Vietnamese cultural context is very different from a Western context where most of these studies are conducted. It seems, however, that the investigators in Ba Vi showed similar signs of 'compassion stress', described in other bereavement studies.

To find a culturally appropriate response to surveyors' 'compassion stress' and to protect both the surveyors and researchers and the bereaved family members is an important ethical issue for the FilaBavi to handle. The *pros* and *cons* of combining death registration and verbal autopsy interviews reported by the study subjects are worthwhile to take into account. In order to minimise harm and protect the rights of both surveyors and the bereaved we advise integration of death registration and verbal autopsy.

Validity of mortality estimates

Mortality estimates such as Crude Death Rate (CDR), Specific Death Rate (SDR), etc, have certain 'true' values in a given population. This can be thought of as the average over a time period when mortality is stable or imagined repeats of a certain time period. When empirical material is used to obtain an estimate, certain errors will always occur. Errors can be systematic, i.e. being the same if the procedure is repeated, or random, unpredictable. Validity of the estimation of mortality indicators in this context is considered as the absence of systematic errors. Implicitly it is also understood that the random errors are small, which is the case when the empirical material is large or the observed time is long. Systematic errors are more serious. They cannot be avoided by increasing the size of the empirical material.

FilaBavi has made great efforts to obtain validity of data collected in general and of death data in particular. Since its beginning, the FilaBavi has tried to detect possible threats to the validity of collected data. These could emerge from local people (respondents), field surveyor and also in the data management process within the FilaBavi. Several quality assurance measures have been implemented.

One of the most important advantages for the FilaBavi is the strong commitment and support of the local authorities at different levels in the district. Besides information programmes disseminated to people, a number of meetings have been held by the local government to inform about the project and to urge for the collaboration of people. Through this, the project has received decent cooperation from local people. A majority of households are always willing to help surveyors to obtain data, although it is quite 'boring' and the follow-up surveys are repeated every quarter. Approximate one percent of all households in the sample do not want to cooperate with the project.

Ideally, a DSS should be maintained for a long time. In order to preserve good relations between the surveyors, the project continuously tries to strengthen the cooperation with the local people. Every year, the project organises a meeting with the representatives of local people to brief them about results produced

from the data collected in the year and to have an open discussion about results and possible shortcomings. Several sub-studies have been conducted within the framework of the FilaBavi such as tuberculosis active case detection, epilepsy, mental disorders screening study on hypertension, reproductive tract infection. These have created interest in the study population and promoted cooperation. Additionally, the personal help from project leaders and research students to disadvantaged people have brought good reputation for the project.

As the surveyors play a very important role for the quality of data, the project has paid much attention to surveyors' competence and to the quality of their work. In FilaBavi, all the surveyors were to meet minimum requirements at the admission and they have then been trained carefully in collecting data and to have good competence in carrying out household survey. The quality of data is also safeguarded by adequate supervision, carried out regularly by field supervisors and research students. The field supervisors are responsible for the review and check of all forms before submitting them for data entry. Five percent of submitted forms are checked routinely by research students. The following measures have been implemented to control data entry: data entry building checking, regularly query checking by data manager, customised query checking by computer consultants, data quality feedback from other consultants (bio-statistician, epidemiologist), and double data entry.

It is beyond the scope of this thesis to make any absolute quantitative statement on the validity and completeness for the FilaBavi registration. To estimate possible biases a reasonably long period of time must be observed. FilaBavi is now in its ninth year and detailed quantitative studies of validity have begun. This thesis shows that FilaBavi provides considerably better information than the official systems. The number of deaths found by the system was the highest. In addition, all conceivable measures were taken to safeguard the quality of information in FilaBavi.

FilaBavi is an active system continuously exploring the vital events happening in the community. In contrast, the official systems are passive, waiting for information. This difference should mean that the risks for influence of

obstacles for reporting as seen from the community are less disturbing for the FilaBavi. In official registration there is a lack of motivation. The surveyors in FilaBavi are employed full-time, specifically trained and continuously informed and reminded about the purpose of the data collection. This stands in contrast to the registrars with less time and interest for death registration. It has to be kept in mind though, that surveyors have reported reluctance against work in relation to death.

This thesis is about studies of death. It can also have bearing on the study of other vital events, particularly birth. However, the studies presented here, in fact suggest that the problems in reporting births are less than in reporting death. If deaths are underreported, mortality estimates will be biased, too low. Most use of mortality involves comparison, over time, between geographical areas or between defined population groups. Differential biases would be the most disturbing effect, e.g. if underreporting is higher in certain social classes. Results from FilaBavi have indicated lower mortality in better off population groups. Such tendencies might of course be reinforced by poorer reporting in these groups. No evidence of this is available, however, and the differences observed can hardly be explained entirely by reporting problems.

Trustworthiness in qualitative research

Qualitative research is sometimes said to lack scientific rigour, objectivity and generalisability. Trustworthiness in qualitative research should, however, not be evaluated in the same way as quantitative research. Trustworthiness is being honest, telling the truth, keeping promises, and being loyal. Simply, a trustworthy person is someone who tells the 'truth' consistently. A trustworthy person can rightly be trusted (Dahlgren et al., 2004). So what is trustworthy research? How can we judge which findings are worth believing and which should be rejected?

Several strategies are available in qualitative research to protect against bias and to create "trustworthiness" of the findings (Lincoln and Guba, 1985; Mays, 1995), assessed through four criteria: credibility, transferability, dependability

and confirmability. Tobin and Begley (2004) have concretised these criteria. Credibility and transferability are comparable with internal and external validity (true value and applicability), while dependability (consistency) and confirmability (neutrality) are comparable with reliability and objectivity in quantitative research.

Several measures have been used to strengthen the trustworthiness of the findings of the studies in this thesis, of which triangulation is one. Triangulation refers to gaining diverse opinions and different views on the same research question or the same phenomenon for the purpose of validation of conclusion. Triangulation is also a technique for strengthening credibility by comparing and cross-checking the consistency of obtained information (Patton, 1990; Dahlgren et al., 2004). According to Lincoln and Guba (1985), there are basically four kinds of triangulation: using different sources of information, methods, investigators and theories. The studies in this thesis were designed and carried out by a multi-disciplinary team including members with different backgrounds: sociology, epidemiology/demography, medicine and nursing, and from two different cultural origins, Vietnamese and Swedish. This diversity has been valuable in discussing and analysing findings from different perspectives. Two types of qualitative data collection methods were applied in the same setting, hopefully resulting in increased dependability and confirmability.

The issue of the researcher's subjectivity is important in qualitative research. Being aware of and describing one's own position and predispositions in the research process makes the findings more transparent and open to scrutiny. I had a close involvement in the FilaBavi activities that permitted 'prolonged engagement' at the field site and the opportunity to test biases in perceptions of myself, as well as of my study subjects (Dahlgren et al., 2004). During both FGDs and individual interviews with bereaved persons, my own pre-knowledge and social position vis-à-vis the study subjects could certainly have

influenced the way the discussions and interviews evolved. I sometimes work in the FilaBavi to supervise surveyors' activities and to conduct studies. I am familiar with the circumstances and known by several focus group participants. It was easy to establish a friendly relationship with them and to create an open discussion. On the other hand, I am also considered as a 'superior' to surveyors, field supervisors and local people. Thus, whilst acting as a moderator for group discussion, I might have influenced the discussion in both directions. I could facilitate the discussion but might also to some extent impede the flow of interaction within the groups as I was partly identified with the 'project' (Asbury, 1995; Morgan, 1995). Being aware of this, I always informed clearly about the objectives and gave detailed explanations of the study topic before starting every group discussion. Because several focus groups were not homogenous and some participants were less communicative than others, I tried to minimise the 'domination' (Johansson, 2001; Morgan, 1993) and to keep the discussion on the right track by posing guiding questions, proper probes and encourage less active participants to speak.

Member checks were done both during and after data collection. The initial findings were reported back to the group participants (FilaBavi surveyors and supervisors). This was a good opportunity for the researcher to gain an in-depth understanding of several statements or expressions made by the participants and very useful in the further analysis of the data. By meeting some of study participants after discussions or communicating with them on initial findings, the author obtained further explanations and confirmations from them on certain issues such as concept of Muong people on 'infancy', the fear of land exemption if reporting a death, observance of rituals after a death, time for death inquiry visits, etc. Peer-debriefings were always conducted with colleagues who were not involved in the studies. Critical comments and input helped the thesis author to further understand the research questions and to deepen the analysis of data. Thus, I expect that the findings in this study are internally and externally valid, that is, the views come genuinely from the study subjects and the findings could be applicable in similar contexts.

CONCLUSIONS

- (i) Household follow-up survey is the best method to detect deaths as far as completeness is concerned. However, death inquiry in the family of the deceased must be considered as sensitive laden research that needs adequate ethical consideration and the establishment of a trustful and close relationship with households.
- (ii) The quantitative result in this thesis revealed that there was a substantial under-registration and misreporting of death, especially for infant deaths, in commune routine registry systems. The qualitative findings support this result.
- (iii) Socio-cultural and health system factors have an important impact on death reporting and registration, especially in cases of infant deaths, elderly deaths and deaths considered to bring shame or bad reputation for the family, such as contagious or hereditary diseases or those associated with 'bad living'.
- (iv) Overload of paper work and administrative weakness related to death registration exist in all commune registry systems. Responsible persons pay inadequate attention to death registration in all commune registry systems. There is an imbalance in the supervision of birth and death registration that leads to insufficient knowledge and competence about death registration among the registrars.
- (v) A multi-purpose, cross-sectional survey with long recall period and surveyors who are unfamiliar to the respondents creates a high risk for missing deaths, especially newborn.

Implications for research and actions

Routine registration systems

- (i) A strong legislative framework for vital registration in Vietnam is essential in generating good mortality information. However, in the present context it must be implemented in parallel with appropriate motivation for more active participation of province and district officials in notification and registration of death.
- (ii) Increased public awareness of importance of death registration should be raised through information, education and communication programmes to strengthen people's motivation and knowledge of their legal obligation to report deaths.
- (iii) The organisation within each existing routine registry system and the inter-system collaboration needs to be reviewed for further improvement with clarified working routines and feasible job descriptions for each position in the system. Combining the roles of the VHW and the population motivator at the village level is recommended. Paper work and reporting instruments in routine registry systems should be reviewed.
- (iv) Local leaders and superiors of each routine registry system should pay adequate attention to death registration and provide adequate supervision, training and motivation to staff.
- (v) Intervention project focused on measures presented in this thesis to improve death reporting and registration and further studies on death registration, for example gender perspectives on death reporting and registration, are also recommended.

Suggestions for FilaBavi and other DSS

- (i) In order to ensure the quality of death inquiries the surveyors should:
 - Be well prepared prior to contacting the family of the deceased.
 - Plan appropriate time and place for inquiry with cultural observances.
 - Find suitable respondents for interviewing.
 - Be sensitive to ethical issues and behave accordingly in order to avoid harm and to protect respondents against distress.
- (ii) Surveyors and field supervisors should be carefully trained with focus on ethical issues, counselling skills and respectful conduct, besides the technical interviewing skills.
- (iii) Information about the DSS and its purposes must be clear and continuous in order to strengthen the motivation of local people.
- (iv) In order to minimise harm and protect the rights of both surveyors and the bereaved we advise integration of death registration and verbal autopsy.
- (v) Researchers using verbal autopsy techniques to investigate causes of deaths should be aware of the risk for incorrect reporting of specific kinds of deaths and consider the most appropriate time for the verbal autopsy for different kinds of deaths in order to avoid harm to respondents.

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