

**Early-Age Health, Survival and Inequity Issues
In a Rural Eastern District of Indonesia**

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A thesis submitted for the fulfilment of the requirements for
the degree of Doctor of Philosophy in Demography

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Declaration

I certify that the work in this thesis entitled “Early-Age Health, Survival and Inequity Issues in a Rural Eastern District of Indonesia” has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree to any other university or institution other than Macquarie University.

I also certify that the thesis is an original piece of research and it has been written by me. Any help and assistance that I have received in my research work and preparation of the thesis itself have been appropriately acknowledged.

In addition, I certify that all information sources and literature used are indicated in the thesis.

The research presented in this thesis was approved by Macquarie University Ethics Review Committee, reference number 5201200938 on 28 March 2013.

A handwritten signature in dark ink, appearing to read 'J. Franciscus Pardosi', is written on a light-colored, slightly textured background.

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Abstract

Little is known about early-age health, survival and inequity issues at the sub-national level in the Eastern part of Indonesia. This study aims to explore these issues among families, local government officials and community leaders in the underdeveloped Ende district. Thirty-two mothers, fifteen fathers and five grandmothers participated in the in-depth interviews, and thirteen participants in the focus group discussions.

Results show that most of the mothers were unable to identify basic childhood illness signs. A lack of midwives in the rural and remote areas was evident. Most of the fathers and all of the grandmothers had only very limited knowledge of the danger signs of childhood illness, and none had received child health-related information from local health staff. Male-dominated forms of decision-making in relation to infant health care were the norm found in this study. The unavailability of midwives and other health staff unavailability, discomfort during delivery and long distances to the closest community health centre remained as a challenge for mothers and fathers in this study. The government officials and local community leaders identified weak leadership, inefficient health management, and inadequate child health budgets as important issues. Midwifery graduates and village midwives were perceived as lacking motivation to work in rural areas. Local traditions were considered to be detrimental to child health.

This thesis identifies a pressing need for improving child health education to be provided by midwives or related health staff to mothers, fathers and grandmothers, particularly basic information relating to childhood illness and its danger signs. This thesis suggests changes to policy relating to early-age health, survival and inequity issues in rural districts of Eastern Indonesia.

Keywords: Early-age · mortality · survival · child health · inequity · rural · Indonesia

To my lovely Ramaida, Ezekiel & Faith

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List of Abbreviations

ANC	: Antenatal Care
ASEAN	: Association of Southeast Asian Nations
ARI	: Acute Respiratory Infections
BAPPENAS	: Badan Perencanaan Pembangunan Nasional (State Ministry of National Development Planning)
BKKBN	: Badan Kependudukan dan Keluarga Berencana Nasional (National Population and Family Planning Board of Indonesia)
BPJS	: Badan Penyelenggara Jaminan Sosial (Social Security Organising Body)
BPS	: Badan Pusat Statistik (Statistics Indonesia)
Buku KIA	: Buku Kesehatan Ibu dan Anak (Maternal and Child Health Book)
CHC	: Community Health Centre
DHF	: Dengue Hemorrhagic Fever
DPRD	: Dewan Perwakilan Rakyat Daerah (District House of Representatives)
ECMS	: Ende Child Mortality Survey
EDHO	: Ende District Health Office (Dinas Kesehatan Kabupaten Ende)
FGDs	: Focus Group Discussions
GRPB	: Gender-Responsive Planning and Budgeting
GSI	: Gerakan Sayang Ibu (Mother Friendly Movement)
2H2	: 2 hari sebelum dan 2 hari sesudah persalinan (2 days before and 2 days after delivery)
HCWs	: Health Care Workers
HDI	: Human Development Index
IDHS	: Indonesian Demographic and Health Survey
INSS	: Indonesia Nutritional Surveillance System
IMCI	: Integrated Management of Childhood Illness
IMR	: Infant Mortality Rate
iMQRES	: International Macquarie Research Excellence Scholarship
IPKM	: Indeks Pembangunan Kesehatan Masyarakat (Public Health Development Index)

Jamkesmas	: Jaminan Kesehatan Masyarakat (Public Health Insurance Scheme)
Jampersal	: Jaminan Persalinan (Maternity Benefit)
KIA	: Kesehatan Ibu dan Anak (Maternal and Child Health)
KMS	: Kartu Menuju Sehat (Children's Health Card)
LDCs	: Less Developed Countries
MCH	: Maternal and Child Health
MDCs	: Most Developed Countries
MDGs	: Millennium Development Goals
MNCH	: Maternal, Neonatal and Child Health
MOH	: Ministry of Health
NFPCB	: National Family Planning Coordinating Board (BKKBN)
NIHRD	: National Institute of Health Research and Development
NMR	: Neonatal Mortality Rate
NTT	: Nusa Tenggara Timur (East Nusa Tenggara)
PHC	: Primary Health Care
Poskesdes	: Pos Kesehatan Desa (Village Health Post)
Posyandu	: Pos Pelayanan Terpadu (Integrated Health Post Service)
Puskesmas	: Pusat Kesehatan Masyarakat (Community Health Centre)
Puskesmas	: Community Health Sub-Centre
Pembantu	
RSUD	: Rumah Sakit Umum Daerah (District General Hospital)
SDGs	: Sustainable Development Goals
SIAGA	: SIAP, ANTAR, JAGA (Alert, Accompany, Guard)
TBAs	: Traditional Birth Attendants (Dukun Bersalin-Beranak)
UNICEF	: United Nations Children's Fund
U5MR	: Under-Five Mortality Rate

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List of Self-contained Papers

This research work is completed as a Thesis by Publication and comprised of the following three self-contained papers:

Paper I: “Inequity Issues and Mothers’ Pregnancy, Delivery and Early-Age Survival Experiences in Ende District, Indonesia. *Journal of Biosocial Science*, 47: 780-802.

Paper II: “Fathers and Infant Health and Survival in a Rural District of Eastern Indonesia”, accepted for publication in the *Journal of Population Research* on 13 April 2016.

Paper III: “Local Government and Community Leaders’ Perspectives on Child Health and Mortality, and Inequity Issues in Rural Eastern Indonesia”, accepted for publication in the *Journal of Biosocial Science* on 16 February 2016.

In terms of contribution to three self-contained papers, Jerico Franciscus Pardosi wrote the manuscripts, performed data analyses and interpretations and acted as a corresponding author (80% of the work). Nick Parr supervised the development of manuscripts, edited and assisted in manuscripts evaluation and provided some substantive suggestions (10% of the work). Salut Muhidin helped to edit and evaluate the manuscripts (10% of the work).

Chapter 1 Introduction

Preventing early-age deaths has been a major challenge for many less developed countries (LDCs), including Indonesia. This thesis investigates the understanding of early-age health and survival among mothers, fathers, grandmothers, and community and government leaders resided in a rural district in Indonesia. The study also considers inequity issues relating to gender and health care services, in mostly rural and remote areas. With the results of this study, rural Indonesian families, government agencies and community leaders should be able to improve their children's health and well-being.

This introduction chapter provides the background to the thesis. Section 1.1 describes the patterns of early-age mortality in Indonesia. A brief overview of the literature on early-age health, survival and inequity issues in LDCs in general and Indonesia in particular is addressed in Section 1.2 (in-depth coverage of the literature relevant to the topics of the papers is presented in Chapters 2-4).¹ An overview of early-age health-related policies in Indonesia is provided in Section 1.3. Section 1.4 focuses on the research site. The next two sections elaborate the main research objectives and the research framework of this study. Finally, the structure of this thesis is presented in Section 1.7.

1.1 Early-age Mortality in Indonesia

Since 2000, the Millennium Development Goals (MDGs) have been a focus of many developing countries, including Indonesia. One of these goals is to reduce maternal and child mortality levels (United Nations 2015). According to the 2015 United Nations Children's Fund (UNICEF) Report on progress on the MDGs for children, there has been a more than fifty percent reduction of under-five deaths in developing countries from 13 million to 6 million

¹ The thesis uses mostly references published since the year of 2000. The search of the sources in this thesis for of early-age health, survival and inequity issues was limited to these years of publication except for papers that are considered as pioneering in the thesis topic or the selected region (Eastern Indonesia). The rationale for limiting the years of publication was mainly to focus on current evidence or up-to-date information relating to early-age health, survival and inequity issues.

under-five deaths per year (UNICEF 2015). Nonetheless, it appears that many LDCs are likely to fail to reduce their child mortality levels by two thirds between 1990 and 2015, the fourth of the MDG (UNICEF 2015). About 3 million neonatal deaths per year still occur in low-income and middle-income countries, with pneumonia and diarrhoea being the leading causes of death for children under-five years old, and preterm-birth complications and pneumonia being the major causes of neonatal deaths (Bhutta and Black 2013; Oza et al. 2015).

Indonesia is still facing challenges in reducing its early-age mortality levels. Table 1.1 indicates that Indonesia's child mortality rates in 2013 were higher than those of five other countries that are part of the Association of Southeast Asian Nations (ASEAN). Indonesia's neonatal and infant mortality rates were three times higher than those of Brunei Darussalam and Malaysia and four times higher than those of Singapore (UNICEF 2014).

Table 1.1 Child mortality levels in ASEAN member countries, 2013

ASEAN Countries	Child Mortality Rates per 1,000 live births		
	Neonatal	Infant	Under-five
Brunei Darussalam	5	8	10
Cambodia	18	33	38
Indonesia	14	25	29
Lao PDR	29	54	71
Myanmar	26	40	51
Malaysia	4	7	9
Singapore	1	2	3
Thailand	8	11	13
Timor Leste ¹	48	46	55
Philippines	14	24	30
Viet Nam	13	19	24

Source: UNICEF 2014

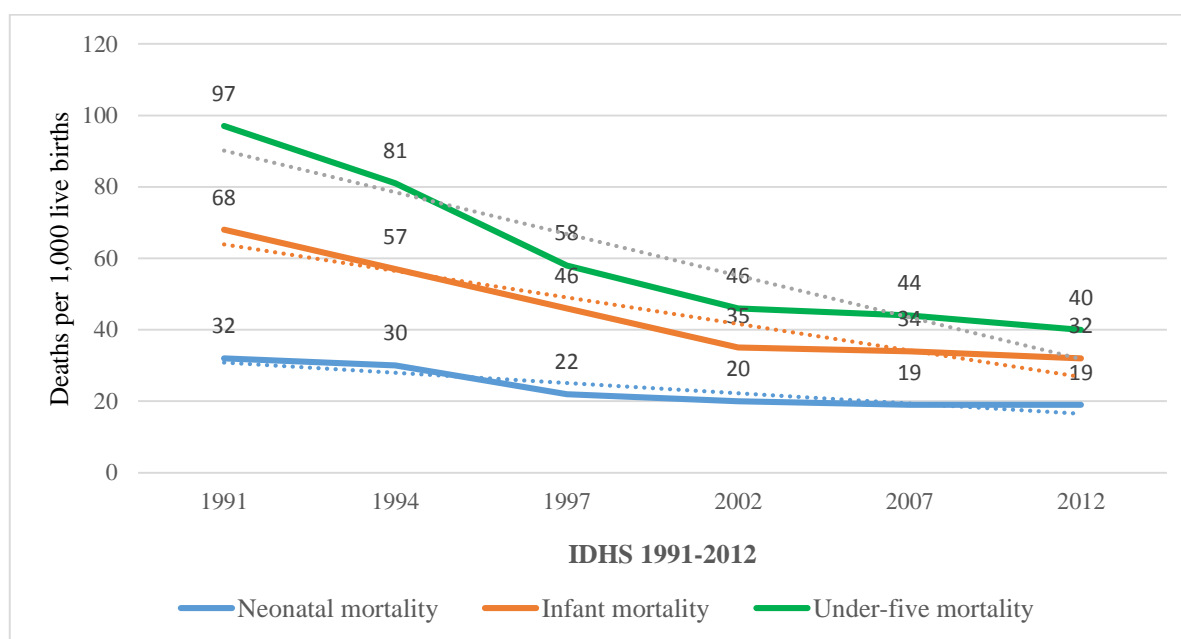
¹Timor Leste's application for joining ASEAN is being considered by the ASEAN Coordinating Council

According to the 2010 National Population Census, Indonesia had a total population of 237,641,326 people who live in 31 provinces, 500 districts and 17,000 islands. The 2012 Indonesian Demographic Health and Survey (IDHS) showed that 60 per cent of infant deaths occurred within the first month of life and 80 per cent of under-five deaths occurred between ages 0 to 11 months (Statistics Indonesia 2013). The rural population had higher early-age

mortality rates than those living in urban areas. The Neonatal mortality rate (NMR), Infant mortality rate (IMR) and Under-five mortality rate (U5MR) of the rural population are 24, 40 and 52 deaths per 1,000 live births compared to the urban areas, which had child mortality rates of 15, 26 and 34 deaths per 1,000 live births respectively (Statistics Indonesia 2013).

Figure 1.1 shows the decline of Indonesia's neonatal, infant and under-5 mortality from 1991 to 2012 based on the IDHS reports. The 2012 IDHS shows that under-5 and infant mortality rates at the national level have declined from 97 and 68 deaths per thousand live births in 1991 to 40 and 32 deaths per 1,000 live births respectively in 2012. However, neonatal mortality rates had a slower rate of reduction than infant and under-five mortality, down from 32 deaths per 1,000 live births in 1991 to 19 deaths per 1,000 live births in 2012 (Statistics Indonesia 2013).

Figure 1.1 Indonesia's early-age mortality rates trends, IDHS 1991-2012



Source: Badan Pusat Statistik-Statistics Indonesia 2003; Statistics Indonesia 2013

Despite the implementation of various child health programmes by the Indonesian government to reduce child deaths across all provinces, the Eastern part of Indonesia remains as a region with higher child mortality rates than other parts of Indonesia. Furthermore, there

are wide variations in child mortality between the provinces and districts in Indonesia (UNDP 2011).

Table 1.2 presents the provinces with the highest and lowest levels of early-age mortality rates, particularly the infant mortality rates (IMR) in 2002 and 2012. The provinces with the highest IMR are mostly located in the Eastern part of Indonesia (e.g. East Nusa Tenggara, Gorontalo, Sulawesi). Meanwhile, the provinces with the lowest IMRs are dominated by the provinces in Java and Sumatera Islands, for example, Bali, Jakarta and Riau (Badan Pusat Statistik-Statistics Indonesia (BPS) and ORC Macro 2003; Statistics Indonesia 2013).

Table 1.2 Provinces with the highest and lowest infant mortality rates, 2002 and 2012

2002 ²		2012	
Highest	IMR	Highest	IMR
1.Gorontalo	77	1.Gorontalo	67
2.South Sulawesi	67	2.West Sulawesi	60
3.East Nusa Tenggara	59	3.West Nusa Tenggara	57
4.Bangka-Belitung	43	4.East Nusa Tenggara	45
Lowest		Lowest	
1.Bali	14	1.Jakarta	22
2.Yogyakarta	20	2.Riau	24
3.Jakarta	35	3.Yogyakarta	25
4.Banten	38	4.Bali	29

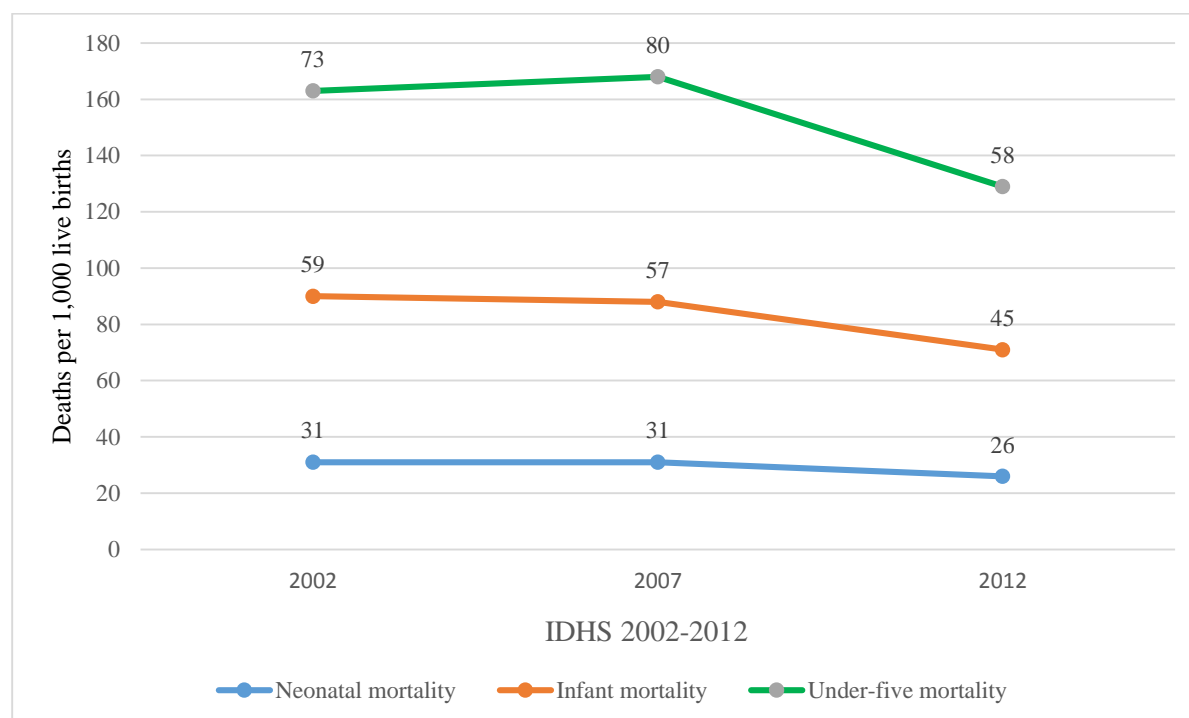
Source: IDHS 2002 and 2012 (Badan Pusat Statistik-Statistics Indonesia 2003; Statistics Indonesia 2013)

²The 2002 IDHS did not cover Nanggroe Aceh Darussalam, Maluku, North Maluku and Papua Provinces due to political and security issues. However, the 2012 IDHS covered those four provinces. For consistency, Table 1.2 only uses 2012 IDHS similar provincial list as the 2002 IDHS. See Appendices A and B for complete provincial tables from IDHS 2002 and 2012.

One of the provinces in the Eastern part of Indonesia with a relatively high early-age mortality is East Nusa Tenggara (also known as Nusa Tenggara Timur (NTT) (Table 1.2; see also Appendices A and B). NTT has made a limited progress in reducing its infant mortality, as shown in Figure 1.2. Whilst the under-five mortality level has declined significantly from 73 to

58 deaths per 1,000 live births, the neonatal and infant mortality rates had a slight decline from 2002 to 2012.

Figure 1.2 Early-age mortality trends, East Nusa Tenggara, 2002-2012



Source: IDHS 2002 and 2012 (Badan Pusat Statistik-Statistics Indonesia (BPS) 2003; Statistics Indonesia 2013).

1.2 Literature Review on Early-age Health, Survival and Inequity issues

This section reviews the literature on the early-age health and survival, particularly on health determinants, gender inequity, health care services and community involvement. It identifies where new contributions could be made of this thesis.²

² To identify literature I applied search terms by using all fields, keywords, and titles (e.g. infant mortality, infant health, child survival, survival, women or gender, gender inequity, gender inequality, Eastern Indonesia, qualitative study, early-age, maternal health, maternal mortality, neonatal, neonatal health, parents decision making, traditions, newborn, cultural values, pregnancy, childbirth, community involvement, community participation, health care services, maternity services, primary health care, local governments, program and policies, beliefs, health care, district health, rural health, grandmothers, health seeking behaviour, male domination, early-age deaths, child mortality). In terms of databases, this thesis used EBSCO, Google Scholar, Web of Science, Annual Reviews, Scopus, CINAHL, Cochrane Library, Ovid Medline, ProQuest and ScienceDirect. The selection publications were journals, books, theses, government reports, national statistics, research reports and websites. In total, this thesis uses 308 references.

Regarding the health determinants, a wide range of studies have indicated that access to water and sanitation, malnutrition, birth-spacing, socioeconomic status and mother's level of education are major determinants of neonatal mortality in Asian and African regions (Agha 2000; Babalola and Fatusi 2009; Chowdhury et al. 2010; Kinney et al. 2010; Mekonnen et al. 2013; Suwal 2001; Wang 2003; Yasmin et al. 2001). Other studies have shown poor health service provision to mothers (e.g. lack of skilled birth attendants and obstetric care services) in association with the lack of access to health facilities have increased the risk of neonatal and infant mortality among rural populations (e.g., Becher et al. 2004; A.G. Hill et al. 2000; McCord et al. 2001; Thaddeus and Maine 1994; Tollman et al. 2008; Weiner et al. 2003; Yanagisawa et al. 2006).

Methodologically, the above-mentioned studies mostly used either large-scale surveys or longitudinal studies as their data sources. Relatively few studies have explored rural mothers first-hand accounts relating to their pregnancy and delivery experiences, including access to health services, by using a qualitative approach (Myer and Harrison 2003; Tlebere et al. 2007; Vallely et al. 2013). Furthermore, there is a lack of studies providing mothers' first-hand accounts of their experiences after childbirth relating to their infant health and survival, especially for those in rural areas.

In terms of gender inequity issues, studies in developing countries have tended to focus on women's difficulty in participating in child health-seeking decisions, which tend to be made by their husbands (Sen and Östlin 2007; Singh et al. 2013; Speizer et al. 2005; Wamala and Ågren 2002). The existing literature shows that fathers' involvement relating to child health in low- and middle-income countries tends to be greatest during and after pregnancy, and that fathers tend to make the final decisions relating to their wives' maternal health and care (Becker et al. 2006; Lee 1999; Mullany 2006). A few studies have identified that higher levels of fathers' support for mothers during pregnancy and after delivery improved their children's health and survival (Z. Hill et al. 2004; Tweheyo et al. 2010). However, there is lack of information about

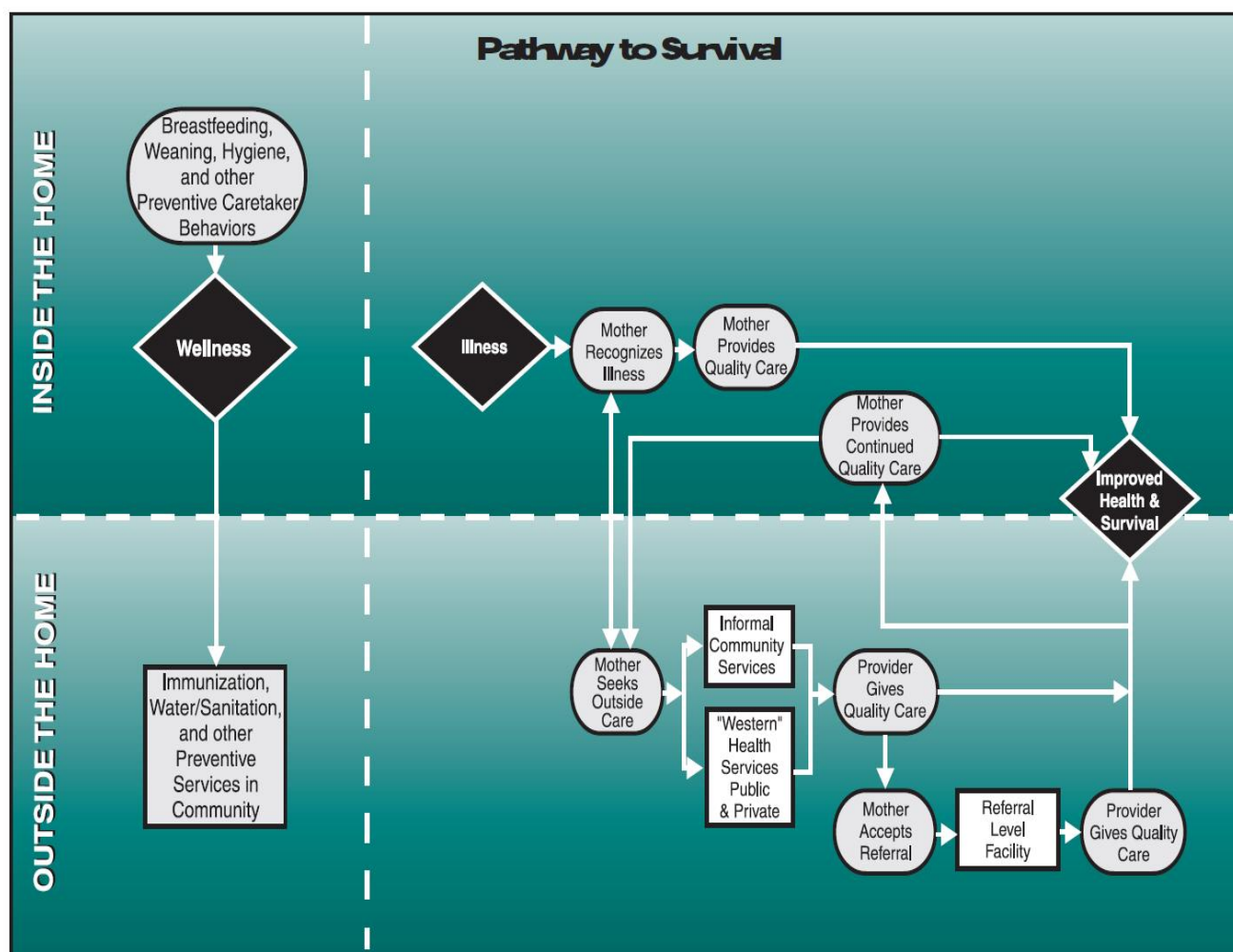
fathers' roles relating to infant health and care. In terms of gender inequity issues, studies in developing countries have tended to focus on women's difficulty in participating in child health-seeking decisions, which tend to be made by their husbands (Sen and Östlin 2007; Singh et al. 2013; Speizer et al. 2005; Wamala and Ågren 2002). The existing literature shows that fathers' involvement relating to child health in low- and middle-income countries tends to be greatest during and after pregnancy, and that fathers tend to make the final decisions relating to their wives' maternal health and care (Becker et al. 2006; Lee 1999; Mullany 2006). A few studies have identified that higher levels of fathers' support for mothers during pregnancy and after delivery improved their children's health and survival (Z. Hill et al. 2004; Tweheyo et al. 2010). However, there is lack of information about fathers' roles relating to infant health and care. The following sections will discuss more in-depth early-age health outcomes, gender equity, family and community involvement with early-age survival, cultural practices relating to early-age health and decision-making processes based on existing studies and reports in Indonesia especially the Eastern part of Indonesia.

1.2.1 Early-age health outcomes in Indonesia

The literature on the determinants of health highlights different factors and pathways through which infant survival is influenced. Marsh et al. (2002) suggested regular maternity and infant care, danger signs during pregnancy, and appropriate care for neonatal illnesses as key determinants of newborn survival. Infant survival is also determined by mothers' health behaviours during the antenatal period and delivery, and postnatal care service use (Marsh et al. 2002). Child survival in developing countries is influenced by the case management of infant illness at home, childhood health management outside the home and the interface between home and outside health care services, as presented in Figure 1.3 (Waldman et al. 1996). Health-seeking behaviour relating to outside health services and the provision of continuous health

information by health personnel to families are represented as horizontal lines in Figure 1.3 (Waldman et al. 1996).

Figure 1.3 The pathways through which infant survival in developing countries is influenced



Source: Waldman et al. 1996

Waldman et al. (1996) recommend the implementation of an integrated management of childhood illness (IMCI) both inside and outside the home to reduce the risk of infant mortality (Figure 1.3). They also argue that not only improving the quality of health care services outside the home but also recognizing and improving the infant's caretaker knowledge of childhood illness is critical to improving early-age health outcomes. Other scholars, such as Christian (2010), argue improving nutrition was the main pathway for improving child health and

wellbeing. Christian stressed the importance of providing adequate food to infants to increase the survival of infants.

For Indonesia, most studies linking child mortality to mothers have tended to focus on health care service provision and performance issues as a determinant of child survival. These include the poor quality of care during pregnancy and delivery, including midwives' skills, and its lack of provision to rural areas (Barber et al. 2007; D'Ambruso et al. 2009; Heywood et al. 2010; Makowiecka et al. 2008; Ronsmans et al. 2001; Sugiharti and Lestary 2011; Titaley et al. 2010a). These studies have focused mostly on the Western and Central Indonesian regions. Other studies have indicated rural mothers' difficulties in accessing village midwives through health facilities such as *Puskesmas* (Pusat Kesehatan Masyarakat) (community health centre (CHC)) are associated with their infants having a higher risk of death than those of mothers living in urban areas with easy access to health services (Adair et al. 2012; Frankenberg 1995; Frankenberg et al. 2005). Low utilization of antenatal care visits has led to mothers' lacking in knowledge and awareness relating to their pregnancy and child health (Agus and Horiuchi 2012a; Effendi et al. 2008; Nuraini and Parker 2005; Pardosi et al. 2015; Titaley et al. 2010b). A few studies have linked a poor quality of obstetric care to maternal mortality at the sub-national level (e.g. D'Ambruso et al. 2010; Supratikto et al. 2002; Taguchi et al. 2003).

Infant deaths could be avoided by improving health-seeking behaviour among mothers and increasing the utilization of health services (Febriany et al. 2011). A study in Indonesia pointed out that poor health-seeking behaviour among mothers was influenced by their husbands' decision-making concerning their child's illness treatment (Ensor and Cooper 2004). Data from the *Sasak* people in West Nusa Tenggara and other regions in Indonesia have shown delays in making the appropriate care decisions by the husband and other family members have led to unnecessary maternal and newborn deaths (Hull et al. 1999a; Simanjuntak et al. 2004).

In contrast, other scholars argued that the nutritional pathway should be considered as the key factor influencing early-age deaths, especially for poor populations (Dijkhuizen et al. 2001;

Inayati et al. 2012; SUMMIT 2008; Titaley et al. 2010d; Untoro et al. 2005). Another possible way of influencing infant survival is through the environment pathway. Using the 1999-2003 Indonesia Nutritional Surveillance System (INSS), Semba et al. (2011) found poor latrine condition among poor families was associated with a high risk of under-five death in rural regions. These scholars argued that environmental factors, such as hygiene and sanitation, were major issues concerning infant survival. The quality of health care services continues to strongly influence the early-age health outcomes (Frankenberg 1995; Frankenberg et al. 2005; Hatt et al. 2009). However mothers still remain as the key actor contribute to infant health and survival (Bhutta et al. 2008).

1.2.2 Gender equity and equality relating to early-age health and survival in Indonesia

The existing literature on gender and development in Indonesia shows that women, particularly rural mothers, have less education, poorer health status and less access to public services, including health care services, than men (Connell 2010; I. Utomo 2006; Levine and Kevane 2003). Women in traditional communities have a heavier burden in their households than those in urban communities. Once married, they are expected to obey their husband, do the domestic duties and child rearing and even act as a secondary earner for their family (AJ. Utomo 2008; Cholil et al. 1998). Despite the implementation of the safe motherhood program in Indonesia, the government has not devoted adequate efforts to women's participation and lacks the political will to reduce these gender gaps (Andajani-Sutjahjo and Manderson 2004; Shiffman 2003).

Sen and Ostlin (2010) argued that providing women with opportunity and freedom to make health-related decisions tends to reduce gender inequalities related to health services and improve their children's health and wellbeing. Increasing women's participation in decision-making by their husbands and communities improves the coverage and effectiveness of public health interventions for women and children (WHO 2002). Scholars and international organisations have recognised the importance of gender inequality issues by promoting global

policies and programs on gender equity and women's rights in order to improve women's health outcomes in developing countries (Loue 2002; Sen and Ostlin 2010; Sweetman 2001).

Mothers in rural Eastern Indonesia are still facing challenges to maintaining their health and wellbeing and their children's survival (Belton et al. 2014; Hull et al. 1999b). Browner and Sargent (1996) cited in Hay (1999) argue that women's social position and the influence of cultural values were key factors to understanding women and their reproductive health needs. A study conducted by The Indonesia National Development Planning Agency (BAPPENAS) in East Nusa Tenggara, South Sumatera and Central Java found that there were gender gaps in education attainment, participation in the workforce, and in opportunities for making decisions (Puspitawati et al. 2008). Furthermore, women's lower social status and poorer socioeconomic conditions are associated with higher risks of maternal and infant deaths (Paruzollo et al. 2010).

The existing studies relating to gender and early-age health for Indonesia have focused far more on examining mothers' roles and responsibilities relating to pregnancy and infant health and their health-seeking behaviour than on issues relating to fathers (Frankenberg et al. 2009; Gryboski 1996; Inayati et al. 2012; Nuraini and Parker 2005; Wulandari and Whelan 2011). Whilst the social determinants of maternal and child health have been studied extensively, it seems that little attention has been paid to understanding mothers' early-age death experiences using their first-hand accounts (Blaney et al. 2015; Inayati et al. 2012; Poerwanto et al. 2003; Schmidt et al. 2002; Titaley et al. 2008; Toyama et al. 2001; Wahab et al. 2001). A study conducted by Andajani-Sutjahjo and Manderson (2004) examining mothers' accounts of their infant death and stillbirth experiences at health facilities in East Java demonstrated a need for health staff to support women during their grief experiences.

A few studies in East Java have examined women's accounts of their depression experiences during their late pregnancy stages and postnatal periods (Andajani-Sutjahjo et al. 2007; Edwards et al. 2006). These studies, however, mostly concentrated in urban settings in Western Indonesia and provided little information on mothers' experiences with early age children.

For Eastern Indonesia, only a few studies in the literature have related gender and mortality. Hull and colleagues (1999a) found that *Sasak* families in Lombok, West Nusa Tenggara received less health information from local health personnel and experienced poorer access to health care services. These conditions tend to increase the risk of infant deaths, especially among rural populations. Another study in Lombok found that maternal deaths still occur in rural regions due to the poor quality of rural health care services and the influence of cultural values and traditional beliefs relating to modern medicine (Hay 1999). Similarly, maternal deaths in East Nusa Tenggara province continue to exist because of geographical barriers to the closest health facility (e.g. mountainous country with poor road condition), the poor quality of health services, traditional practices, and financial cost of transportation to health facility (Belton et al. 2014).

1.2.3 Family and community roles in reducing early-age deaths

Regarding fathers involvement with infant care, scholars have identified the influences of fathers relating to maternal health-decision making and infant nutrition practices, such as breastfeeding (Beegle et al. 2001; Februhartanty et al. 2006; Shefner-Rogers and Sood 2004). However, these studies have given little consideration to fathers' experiences of infant health and survival, including their knowledge and involvement in early-age health or to gender equity in health-related decision-making. An ethnographic study in one sub-district of NTT indicated delays in making decisions by family members and in reaching health facilities as a cause of maternal deaths (Belton et al. 2014).

Relating to community participation in local health programs, a few studies in rural Western Indonesia identified the need for promoting health information to local community leaders to increase their awareness of maternal and child health and their engagement with local health activities (D'Ambruoso et al. 2013; Titaley et al. 2010c). A study by Paknawin-Mock et al. (2000) demonstrated that community participation with local health programs such as *Posyandu*

(integrated health post) improved child growth. For developing countries, community-based interventions have been found to increase local community participation relating to local health programs and to improve maternal health outcomes and infant survival (Gwatkin et al. 2004; Haines et al. 2007; Z. Hill et al. 2004; Lassi et al. 2010; O'Rourke et al. 1998; Rosato et al 2008). Thus far, community leaders' roles and participation in programs relating to early-age health have not been extensively studied for the Eastern part of Indonesia.

1.2.4 Cultural practices and beliefs relating to early-age health, survival and inequity issues

The existing literature on early-age health and survival suggests that there is a lack of evidence for understanding the influence of ethnicity and cultural practices relating to maternal and child health and wellbeing, particularly for rural communities in Eastern Indonesia (Hull et al. 1999; Maas 2004). Nutbeam and Harris (2004) argue that health beliefs in the community should be considered by intervention programs relating to maternal and child health. This suggestion was also supported by Ronsmans and Graham (2006) who pointed that culture and health beliefs are influential factors affecting maternal and infant mortality.

In Indonesia traditional societies, certain food preferences and traditional practices during pregnancy and delivery which could contribute to poor early-age health and survival outcomes still occur which could contribute to poor early-age health and survival outcomes. A study conducted among *Javanese*, *Lomboknese* and *Balinese* women indicated that according to local tradition pregnant women must not eat meat frequently (Wulandari and Whelan 2011). Husbands and local leaders advise pregnant women to eat more vegetables than meat. This belief has been criticized for increasing the risk of anaemia that would lead to iron deficiencies among pregnant women (Tapiero et al. 2001; Thompson 2007). To prevent this health issue, pregnant women need to understand which types of food contain iron, which is an essential part of nutrition during pregnancy, and to consume appropriate foods (Agus and Horiuchi 2012a).

Another study on local beliefs described a traditional plant, so-called *Torbangun*, being consumed after delivery in order increasing the breast milk production among *Bataknes* mothers (Damanik 2008). This traditional plant is also used after one month of delivery to ensuring the mother's good health. Similarly, other ethnic groups practice using certain traditional plants for women's treatments during pregnancy, for instance cinnamon, turmeric and coconut (Wulandari and Whelan 2011).

For Eastern Indonesian communities, food taboos are practiced among pregnant women in the belief this will prevent the mother having mental health problems or certain unwanted issues with their babies, such as disability or mental health issues. Pregnant mothers are not allowed to eat seafood-related products (e.g. lobster, squid, prawns, turtles and octopus), certain fish such as eels (*ikan belut*), and fruits such as pineapple (Alwi 2007; S. Handayani 2011; Suryawati 2007). These foods are believed to make the delivery process much more difficult and longer than usual (S. Handayani 2010). Further, the community still perceives that pregnant women eating these taboo foods would affect fetal health (Agus et al. 2012b). Similarly, rural women in Manggarai District, East Nusa Tenggara are advised by their husband or parents (in-law) during pregnancy to eat green beans and cassava leaves in order to improve their nutrition, and not to consume milk (Raflizar et al 2012).

Local ceremonies and traditions during pregnancy and delivery continue to exist across Indonesia particularly in rural and remote communities. During pregnancy, women are not allowed to do certain activities at night such as taking a shower, sleeping on a mattress, cutting animals, going to the river or standing in front of the entrance door. It is believed that if a pregnant woman does such activities she will experience problematic labor or even have a disabled baby (Kurniawan et al. 2012; S. Handayani et al. 2012; Raflizar et al. 2012; Riswati et al. 2012; Wulandari and Whelan 2011). After the second trimester, according to custom, pregnant women in Gorontalo should wear a belt, known as *Bintholo*, around their bellies, to avoid evil spirits and women in Manggarai should bring garlic pierced with nails and place it

into their bag when going out their home at night (S. Handayani et al. 2012; Raflizar et al. 2012). It is argued that these traditions may contribute to early-age health, survival and inequity issues especially for rural families (Agus et al. 2012b; Belton et al. 2014; Wulandari and Whelan 2011).

Before delivery, pregnant women in *Ngalum* tribe, Papua are expected to confess their sins and mistakes to their husbands, parents, parents-in-law and neighbours so that they will not experience difficulty during delivery and in order to ensure the baby is healthy (Kurniawan et al. 2012). Other tribes in Indonesia prefer a specific location for the place of delivery. The *Dayak Kenyah* tribe in East Kalimantan chose the kitchen as the place of delivery while the *Mentawai* people in Sumatera prefer their farm as the location for childbirth (S. Handayani 2010). Despite the efforts of the Ministry of Health to provide adequate health care services with village midwives in rural and remote villages, most people in rural communities in Indonesia strongly believe that the home is the more appropriate place of delivery, and that birth should be supported by a traditional birth attendant (TBA) so-called *Dukun Bersalin* or *Dukun Beranak* (Agus et al. 2012b; Alwi 2007; Anggorodi 2009; Kurniawan et al. 2012; Titaley et al. 2010c).

The Timorese communities in NTT tell mothers and their newborn children to follow a smoke tradition (known as the *Sei* tradition) for 40 days (Soerachman and Wiryawan 2013). The smoke tradition involves the new mother and her baby being placed into a traditional house (so-called *Ume Kbubu*). Both should sleep or lie with firewood burning or solid fuels continuously beneath their bed for 40 days. The *Ume Kbubu* does not have any ventilation and is mostly used for cooking and family meetings. New mothers and their babies are not allowed to go outside the house in order to protect them from cold air, evil spirits and to keep them warm (Prasodjo 2009; Prasodjo et al. 2015). The main concern with this traditional practice is the increased risk of acute lower respiratory infections for the newborn child as a result of high levels of indoor air pollution and lack of access to health facilities and personnel. A few tribes

in Timor Tengah Selatan and Timor Tengah Utara districts still follow this tradition (Prasodjo et al. 2015). Loue (2002) recommends that more research should be considered traditional beliefs and cultural practices among ethnic groups in providing appropriate public health intervention program for mother and child.

1.2.5 Health decision-making by mothers for children in Indonesia

Rural women in Indonesia and other developing countries tend to have less power than men in pregnancy and child-health decision-making due to the influence of patriarchal domination driven by traditional beliefs and cultural practices (Jansen 2006; Speizer et al. 2005; Wulandari and Whelan 2011). The literature points out that the primary decision maker in rural families is mostly the husband influenced by the parents (in-law) and the community leaders (Hull et al. 1999b; Ronsman et al. 2001; Shefner-Rogers and Sood 2004).

Despite Catholic teachings on the importance of the equal positions of men and women, *praktek adat* or cultural practices and traditional beliefs adopted by the husbands tend to limit mothers' care-seeking behaviour, especially for those in rural communities (Adeney 2003; Alwi 2007). Women are often second social class citizens in rural communities and have weaker bargaining power in family decision making, including in their infant health-seeking behaviour (Beegle et al. 2001; D'Ambruoso et al. 2009; I. Utomo 2006). Rural women with low social positions in their communities more frequently seek for treatment of their infant illnesses late, which contributes to poor infant health outcomes (D'Ambruoso et al. 2009; Hull et al. 1999b; Iskandar et al. 1996).

Heaton et al. (2005) point out that poor communication between mothers and their husbands was associated with higher infant mortality and malnutrition (Heaton et al. 2005).. Qualitative studies in rural Indonesia have shown that delay in making decisions by the husband during delivery can lead to obstetric complications and neonatal death (Adisasmita et al. 2008; Belton et al. 2014; D'Ambruoso et al. 2010; Hull et al. 1999; Shefner-Rogers and Sood 2004). Delay

in decisions causes delay in seeking appropriate health care services and ultimately delays in reaching the health facility and receiving the required care services for mothers and children (Cholil et al. 1998).

Prasilowati (2000) argue that increasing women's education to higher levels than their husbands tends to increase women's ability to make decisions in their household and community. Furthermore, maternal education has been shown improve infant health outcomes (Frost et al. 2005). However, mothers in rural Indonesia still have lower education and weaker opportunity in managing their household economy resources than their husbands (Agus and Horiuchi 2012a; Kristiansen and Santoso 2006; Rammohan and Johar 2009). This causes lower utilization of health services among mothers in Eastern Indonesia than in Western Indonesia (Titaley et al. 2010b). The bargaining power within the family is greatly influenced by women having higher social and economic status than their husband (Beegle et al. 2001). A woman having low socio-economic status is associated with less use of health care services, decision-making power and knowledge of infant health and survival (Bhutta et al 2004; Portela and Santarelli 2003; Victora et al. 2003).

Scholars have argued that involving men in reproductive health programs has improved maternal and infant survival and increased women's health seeking behaviour and participation in decision making (Hull et al. 2000; Shefner-Rogers and Sood 2004). Increasing father's involvement in antenatal care services has been shown in the literature to influence care decision-making by their wives (Carroli et al. 2001; Mullany et al. 2007; Sarkardi et al. 2008). In addition, delays in decision-making may be due to very limited knowledge among husbands relating to maternal and child health and inequity issues (Cholil et al. 1998). Parents and the elderly in rural Indonesian influence household decisions by husbands during pregnancy and childbirth. Ethnographic studies in Indonesia found that when husbands are unable to make decisions concerning their wife's pregnancy and delivery, they usually involve their parents or traditional leaders in making the final decision (Kurniawan et al. 2012; S. Handayani et al.

2012; Raflizar et al. 2012; Riswati et al. 2012). Thus, rural women's limited participation in making decisions, due to cultural beliefs and male domination, should be considered as barriers to increasing early-age health and survival which needs to be addressed by the government, local organisations and traditional leaders (Cholil et al. 1998).

In view of the inadequacies of existing knowledge in the Indonesian literature, this study aims to contribute evidence to the body of knowledge regarding the understanding of early-age health and survival in a rural district of Eastern Indonesia. This study also focuses on exploring gender and health care inequity issues through the perspectives of a range of different types of respondents, while attempting to propose policy measures to reduce infant deaths at sub-national level. The investigation of mothers', fathers', local community leaders' and government officials' experiences and perspectives using their first-hand accounts is very rare for Indonesia. Therefore, the present study uses a qualitative approach to provide more evidence for in-depth analysis of the findings in rural Eastern Indonesia context.

1.3 An overview of Early-age Health Policy in Indonesia

Since the 1990s, the Indonesian government has adopted different approaches to reducing child deaths. It started with the Safe Motherhood Initiative (so-called *Gerakan Sayang Ibu (GSI)*) promoting community participation in Maternal and Child Health (MCH) programs in villages. The government distributed around 54,000 midwives between 1990 and 1996 to more than 60,000 villages across Indonesia to improve antenatal care services for rural mothers. Despite this program, many mothers still experienced poor health care service performance (Heywood and Choi 2010). The influence of local beliefs, together with other issues such as high medical expenses and a lack of health personnel in local community health centres, known as *Puskesmas*, have led to the continual use of traditional birth attendant (TBA) services among rural women (Agus et al. 2012b).

In 1999 the government initiated a program, the so-called *Suami SIAGA (Siap, Antar, Jaga)* (Alert Husband), to increase husbands' involvement during pregnancy and the delivery period.

In this program, husbands were expected to be alert or ready for their wives' possible complications during pregnancy and for the signs of delivery (*Siap*). They were also expected to prepare for transportation before childbirth, to accompany their wives during delivery (*Antar*), and to ensure that their wives receive appropriate care services in the health facility (*Jaga*) (Sood et al. 2004). The Ministry of Health launched a massive *SIAGA* publicity campaign across Indonesia through the mass media, both local and national, and expected to promote husbands' knowledge of and influence their behaviour towards maternal and child health. This campaign increased community awareness of other *SIAGA* programs such as the *Bidan* (midwife) *SIAGA* and the *Desa* (village) *SIAGA* (P.S. Hill et al. 2013; Sood et al. 2004). The *Suami SIAGA* program mainly focused on maternal health and childbirth and paid little attention to fathers relating to their infants' health and survival (Shefner-Rogers and Sood 2004).

Studies in both developed and developing countries have shown the positive influence of husbands' participation in maternal and child health programs in preventing infant deaths (Z. Hill et al. 2004; Hodnett et al. 2013; Yargawa and Leonardi-Bee 2015). This indicates a need for the Indonesian government to consider involving husbands not only in maternal health programs and policies, but also in child health-related programs and policies at the sub-national level to reduce early-age deaths, especially for those in rural regions. Since 2010, the government has expanded the *SIAGA* program to involve the community through *Desa SIAGA* (Alert Village) in order to increase community participation, awareness and action for saving maternal and infant lives (Hill et al. 2013). However, this community-based program focuses on pregnancy and childbirth and provides little information about husband's roles and responsibilities for improving child survival.

Antenatal and postnatal care programs for pregnant mothers, provision of trained health professionals for deliveries, regular health examination for neonates and infants, supplementary food programs and provision of immunization services (e.g. DPT, OPV, measles vaccine, and

vitamin A capsule programme) for children under five have been developed and distributed by the government and by non-government organisations (NGOs). Children aged 12–59 months are eligible to receive 60 mg retinol equivalents every 6 months in the Indonesian vitamin A capsule programme (Berger et al. 2008). The responsibility for providing primary care and immunization services at the village level often uses the approach of *Posyandu* (from *Pos Pelayanan Terpadu*, meaning integrated services post), which includes provision of family planning, sanitation, general health care, baby weighing, and immunization. *Posyandu* activities are often held bimonthly in the house of the village leader or at a community health sub-centre (puskesmas pembantu), with help from volunteers who are usually responsible for recording weights, preparing food supplements for the children, and caring for the weighing equipment.

Non-profit organisations, such as Save the Children, have focused on improving neonatal health and survival by delivering postnatal care services and home visits to ensure both availability and accessibility of essential neonatal care services for poor mothers and children in Garut, West Java (Save the Children 2011). These programs are expected by the government to contribute significantly to the health and wellbeing of pregnant mothers and children under-five (AIPMNH 2015a; AIPMNH 2015b; Dwicaksono and Setiawan 2013; F. Anwar et al. 2010; Leimena 1989; Syarif 2012).

There have been changes to local government roles and responsibilities for managing local health policies and programs since the implementation of decentralization in 2001. These include changing the health care system at the sub-national level. The transition process from the central to district governments has not been successful (Heywood and Choi 2010; Simatupang 2009). Poor performance in the district health systems has been a concern, with a range of health care issues apparent, such as a lack of funding for MCH, lack of commitment to increase the quality of health services from local government leaders, a low proportion of children under-five being vaccinated, and weak leadership on existing health issues (Heywood and Choi 2010; Kristiansen and Santoso 2006). Other concerns are the unequal distribution of

midwives or nurses in rural areas, and contract agreements by central government, which resulted in inadequate skills in and knowledge of newborn and infant care among young graduates (Heywood and Choi 2010; Lieberman et al. 2005; Makowiecka et al. 2008).

Countries such as India, Bangladesh and Pakistan have succeeded in reducing their early-age death rates by 30 to 60 per cent by implementing essential neonatal and infant care services, by involving family members and the local community, and by gaining strong commitment from multi-sectoral government agencies (Save the Children 2011). Yet, for Indonesia, there has been a lack of information relating to sub-national early-age health care services and on local community involvement with infant health and survival.

1.4 Research Site

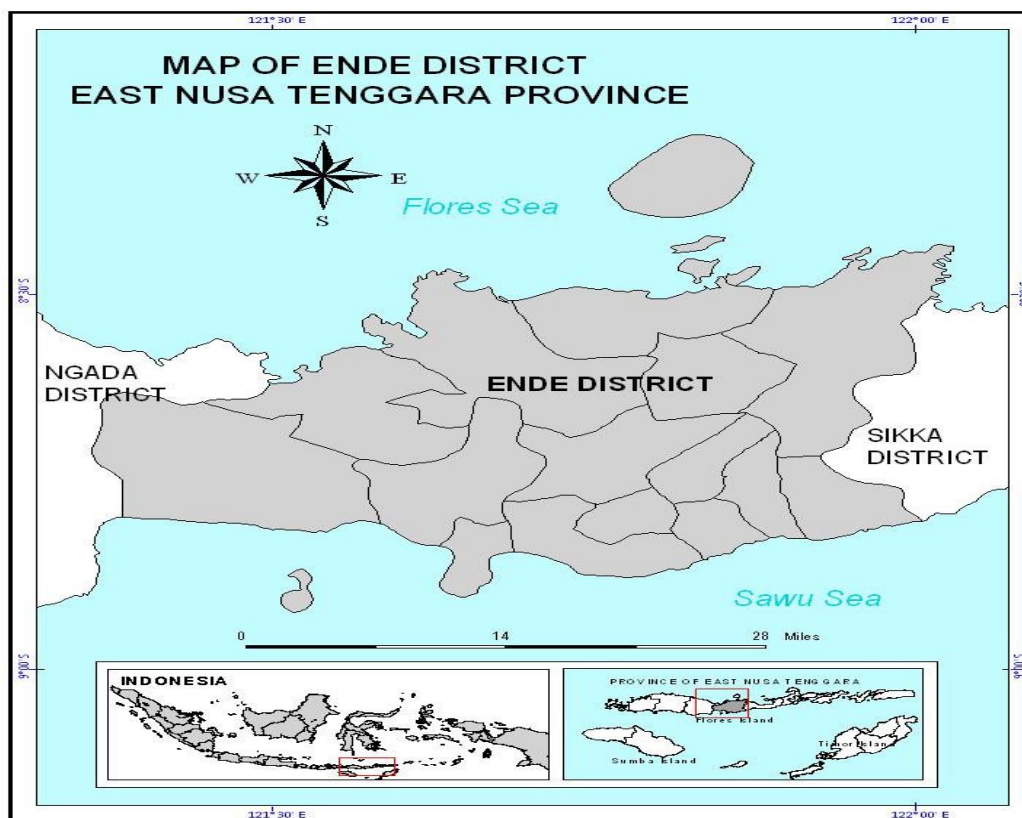
The research site of this thesis was located in Ende district, NTT province. NTT had 21 districts and a total population of 4,953,967 people (Statistics Nusa Tenggara Timur 2012). In 2013, NTT province had a human development index (HDI) of 68.77, compared to 74.11 and 73.54 in Bali and East Java respectively (Statistics Indonesia 2014).

Ende district is one of the poorer and lower public health development index (IPKM) districts in NTT. It was ranked 316 of 500 districts in Indonesia (Ministry of Health 2010a). According to the 2013 Indonesian Human Development Index (HDI), Ende has a lower life expectancy (65.31 years) than neighbouring districts such as Ngada dan Sikka (67.46 and 69.66 years respectively) (Badan Pusat Statistik 2013). Life expectancy at birth in Ende (67.6 years) is below than those of NTT province and Indonesia (Statistics Nusa Tenggara Timur 2011). With a total fertility rate (TFR) of 2.8 births per woman, Ende district has a higher fertility rate than the provincial fertility rates for other districts in Indonesia (NFPCB 2013).

Ende consists of 21 sub-districts and 255 villages with a total population of 279,538 people in 2014 (Statistics Ende District 2014). Ninety-five percent of its population lives in rural areas (EDHO 2012). It has a natural border in the South with the Sawu Sea, in the North with Flores

Sea, in the West with Nagekeo district and in the East with Sikka district, as shown in figure 1.4.

Figure 1.4 Map of Ende District



Source: EDHO 2012, 2013

Selected socio-demographic indicators of Indonesia, NTT and Ende are presented in Table 1.3 based on the 2010 Indonesian Population Census. NTT has 1.99% of Indonesia's total population. The population of Ende is 5.5 per cent of NTT's total population. NTT and Ende have younger populations than that of other districts in Indonesia. Whilst the percentages of people living in rural areas (50.60) and in urban areas (49.40) were similar in Indonesia, a majority of people live in rural areas in both NTT and Ende. In Indonesia, 87.18 per cent of its population were Muslim believers. In contrast, in both NTT and Ende Catholics is the largest religious group. Ende has a lower percentage of people with incomplete primary school education (including no schooling) than those in NTT. According to the 2013 Ende District

Statistics Profile, the majority are Catholics (73%), followed by Moslems (25%) and Protestants (2%) (Statistics Ende District 2013).

Table 1.3 Socio-demographic indicators of Indonesia, NTT and Ende District, 2010

<i>Background</i>	Indonesia	NTT	Ende
<i>Population</i>			
Total population	236,030,490	4,700,970	260,605
Median age	27.20	22.40	23.00
<i>Residence</i>			
Urban	49.40	19.34	5.00
Rural	50.60	80.66	95.00
<i>Religion</i>			
Buddhist	0.71	0.00	0.00
Catholic	2.91	54.67	68.78
Hindu	1.68	0.11	0.14
Confucius	0.57	NA	NA
Muslim	87.18	9.14	29.07
Protestant	6.95	35.08	2.01
<i>Education</i>			
Less than primary completed	28.70	42.50	40.10
Primary completed	47.50	42.10	45.90
Secondary completed	20.60	13.30	12.20
University completed	3.30	2.10	1.80

Source: EDHO 2012; Statistics Indonesia 2013

Ende's neonatal, infant and under-five mortality rates are significantly higher than those for Indonesia (Pardosi et al. 2011; Statistics Indonesia 2013). Northern Ende has the highest infant and under-five death rates within Ende district, followed by the Eastern part of Ende (EDHO 2012). Acute respiratory infections (ARI), allergic skin diseases, diarrhea, skin disease infection and worm diseases were the five most prevalent diseases among children under-five. The five leading causes of death among under-fives between 2009 and 2013 were pneumonia, diarrhoea, malaria, malnutrition and dengue haemorrhagic fever (DHF). The leading causes of infant deaths were asphyxia, infection, low birth weight, congenital abnormalities and pneumonia (EDHO 2012, 2013).

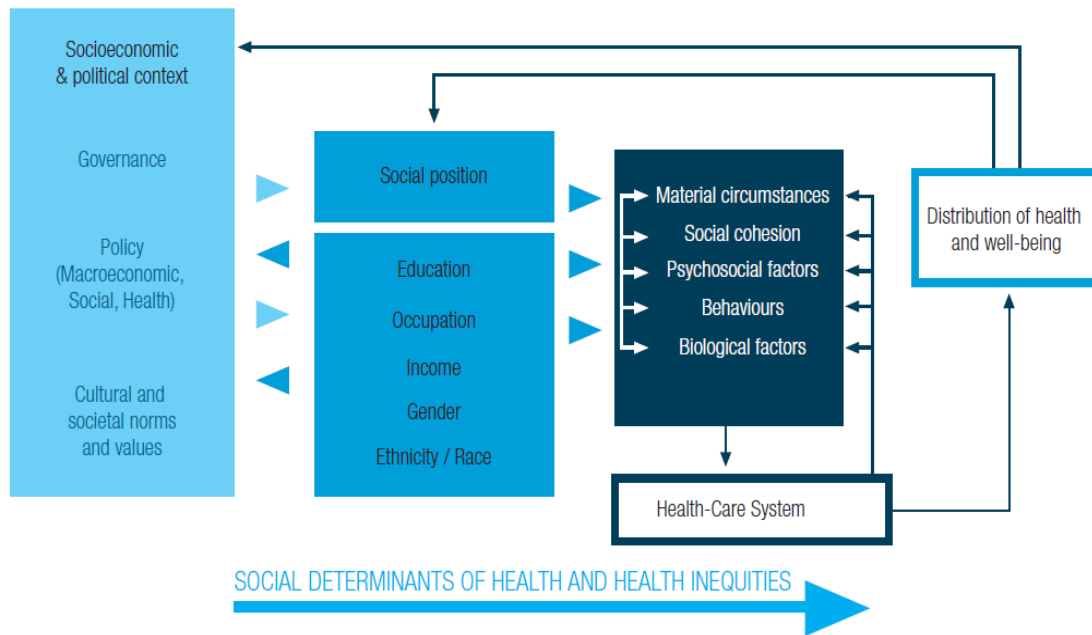
A patriarchal family structure is the norm in Eastern Indonesia. Fathers hold the decision-making power (Williams and Widodo 2009). In rural areas of Ende, male breadwinner families are still the most common, although there has been a slight increase over time in the percentage of working mothers (Williams and Widodo 2009). The majority of families in Ende, especially those in rural areas, co-reside with the male partner's parents (Statistics Ende District 2013).

1.5 Research Framework

1.5.1 Theoretical framework relating to early-age health, survival and inequity issues

The World Health Organization (WHO) through the Commission of Social Determinants of Health (CSDH) (2008) provided a framework on social determinants of health and health inequities, which adopted from Solar and Irwin (2010). The CSDH divided the framework into three categories: socioeconomic and political, social position and intermediary determinants (Figure 1.5). The main focus of this framework is the distribution of health and well-being in the population which is determined by the conditions and the performance of the health care system.

Figure 1.5 The 2008 WHO Commission of Social Determinants of Health Framework³



Solar and Irwin (2010) emphasize that income, education, occupation, social class, gender and race should be considered as key driving forces to reduce health inequities and infant deaths. These factors would influence the performance of the health care system and affect the health outcomes of the population (Figure 1.5).

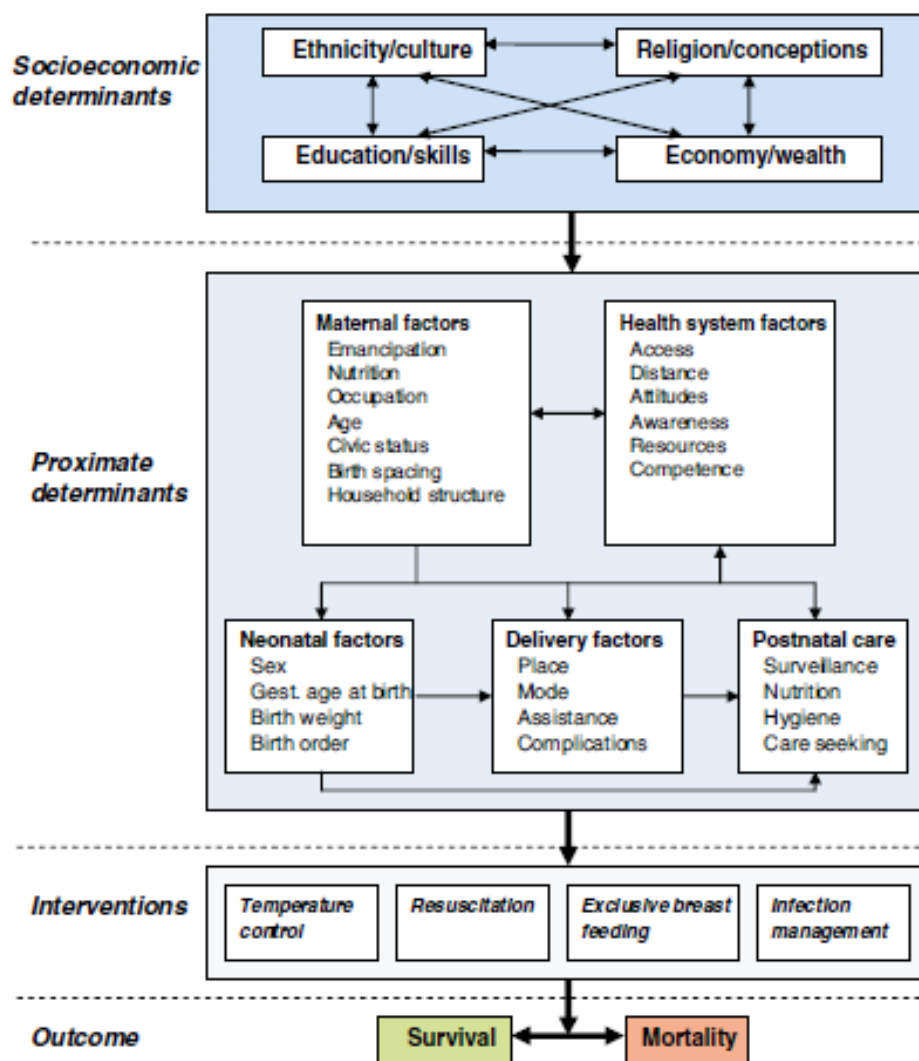
Using Mosley and Chen's (1984) framework, Målqvist (2011) examined neonatal mortality in Vietnam by exploring the hierarchical relationship between socioeconomic and proximate determinants, shown in Figure 1.6. Målqvist argued that neonatal health and survival were influenced by type of interventions provided by health care services to the specific determinants such as ethnic and religion. Neglecting mothers from traditional communities in existing local health programs have been shown associated with an increased risk of early-age mortality (Målqvist 2011). Traditional mothers should be recognised as the target population for developing both effective and efficient public health interventions in the population as also suggested by Keleher (2010). This is mainly because of their inadequate knowledge, poor health

³ The WHO CSDH framework is for health inequities with specific focus on social determinants of health. The original framework is proposed by Solar and Irwin (2007) and revised the proposed framework in 2010. The recent social determinants of health and inequities are obtained from http://whqlibdoc.who.int/publications/2010/9789241500852_eng.pdf.

behaviour and attitudes relating to maternal and child health which influenced by their cultural beliefs and practices (Assan et al. 2009; Titaley et al. 2010a).

Targeting traditional communities relating to maternal and neonatal health and delivering cultural-based interventions towards pregnancy and delivery have been shown to improve mothers' behaviour and better infant health outcomes (Nasution et al. 2015; Swanepoel and Almec 2008). The pathway for increasing neonatal health and survival depends on the interaction between individuals and the health care system with the application of essential interventions to prevent infant deaths in the community including those most in need.

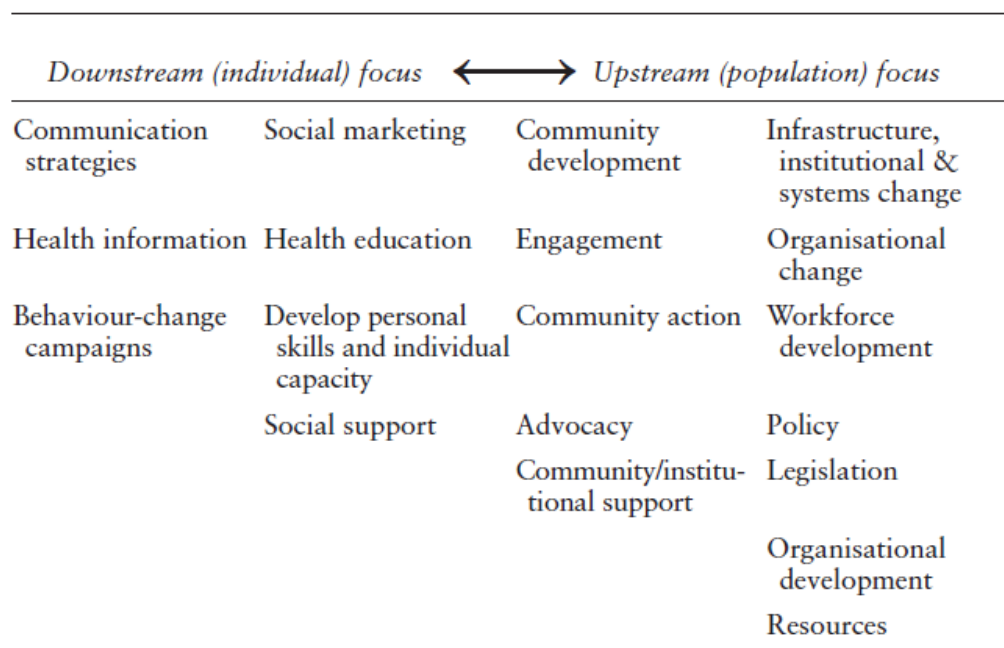
Figure 1.6 Conceptual framework of neonatal health and survival



Source: Målqvist 2011

A study of neonatal mortality in Indonesia also adopted the Mosley and Chen framework, analysing the community level, socio-economic status and proximate determinants using the 2002-2003 Indonesia Demographic and Health Survey (Titaley et al. 2008). This study focuses on macro level proximate determinants rather than micro levels (e.g. mothers, families and communities). Keleher (2010) advocate a focus on individuals, especially women, for developing effective public health interventions to reduce maternal and child deaths. Keleher also suggested that promoting health information to poor women would greatly increase equity relating to their health and wellbeing, including in relation to children.

Figure 1.7 Upstream and Downstream continuum framework for public health interventions

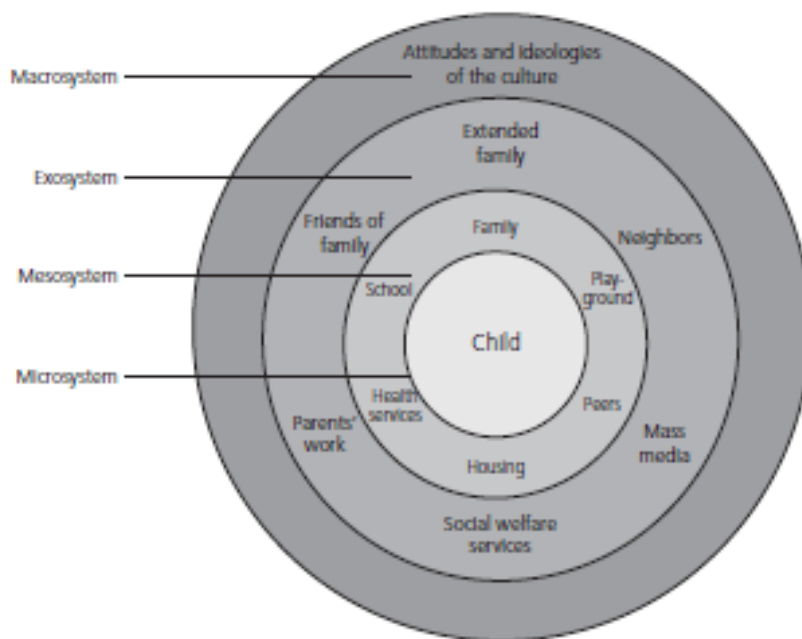


Source: Keheler (2010)

Reifsnider et al. (2005) argued for the use of ecological models for determining health disparities among vulnerable populations, such as mothers and infants. Their argument was adopted from a previous study on children's development by Bronfenbrenner (1977) who claimed that environment and its structure tend to influence the child's development (Figure 1.8). Children's development, including their health and wellbeing, are influenced by

biological, psychosocial and physical factors as part of their ecological environment. The four nested systems that could influence child health in urban areas were Macrosystem (urban environment), Exosystem (Neighborhood), Mesosystem (the parent and child relationship) and Microsystem (housing quality) (Ferguson et al. 2009).

Figure 1.8 Bioecological model of Bronfenbrenner (1977)



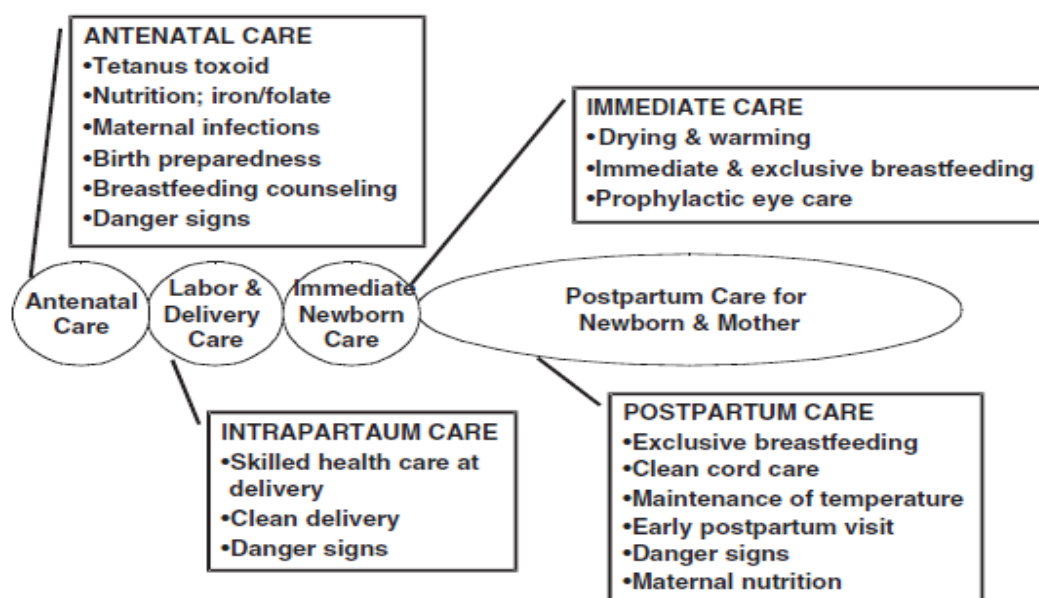
Baranowski et al. (2003) suggested that the social ecological model would be a suitable model for investigating health issues and health behaviour change by exploring the interactions between individuals and its environment. The social ecological model provides more in-depth information for understanding the relationships between individuals' health and their families, communities, health care providers, social organisations and policy environment (local, national and international level) (Ulin et al. 2005).

This model identifies the linkages between individuals and its upstream levels (e.g. communities, health care providers and governments). Similar to Keheler (2010), this framework focuses on the interactions between multiple levels of the population to develop both effective and efficient health promotion programs by exploring the behavioural influences between the individual and his or her community (Ulin et al. 2005). The social ecological model

also provides a specific approach for modifying unhealthy behaviours among individuals to increase community health and well-being (Stokols 1996). This model has been widely used in the study of public health issues, such as child obesity, cancer, chronic illnesses and other community health issues (Schneider and Stokols cited in Shumaker et al. 2009).

The outcome of early-age survival would also be determined mostly by acknowledging the mothers health behaviour during the antenatal period, and delivery and use of postpartum care services as shown in Figure 1.9 (Marsh et al. 2002). Identifying mothers' health behaviour and their knowledge on child health during pregnancy, delivery and after delivery would be fundamental to developing intervention program for reducing the risk of deaths among mothers and infants.

Figure 1.9 The early-age health and survival periods of care



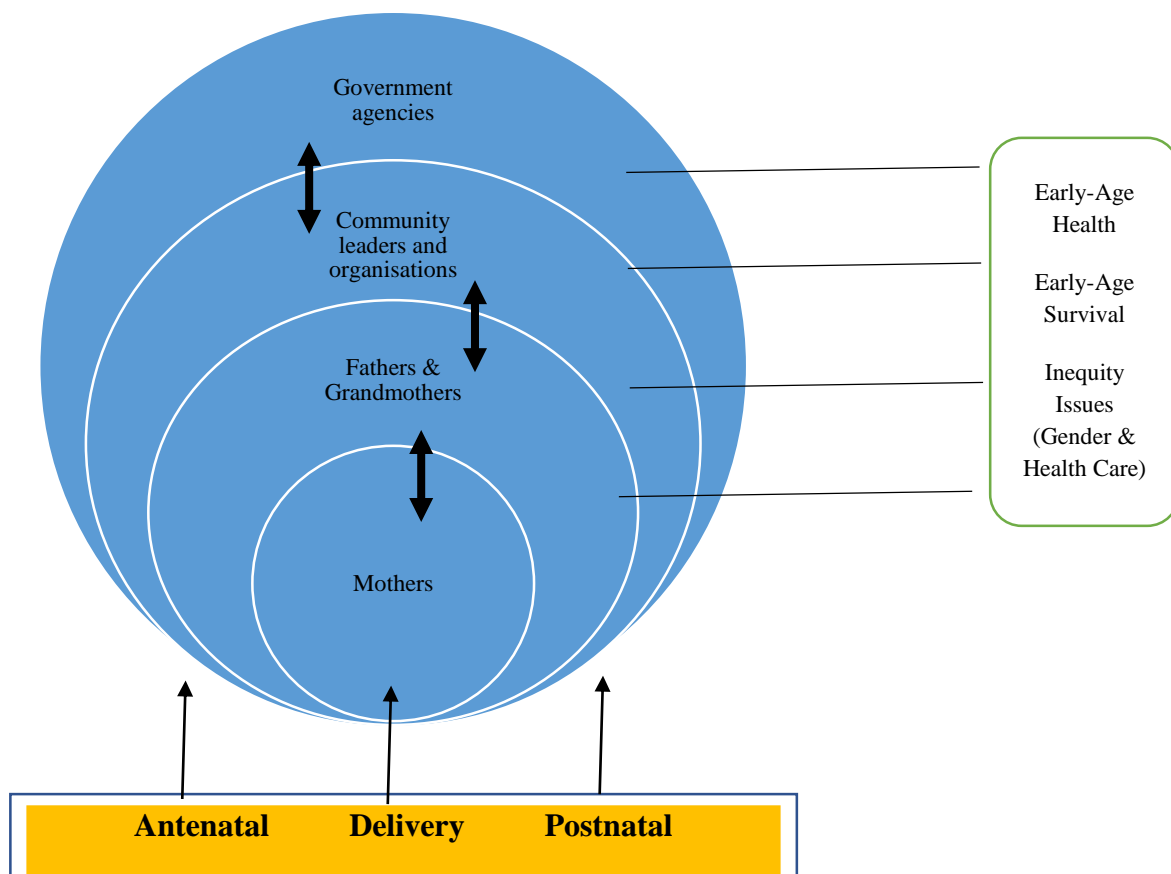
Source: Marsh et al. (2002)

In summary, the social ecological model combines socioeconomic factors along with cultural and social approaches to underlying contributing factors that could influence early-age health, survival and inequity issues in the population.

1.5.2 Conceptual framework

As previously discussed in the literature sections, this thesis focuses on understanding of the demand side relating to early-age health, survival and inequity issues. This thesis applies the social-ecological model by combining the essential periods of maternal and child health as its research framework to identify early-age health, survival and inequity issues. The ecological model has mostly been used to analyse health behaviour and intervention by considering the influences of intrapersonal, interpersonal, institutional, community and policy factors in the population (Sallis and Owen 2008). The focus of this approach is to assess child health and well-being problems that are resulted from multiple factors, such as social values and the environment of the population (Earls and Carlson 2001). This framework includes individuals, families, communities and the government. In addition, it is critical to identify mothers' and families' interactions with other key parts of the population with the purpose of saving infants' lives (Darmstadt et al. 2013).

Figure 1.10. Early-age health, survival and inequity issues research framework



As presented in Figure 1.10, the framework applied in this thesis assumes that early-age health, survival and inequity issues at the sub-national level are influenced by the interactions of various population elements: mothers, families, communities and local government agencies and their interrelations with one another. Each element of the sub-national population has its own roles and responsibilities that may influence early-age health, survival and inequity issues.

As noted earlier in Section 1.2, mothers have less opportunity than their husbands when seeking the appropriate health care during their pregnancy and delivery, yet they also have multiple burdens in the household. The existing literature suggests that fathers' involvement in the health care services during pregnancy and delivery leads to improved childbirth outcomes and infant survival (Beegle et al. 2001; Hill et al. 2004; Tweheyo et al. 2010; Umami and Puspitasari 2007). This could indicate that fathers have a strong influence on their infant's health and wellbeing. Therefore, understanding husbands' interaction with their wives would provide further solution on reducing mothers' burden during pregnancy and delivery and improving better pregnancy outcome.

Local practices and traditional beliefs need to be addressed by promoting continuous health information to parents, the elderly and community leaders. This is mainly to increase their participation in reducing early-age deaths. Studies have shown that increasing local community involvement has prevented early-age deaths among poor populations in rural areas (Haines et al. 2007; Rosato et al. 2008). Furthermore, a community-based intervention program is required to bring mutual benefit between mothers and the community members, including their extended families, to improve maternal and child health outcomes (Bhutta et al. 2005; Lassi et al 2010). If both extended families and community leaders have a better understanding of the importance of their roles and responsibilities for mothers and infant survival, then it will influence also the formulation of local government policies and programs. At the same time, mothers will increase their participation in care-seeking decision and change their health behaviour during pregnancy, delivery and after delivery.

According to Kristiansen and Santoso (2006), the local governments have received more responsibilities for managing their local health policies and programs than the central government. The decentralised system in Indonesia could also provide local-specific policies and programs involving local organisations and leaders. WHO (2008) emphasized the importance of sharing leadership between government and community leaders to ensure effective and efficient health care services, especially for poor populations, to minimize health inequity issues.

The conceptual framework of this study also considers cultural values, knowledge, perspectives, support, involvement and experiences among different levels of population relating to early-age health and survival to be key variables for investigation (see Figure 1.10). In addition, the proposed framework includes essential care services during pregnancy, delivery and post-delivery periods that would be investigated at multiple levels of the rural population. Understanding the interactions between mothers and other levels of population, as shown in Figure 1.10, could inform more depth solutions to reducing early-age deaths and inequity issues by recognizing also the influence of cultural practices, and traditional beliefs. At the same time, this framework would complement the existing evidence on the supply side for rural Indonesia by providing the voice from the demand side.

The application of this framework in this thesis focuses on three levels. Firstly, this study focuses individual level issues relating to early-age health, survival and inequity issues. This thesis also examines the roles and experiences of mothers during their pregnancy, delivery and post-delivery periods (Chapter 2). Secondly, in Chapter 3 fathers and grandmothers are used as representatives at the family level. Considering the family level should provide possible direct and indirect influences on mothers' practices relating to child health and survival, the importance of which is often ignored by health personnel (Darmstadt et al. 2013; Grzywacz and Fuqua 2000; Hill et al. 2004). Chapter 4 focuses on local community and government agencies which are involved in ensuring child health and survival. The participation of community and

government agencies should be taken into account due to their influence on preventing early-age deaths, especially for poor populations (Earls and Carlson 2001; Kerber et al. 2007; Rosato et al. 2008).

1.6 Research Questions

Based on the research background, relevant information on Ende district and the existing literature, this thesis will answer the following research questions:

1. Why Ende's rural region still has a higher early-age death rate than its urban region?
2. To what extent do health and gender inequity issues persist in Ende district?
3. What factors influence early-age health, survival and inequity issues in Ende district?
4. How are mothers involved in their pregnancy, delivery and after delivery care-seeking decisions in their household and communities?
5. Do families in Ende district have an adequate knowledge and sufficient support relating to early-age health and survival?
6. What is the importance of early-age health and survival for Ende's local government?
7. How do local community leaders in Ende district contribute to ensuring early-age health and survival and reducing gender inequity issues?
8. How have the local child survival program and policies influenced early-age health and survival and inequity issues in Ende district?

These questions will be examined in further detail in Chapter 2, 3 and 4.

1.7 Research Objectives

This study has three main research objectives.

1. To explore mothers' knowledge, understanding, and experiences of pregnancy, delivery and early-age survival.
2. To investigate fathers' and grandmothers' knowledge, experiences and involvement with infant health and survival.
3. To examine local government agencies' and community leaders' roles and responsibilities related to local child health programs

These research objectives are discussed further in Chapter 2, 3 and 4 as follows:

1.7.1 Mothers' knowledge, understanding, and experiences of pregnancy, delivery and early-age survival

To address the first research objective Chapter 2 of this study focuses on whether mothers with infant death experience and mothers without infant death experience have adequate knowledge and practices relating to early-age health and survival, especially of basic childhood illnesses and their danger signs. It proceeds with the identification of inequity issues relating to the quality and performance of rural health care services and its personnel between the pre and post-natal periods. The influences of their husbands and extended family members, such as paternal grandmothers, relating to infant health are also considered. The investigation of mothers' personal views and experiences relating to early-age health, mortality and inequity issues is essential to improving the quality of child health care services in rural regions of Indonesia, especially for poor populations.

1.7.2 Fathers' and grandmothers' knowledge, experiences and involvement with infant health and survival

Chapter 3 examines fathers' and grandmothers' roles and responsibilities during pregnancy, delivery, health-seeking behaviour and child raising in order to identify their potential

influences on infant survival. Chapter 3 also illustrates fathers' personal experiences of infant deaths. Fathers' and grandmothers' decision-making power and its influence on gender inequity issues facing mothers is also examined.

1.7.3 Local government agencies' and community leaders' roles and responsibilities related to local child health programs

Local government agencies' and community leaders' roles and responsibilities related to local child health programs are selected to address the third objective of this thesis in Chapter 4. Both government and community leaders' perceptions of child survival, and of gender and health care inequity issues are explored. The focus group discussion method is used.

1.8 Methodology and Sampling

This thesis is based on a qualitative study applying in-depth interviews about early-age health, survival and inequity issues to mothers, fathers and grandmothers and focus group discussions involving local community leaders and government officials. This study uses primary data from both interviews and focus group discussions. Secondary data sources in Ende district and other relevant sources will be used as part of triangulation method in this thesis.

For sampling purposes Ende district was divided into four regions; the North, South, East and West regions. The sub-districts of these regions with highest and the lowest under-five mortality were selected as interview locations, based on Ende District Health Office (EDHO) data between 2010 and 2012. Nangapanda, Ende Timur, Wolojita and Wewaria were the sub-districts with the highest under-five mortality, while Maukaro, Ndona, Ndori and Detusoko were the sub-districts with the lowest under-five mortality. Of these, only Ende Timur is located in an urban area (Table 1.4).

Table 1.4.Sample design, Ende District 2013

Regions of Ende district	Under 5 Mortality Rate (U5MR)	Sub-districts chosen from each region and U5MR	Number of mothers (M) and number of fathers (F) chosen from each sub-district
North	Low U5MR	Detusoko	$(2M + 2F) \times 2 = 4M + 4F$
	HighU5MR	Wewaria	$(2M + 2F) \times 2 = 4M + 4F$
East	Low U5MR	Ndori	$(2M + 2F) \times 2 = 4M + 4F$
	HighU5MR	Wolojita	$(2M + 2F) \times 2 = 4M + 4F$
South	Low U5MR	Ndonga	$(2M + 2F) \times 2 = 4M + 4F$
	HighU5MR	Ende Timur	$(2M + 2F) \times 2 = 4M + 4F$
West	Low U5MR	Maukaro	$(2M + 2F) \times 2 = 4M + 4F$
	HighU5MR	Nangapanda	$(2M + 2F) \times 2 = 4M + 4F$
Total		8 sub-districts	32 (M) + 32 (F)

I selected mothers who had at least one child in the last five years prior to the study's data collection, with equal numbers of mothers who had experienced one or more child deaths over this period and mothers who had not experienced a child death over this period. In the selection of mothers with experience of child deaths, priority was given to selecting those with the most recent child deaths, in order to minimize recall bias. A purposive sampling procedure was applied to select two mothers who had child under-five deaths in the five years prior to the data collection and two without child deaths during this period together with their husbands from each sub-district were targeted for interview. Thus thirty-two pairs of mothers and fathers in total were targeted. The selection of the mother and father informants from each of the selected sub-districts was made using the birth register, which was obtained from a local midwife coordinator (known as *Bidan Koordinator*) from the community health center (CHC) (so-called *Puskesmas*).

All the targeted mothers were successfully interviewed. For the fathers, 15 informants were interviewed in-depth. Fifteen more fathers were absent working in the farm, at sea, or visiting their relatives in the cities, and two fathers declined to be interviewed. Where the father was unavailable or unwilling to be interviewed a grandfather or a grandmother was then approached. None of grandfathers were willing to be interviewed. Five paternal grandmothers were

interviewed as replacements for unavailable fathers. Thus total sample size of the fathers (including replacements) was 20 informants which covered in Chapter 3.

Thirteen participants were involved in two separate focus group discussions. The first group consisted of eight participants from Ende local government departments, and the second group of five community leaders. Purposive sampling was conducted to select participants in this study based on the following criteria: a) being between 18 to 65 years old, b) currently holding a position as a supervisor or higher either in the Ende District Health Office (EDHO), a Social and Women's Empowerment local government agency or a local community organisation, and c) having experiences related to Ende's children's health and survival programs and policies. The participants were chosen to have similar levels of seniority in their respective local government and community hierarchies in order that they could share their views free from the influence of superiors. A field supervisor from EDHO was selected to organise the focus group discussions (FGDs).

The transcriptions of all interviews including the FGD recordings were listened to and checked. Before data collection, in-depth training for the interviewers was conducted to ensure the trustworthiness of the qualitative data and ensure the process for interviewing participants was fully understood. Sessions in the training included; the art of interviewing, interview practices, transcription process, and probing techniques. I also accompanied both interviewers during data collection and checked the interview recordings to ensure all the information had been collected

This study applies open-ended questions. The rationale for using open-ended questions is to obtain more information from the informant by probing the informant's response and allowing the informant to lead the interview. By doing so, this study allowed informants to answer giving their own views, values and experiences without direction. The probing was used to stimulate more detailed information based on the informants' responses. At the same time, the open-

ended questions were intended to create a dynamic discussion and develop trust of the interviewer by the informants (see Appendix I for example case studies).

1.9 Thesis Structure

The remainder of this thesis is structured as follows: *Chapter 2* investigates mothers' pregnancy, delivery and early-age survival experiences in Ende district, Indonesia. This recruited interviewees from mothers who had child deaths as well as mothers without child deaths experiences between 2008 and 2013.

Chapter 3 focuses on fathers' and paternal grandmothers' knowledge and their early-age health and survival experiences in Ende. *Chapter 4* investigates local government agency and community leaders' perspectives on child health, mortality and inequity issues in Ende district. *Chapter 5* provides a summary of the significant findings of this research from the preceding chapters and the related policy implications, the contribution of the present study to the body of knowledge, its limitations and further directions for future research on early-age health and survival and inequity issues at the sub-national level in Indonesia and personal evaluations and reflections from the author.

Chapter 2 Inequity Issues and Mothers' Pregnancy, Delivery and Early-Age Survival Experiences in Ende District, Indonesia

Abstract. Indonesia's infant mortality rates are among the highest in South-East Asia, and there are substantial variations between its sub-national regions. This qualitative study aims to explore early mortality-related health service provision and gender inequity issues based on mothers' pregnancy, delivery and early-age survival experience in Ende district, Nusa Tenggara Timur province. Thirty-two mothers aged 18–45 years old with at least one birth in the previous five years were interviewed in depth in May 2013. The results show most mothers have little knowledge about the danger signs for a child's illness. Mothers with early-age deaths generally did not know the cause of death. Very few mothers had received adequate information on maternal and child health during their antenatal and postnatal visits to the health facility. Some mothers expressed a preference for using a traditional birth attendant, because of their ready availability and the more extensive range of support services they provide, compared with local midwives. Unprofessional attitudes displayed by midwives were reported by several mothers. As elsewhere in Indonesia, the power of health decision-making lies with the husband. Policies aimed at elevating mothers' roles in health care decision-making are discussed as measures that would help to improve early-age survival outcomes. Widening the public health insurance distribution, especially among poorer mothers, and equalising the geographical distribution of midwives and health facilities are recommended to tackle geographical inequities and to increase early-age survival in Ende district.

Keywords: Mothers · Inequity · early-age survival · delivery · mortality · pregnancy ·
Ende · Indonesia

2.1 Introduction

This study aims to provide insights into mothers' pregnancy, delivery and early-age survival experience in Ende district in Nusa Tenggara Timur (NTT) province, Indonesia, highlighting inequity issues. In 2012, the neonatal, infant and under-five mortality rates for South-East Asia as a whole were 15, 17 and 30 deaths per 1000 live births respectively (UNICEF 2013). Early-age mortality rates in Indonesia were above the regional average: Indonesia was ranked seven out of 11 South-East Asian countries for its neonatal, infant and under-five mortality, with rates of 15, 26 and 31 deaths per 1,000 live births respectively (UNICEF 2013). However, there are substantial variations between its sub-national regions, with some having child mortality rates that are well above the global averages (UNDP 2011).

Studies linking child mortality to the use of antenatal care in Indonesia have tended to focus on the quality of care (D'Ambruoso et al. 2009; Ensor et al. 2009; Hatt et al. 2009; Shrestha 2010; Sugiharti and Lestary 2011) and the social determinants of maternal and child health at the national level (Anggorodi 2009; Titaley et al. 2008; Wahab et al. 2001), and have paid less attention to sub-national-level variations. Only a few studies have focused on mothers' knowledge and attitudes to child health, their practices during pregnancy, or their delivery experiences (Adair et al. 2012; Kalsum 2013; Titaley et al. 2010a) and few have investigated the equity of health in Indonesia (Hidayat et al., 2004; Thabrany, 2006; Utomo et al., 2011; Pitriyan & Siregar, 2013). These studies focused on the equity of the health system and the allocation of health resources relating to universal health coverage, and have given less consideration to health-seeking knowledge and practices, experience of health services, and to gender equity in health-related decision-making.

This study aims to address a gap in the literature by presenting qualitative insights into mothers' pregnancy, delivery and early-age survival experiences and identifying health service equity and gender inequity issues for a relatively underdeveloped subnational area of Indonesia, namely Ende district.

Study location

The study was conducted in Ende district, NTT province, one of the eastern provinces of Indonesia. Nusa Tenggara Timur province had relatively high early-age mortality with an infant mortality rate (IMR), neonatal mortality rate (NMR) and under-5 mortality rate (U5MR) of 45, 26 and 58 per thousand live births, respectively (Statistics Indonesia 2013). Geographically, Ende district is divided into highland (65% of the land area) and lowland areas (35%). The total population of Ende district in December 2011 was 261,093 people (EDHO 2012). It has 21 sub-districts and 259 villages, with the most populated sub-districts being South Ende, North Ende, Central Ende and West Ende. Only 5% of Ende's population lived in urban areas. The total fertility rates of Nusa Tenggara Timur province (3.3 according to the 2012 Indonesian Demographic and Health Survey (IDHS)) and of Ende district (2.7 according to 2010 Indonesian Population Census) were both above the national averages (Statistics Indonesia 2013; Statistics Ende District 2013b). In contrast to the national picture, Catholicism was the predominant religion in Ende, with 73% of the population, followed by Islam and Protestantism with 25% and 2% respectively. The major employment sectors were agriculture, trade, tourism and other services (Statistics Ende District 2013a).

Ende's population has relatively poor health, being ranked at 316 out of 500 districts across the country based on the public health development index known as *Indeks Pembangunan Kesehatan Masyarakat* (IPKM) (Ministry of Health 2010a). The life expectancy at birth in 2011 was estimated to be 67.6 years compared with the national and provincial life expectancies of 70.9 and 69.9 years respectively (EDHO 2012; Statistics Nusa Tenggara Timur 2011). Based on the 2012 Ende District Health Office (EDHO) annual report, the top ten diseases among under-five children in Ende were acute respiratory infections, diarrhoea, allergic skin disease, worm disease, skin disease infection, clinical malaria, vivax malaria, vulnus infection, conjunctivitis and pneumonia (EDHO 2012).

In 2009 the NTT Provincial Health Office initiated a maternal and child health program, known as *Revolusi KIA*, which aims to improve maternal, neonatal and child health (MNCH) and to reduce maternal and early-age mortality. This program emphasises the importance of ensuring mothers to give birth at appropriate health facilities. This strategy considers that for births at home there are higher risks of maternal and neonatal deaths, especially for deliveries in the villages, where health care facilities are still insufficient. The issue of mothers' safety is the main reason for promoting childbirth at health-care facilities instead of at home or at non-health facilities, where adequate medical emergency support is often not available (EDHO 2012; NTT Provincial Health Office 2012).

In 2005, the Indonesian government launched a free public health insurance scheme known as *Jaminan Kesehatan Masyarakat (Jamkesmas)* to cover access to primary health care, including maternity and child care at *Puskesmas (community health centre)*, especially for poorer people. However, even after the introduction of this programme, significant geographic shortfalls in the availability and quality of health care, especially for those living in relatively remote and rural locations, have persisted. Poorer people continue to experience lower levels of access to health facilities than the wealthier (Harimurti et al. 2013; Simmonds and Hort 2013). In 2011, a universal maternity benefit, known as *Jaminan Persalinan (Jampersal)*, was implemented to enable all pregnant women to deliver at health facilities (EDHO 2012). However, a lack of dissemination of information about the programme to the community, and inadequate preparedness for implementation of the health district office's and other government agencies' programmes, has limited the effectiveness of the programme (Ministry of Health 2010b).

2.2 Methods

Thirty-two mothers aged 18–45 years with at least one birth in the last five years prior to interview were recruited using purposive sampling. The sample was designed to include an equal number of mothers with a child death, including neonatal, post-neonatal, and under-five deaths, between 2008

and 2013 and mothers without a child death during this period. Where possible either the informant's husband or one of her parents was also interviewed about their experience, knowledge, perceptions and understanding of early-age survival.

2.2.1 Sampling method

Ende district was divided into four regions: the North, South, East and West regions. The informants were selected by targeting the sub-districts with the highest and the lowest under-five mortality, based on advice from the Ende District Health Office (EDHO) and EDHO data between 2010 and 2012. The selected sub-districts with the highest children under-five mortality were Nangapanda, Ende Timur and Wolojita, and Wewaria. Maukaro, Ndonga, Ndori and Detusoko were the selected sub-districts with the lowest child mortality. Of these, the only sub-district located in an urban and lowland area was Ende Timur. From each of the selected sub-districts, four informants, including two who had experienced early-age deaths and two without deaths, were interviewed. The selection of the informants from each sub-district was conducted by checking the sub-district midwife's birth register as a sampling frame, and targeting the latest early-age death cases in order to minimise any recall bias from informants. Responses were obtained from all 32 mothers.

2.2.2 Research questions

This study examines the extent of mother's knowledge about child health and survival influences during pregnancy, delivery and post-delivery, their views on the support provided by health services and their families, and how the experiences of those mothers with early-age deaths reveal health service provision and gender inequity issues that exist in Ende district. In order to assess the mothers' knowledge and experience of pregnancy, childbirth and child death, respondents were asked a wide range of open-ended questions. These included questions relating to the pregnancy and delivery experiences, particularly in relation to the antenatal care received, the type of place of delivery and type of delivery assistance received. The mothers were asked about their children's illnesses, how they identified the signs of illness, their access to health care

services, the types of support they received from their family, the community and the government, and about their participation in traditional ceremonies (see Appendix G). Additional questions probed the experiences of mothers who had delivered with a traditional birth attendant and of mothers who had experienced an early-age death. Information on the birth history and the demographic characteristics of both the mother and her husband was collected from all participants.

2.2.3 Data collection

The data were collected in May 2013. All interviews took place at the interviewee's house, and were conducted using mixed languages (local and *Bahasa Indonesia*) and fully transcribed into *Bahasa Indonesia*, except for important indigenous terms. The interviews lasted up to 60 minutes with an average of 40 minutes. Local terms used by participants in the interviews have been translated and explained in the narrative. After the initial stage of analysis, all transcripts were translated into English, using a professional English translation service. Photos of each participant's house condition were taken, with their consent. The photographs of participants' homes were used in the analysis to provide additional information regarding participants' socio-economic conditions (see Appendix E).

2.2.4 Data analysis

For the purpose of analysis, the study used an anonymous code for each participant without any specific information that could reveal their identity. A theme-based approach (thematic analysis) was applied. After transcription, a coding framework, using *a priori* themes, such as 'inequity issues' and 'community health quality of care' and other possible themes that emerged during the thematic framework process, was applied. Then, indexing by applying either numerical or textual codes was conducted, following a thematic chart. Finally, connections, patterns and further implications were identified in order to develop interpretations.

Triangulation was applied using multiple sources, especially from EDHO data between 2008 and 2013, local laws/acts. In addition, Indonesian Ministry of Health (MOH) reports related to

child health and survival was applied in order to improve the objectivity and internal validity of the project (Hansen, 2006). Ethical clearance was obtained from Macquarie University and the National Institute of Health Research and Development (NIHRD), Ministry of Health, Indonesia (see Appendices C and D).

2.3 Results

Table 2.1 presents the demographic characteristics of the mothers, and disaggregated figures for the mothers with experience of early-age deaths and for those without such experience. Only fifteen husbands participated in this study, and five mothers or mothers-in-laws were interviewed in place of husbands. For ten of the remaining families, no other relative could be interviewed, because at the time of interview they were working on the farm, visiting other cities, working in another city/province/country or studying in another city. For the remaining two families, the relatives declined to be interviewed. The modal age group of mother was 30–34 years (43.8%). Just over one-third (37.5%) of the mothers had completed junior high school or passed year 9. Most of the mothers were not working (81.3%), and most (87.5%) lived in rural areas.

Similar to the mothers, almost half the husbands were 30–34 years old. Over a third of the responding husbands had completed senior high school (37.5%) or passed Year 12. The most common occupations of responding husbands were farmer (34.4%) and fisherman (31.3%).

The mothers with early-age death experience were more likely to have junior high school education or below than those without early-age deaths. Only one mother with early-age death had academy level education, compared with 25% of mothers without early-age deaths. Similarly, husbands with early-age deaths had lower levels of highest education than those without early-age deaths. Almost all mothers without early-age deaths were housewives, whilst a significant minority of those with early-age deaths worked on the farm or helped with fishing activities, a pattern that could indicate difficult financial circumstances (Table 2.1).

In total, 47 births were delivered between 2008 and 2013 to the women in the study (Table 2.2). Most of the deliveries took place at health facilities, such as *Puskesmas*. Seven births were

delivered at home, all of which were assisted by traditional birth attendants (TBAs). The proportion of home deliveries that resulted in neonatal deaths (57.1%) was much higher than the proportion of births at health facilities that did so (15.0%). In this study, neonatal death refers to deaths during the first 28 days of life and post-neonatal death refers to those that occur between 28 days of life and one year. Of the sixteen early-age deaths among the responding mothers, ten were neonatal deaths and the remainders were post-neonatal deaths. Six early-age deaths occurred at home and the remaining ten at a health facility. Analysis of the qualitative data from mothers identified the following seven major themes.

Table 2.1. Demographic characteristics of mothers with and without early-age deaths and other household informants, Ende District, 2013

Characteristics	With early-age deaths		Without early-age deaths		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
All mothers	16	100	16	100	32	100
Mother's age (years)						
18–24	2	12.5	3	18.8	5	15.6
25–29	3	18.8	8	18.8	6	18.8
30–34	6	37.5	1	50.0	14	43.8
35–39	4	25.0	1	6.3	5	15.6
40–44	1	6.3	1	6.3	2	6.2
Mother's highest education						
Primary school	4	25.0	4	25.0	8	25.0
Junior high school	7	43.8	5	31.3	12	37.5
Senior high school	4	25.0	3	18.8	7	21.9
Academy/university	1	6.2	4	25.0	5	15.6
Mother's occupation						
Fishing	1	6.2	0	0.0	1	3.1
Farmer	2	12.5	1	6.2	3	9.4
Private worker	1	6.2	0	0.0	1	3.1
Government employee	1	6.2	0	0.0	1	3.1
Other (housewives)	11	68.8	15	93.8	26	81.3
Place of residence						
Urban	2	12.5	2	12.5	4	12.5
Rural	14	87.5	14	87.5	28	87.5
Husband's age (years)						
18–24	2	12.5	0	0.0	2	6.3
25–29	2	12.5	3	18.8	5	15.6
30–34	4	25.0	9	56.3	13	40.6
35–39	6	37.5	2	12.5	8	25.0
40–44	1	6.3	1	6.3	2	6.3
≥45	1	6.3	1	6.3	2	6.3
Husband's highest education						
Primary school	6	37.5	4	25.0	10	31.2
Junior high school	5	31.3	3	18.8	8	25.0
Senior high school	5	31.3	7	43.8	12	37.5
Academy/university	0	0.0	2	12.5	2	6.3
Husband's occupation						
Fisherman	6	37.5	4	25.0	10	31.3
Farmer	4	25.0	7	43.8	11	34.4
Private worker	0	0.0	2	12.5	2	6.2
Government employee	1	6.3	2	12.5	3	9.4
Motorcycle taxi	2	12.5	0	0.0	2	6.2
Other	3	18.8	1	6.3	4	12.5

Source: Pardosi et al. 2015

Table 2.2. Health-related variables for labour and early-age survival by mother's birth history, Ende District, 2013

Variables	<i>n</i>
Type of place of delivery	
Home	7
Health facility	40
Total deliveries	47
Early-age deaths	
Neonatal	10
Post-neonatal	6
Total	16
Place of early-age deaths	
Neonatal	
Home	4
Health facility	6
Post-neonatal	
Home	2
Health facility	4

Source: Pardosi et al. 2015

Pregnancy and delivery experience

Pregnancy checks were made at *Puskesmas*, *poskesdes* (village health post) or other health facilities. Several women reported that they felt happy and thankful once the midwife confirmed their pregnancy, and had told their pregnancy result to their husband and family members. Several reported the pregnancy test was conducted at the health center between two and five months after their last period.

Most mothers explained that they experienced nausea, vomiting, dizziness, feeling unwell, weak and lethargy as signs of early pregnancy. One woman was hospitalised at an early stage of pregnancy and decided not to have another child after considering her health condition:

I realised I was pregnant for the second time when it reached two months, then I visited the midwife at Puskesmas. I experienced regular morning sickness over and over, and even worse I was admitted to the hospital. I stayed in the hospital for one week, after that I was released from hospital, but I was admitted to hospital again. I had a problem with gastric ulcer and malaria, so that's probably the reason for me always vomiting. In fact, when I was giving birth, I threw up first, after that my child was born. (Mother, 32-year-old, E1)

The Indonesian Ministry of Health recommends that at least four visits are made during a pregnancy, with at least one visit during each of the first and second trimesters and two visits in

the third trimester. This is mainly to prevent possible risks and complications during pregnancy, and also to monitor the fetal growth (Ministry of Health 2010c). Most mothers in the study had routine pregnancy visits at health-based facilities such as *Puskesmas* and almost all had their pregnancy checked at least twice a month by a midwife. The numbers of antenatal care (ANC) visits varied between four and nine. None of the mothers who complied with the Ministry of Health recommendations had experienced neonatal deaths. However, some mothers whose ANC visits were irregularly spaced over the pregnancy did so. The mothers with higher education had more antenatal visits on average than those with lower education. The frequency of antenatal visits differed by birth order. Some mothers visited a midwife more often for their second or third pregnancy compared with the first pregnancy, while others reported more antenatal visits for the first pregnancy than for the second or third pregnancies:

My first pregnancy was five times and the second one was seven times for antenatal visit. (Mother, 22-year-old, E8)

A few mothers understood the importance of visiting *Puskesmas* during their pregnancy. One expressed a belief that visiting a midwife regularly at the community health center (CHC) would prevent a repeat of the health problems that occurred in her previous pregnancy:

I checked my pregnancy more often than before. I checked my previous pregnancy regularly, but this one was more more often. Because I was afraid that something will happen like my previous child if I did not visit midwife regularly (Mother, 33-year-old, E6)

Some mothers said that midwives had not fully checked their pregnancy and had provided them with insufficient information. They also felt there was a lack of attention from the midwives, and that they had not provided them with enough time to discuss their pregnancy experience:

The midwife never explained about my pregnancy during the antenatal visit, never... (Mother, 28-year-old, E23)

Midwife usually checked my weight, touched my belly, took a blood test but she never told me about the result. (Mother, 33-year-old, E2)

Most mothers showed a high level of awareness of the importance of giving birth at the CHC and assisted by health personnel. Midwives were the main birth assistants for most women, followed by doctors, nurses and TBAs. Some mothers gave birth at a hospital or a private clinic. However, most women chose the *Puskesmas* as the place for delivery.

In certain cases midwives referred mothers to higher health care levels, such as Ende District Hospital (RSUD). Most of these cases involved Caesarean operations or complications during pregnancy or deliveries that needed to be handled by an obstetrician. One informant said that Ende District Hospital would be the best place for the delivery, because it had well supported health facilities and had enough doctors. This informant felt more comfortable delivering at a public hospital. She said that if unexpected things happened, then the hospital would ensure adequate emergency treatment to prevent death to the mother or the baby, especially for a late delivery:

I went to Puskesmas when I was in labour with my first child, but when I was in labour with my second child, I went to Rumah Sakit Umum Ende, because the baby was two weeks late. If you are giving birth in the hospital and you are bleeding, you can be admitted to a public hospital or maybe there is another way to solve that problem. If you are giving birth with a midwife or TBA in the village, and you are bleeding, they will give you a certain herbs, then if it does not work, you must be run out of blood and die. (Mother, 32-year-old, E1)

Since the 1990s the Indonesian government has operated a village midwife program, which is intended to replace the use of TBAs. However, seven respondents experienced a home delivery and were helped by a TBA. The neonatal death rate was much higher for this group than for those who gave birth at a health facility. The mothers who used TBAs for delivery, rather than health personnel and health services, gave a range of reasons for their doing so including: economic problems, the long distance to reach *Puskesmas*, a lack of health facilities such as *poskesdes*, and their family history. Some mothers explained that they visited the TBA because they had experienced bleeding or other health-related problems. The following quote illustrates this:

I chose to go to the traditional birth attendant because the bleeding stopped when I was massaged by the traditional birth attendant. But not permanently. It happened again. I think it was just pain, not the term yet. It was a seven months' pregnancy. I thought I was at term, I thought the baby was about to deliver, what people say

contractions. I called the traditional birth attendant to give me a massage on my back. But suddenly I delivered the baby. (Mother, 28-year-old, E23)

One informant gave birth with a TBA, because the village midwife did not live in her official government-provided house in the village known as *rumah dinas*. This mother tried to call the midwife but she did not respond, so this informant decided to call a TBA who lived nearby her house:

I gave birth at 2.30 am. We had called the midwife but she did not stay in her official house. I called, but she didn't sleep there, she came in the morning. I called a TBA and she assisted me with my delivery at my home... (Mother, 32-year-old, E18)

Another mother decided to ask a TBA to assist her with the delivery process and delivered at home, because her husband was away working on the farm. This informant explained that initially she was planning to give birth at the *Puskesmas* but the baby arrived unexpectedly:

In the morning, I was selecting corn to be cooked, after that I felt sick, no one was there, everyone went to receive the education report, and my husband was on the farm. I cooked the corn because we as Lio people like to eat corn. When I arrived here [home], I was so sick. I entered home and I was alone. When the baby was in the process of delivery, I screamed to my neighbours and my neighbours came. Our traditional birth attendant helped me. I wanted to give birth in Puskesmas, but suddenly the time arrived, how could I? (Mother, 37-year-old, E20)

This mother shows her regret for not giving birth at a health facility. However, with her condition, she had no other option available other than a TBA. She was unaware of the normal 9 months term of pregnancy.

A majority of the respondents had visited TBAs. However, this was only to be massaged due to back pain. Some mothers preferred childbirth using TBAs because they were family relatives and no fees applied. However, some mothers voluntarily gave the TBA food or even transport fees. The following quotes provide illustrations:

My sister is a traditional birth attendant so I didn't need to pay her. (Mother, 37-year-old, E7)

We did not give her money. It was free because we have [a] close family relationship. It depends on us, if we care for her. The TBA never asked for money. (Mother, 33-year-old, E6)

An advantage of using TBAs that several women reported was that most are available 24/7, in contrast to village midwives or health personnel who usually work 6 days a week from 7 am to 4 pm. Other participants saw delivery at CHC and assisted by a midwife as the best and safest option, due to the availability of medical equipment and drugs:

The midwife's service is better. Giving birth in the Puskesmas is better. Because when we give birth and our baby does not breathe, they can help by giving the oxygen or another way. They can think of another way to help the baby. (Mother, 33-year-old, E6)

I think midwife is better because the medicine is guaranteed, I compare it with my first child in the home. Maybe my condition was not too good, until the two months I got my health better. And the second child, because of the medicine, the medicine from midwife, so that my condition got better faster. (Mother, 31-year-old, E19)

The mothers who gave birth at home assisted by a TBA all came from the less developed East, West and North regions. These informants mostly lived in villages with poor housing conditions and poor road conditions, and their husbands were either fishermen or farmers. Several women had preferred TBAs over midwives because they feared that there would be costs if they delivered at the health facility. This finding points to a lack of suitable information on fees among mothers, especially for young mothers with low socioeconomic conditions. In the words of one mother:

...all childbirth with traditional birth attendant. At that time, our life was so difficult financially. So, I laboured in the house. I am afraid if I deliver at Puskesmas, there will be money that I have to pay. (Mother, 32-year-old, E7)

Health personnel's attitudes during pregnancy and delivery

Inappropriate or discomforting attitudes of health personnel towards mothers during pregnancy and, especially, during delivery, were reported by several mothers. For example, one mother reported that during her delivery in a public hospital, she was being yelled at by the midwife because she complained about her pain. She believed that midwives should be patient and should comfort mothers during delivery. This informant had her delivery without any help from the midwives:

Midwife yelled at me and said that I was sloppy, but I really really thought I was painful. I know how it felt when I was delivering my first child. The midwife was getting angry and yelling at me. She said the dilation was not enough to give birth. I told her that it was so painful, and even though I tried to change position in bed, I still felt the pain. At 5 am they brought me to the delivery room, but there was no one there only my husband accompanied and hugged me because it was so painful. Suddenly, the baby came out and my husband looked for a midwife. (Mother, 32-year-old, E1)

A few mothers expressed their disappointment about midwife unavailability at community health centres (CHCs). The Indonesian government has operated its village midwife (*Bidan Desa*) program since 1990 to ensure the accessibility of maternal and child health program for all mothers (Frankenberg et al., 2005). Several of the mothers said they thought that midwives should live in *Puskesmas* or in their village.

Mother's knowledge of child health and determinants of survival

Most of the mothers, even those with larger numbers of children, displayed a lack of knowledge of the signs for identifying childhood illness, other than fever. One reason for this is that during antenatal visits, they did not receive enough explanation from midwives about the 'do's and don'ts' during pregnancy and the signs of illness. Almost all mothers suggested that midwives should give more information during antenatal visits and that there should be continuous maternal and child health (MCH) promotion, especially of information relating to early-age survival. The following quote is an example:

...never received any information about baby health from midwives. They just said that the baby's weight decreased. (Mother, 33-year-old, E2)

The mothers who did identify the signs of illness once they felt sick usually took preventive action by giving medicines and immediately taking their child to the closest health facility. Most mothers could identify a high fever as an early warning sign for child illness. However, in some cases a lack of awareness of their child's health condition resulted in mortality:

...when the baby was sick, the baby was just crying all the times. I did not know whether my baby was sick or not whether my baby was just crying a lot. (Mother, 33-year-old, E2)

...I know a little, just if they are sick, the body gets a fever. (Mother, 33-year-old, E9)

Some women reported giving paracetamol to their toddlers if one or two of these signs were observed, as illustrated by the following quote:

Emm, for the toddler, maybe if they got a high fever, I was afraid it become stiff or convulsions so I prepared paracetamol at home to decrease the body temperature. Diarrhoea and vomiting really scared me. (Mother, 31-year-old, E28)

One informant said that she learned from the maternal and child book (*Buku KIA*) about the signs of childhood illness but she only mentioned two signs:

I read from KIA book. hehehe [laughing], ih maybe like the high fever and, eih I forget it, what else, I forget it,...hihihi [laughing], the feet swollen, I forget the name, anaemia, ha I forget the others. (Mother, 32-year-old, E29)

Cough and fever were the two most common child illnesses mentioned by the participants, a pattern which reflects acute respiratory infections being one of the most prevalent illnesses among under-five children (EDHO, 2012). Two mothers replied:

Yes, they usually had cough, flu and fever. I bought medicine from a local drugs store. If they have it more than 2 days, I took them to Puskesmas. (Mother, 22-year-old, E8)
I visited the Puskesmas twice because my baby had fever and cough. (Mother, 39-year-old, E13)

Most of the mothers in this study lived in houses where conditions were not conducive to child health, with many having inadequately ventilated kitchens. Thus, when these mothers cooked, the smoke was inhaled by their children, particularly when they were sleeping in the morning or afternoon.

Health-seeking behaviour

Almost all the mothers reported taking their child to *Puskesmas pembantu* (community health sub-centre), *Puskesmas*, a doctor's clinic or hospital, even when it only had a fever or a cough. However, prior to doing so most relied on local traditions when taking action for their child's

illness. For example, one informant mentioned that she had administered traditional remedies, such as mixing lemon with soy sauce, as first-aid before visiting a health facility:

Just the usual sickness, like flu and diarrhoea. I just took my children to Puskesmas to check. (Mother, 32-year-old, E7)

Yes, they did, cough and flu. If they have it more than 2 days, I took them to Puskesmas. Usually, I give them traditional medicine, like lemon mixed with soy sauce. And the quantity is different; my youngest child was given half a spoon and the oldest got one spoon. (Mother, 22-year-old, E8)

A few mothers reported using medicines from street vendors. Some informants reported their children never became sick, and attributed this to their giving their child massage as a preventative measure. One said:

... from birth until now, my son has never been sick. If I sense that he might experience falling down, I will massage him, massage their chest. (Mother, 32-year-old, E1)

Several of the mothers expressed a preference for using traditional massage for their child illness as an early treatment, for example:

For 3 or 4 nights, I brought my baby to be massaged by TBA and she bathed my baby with coconut water to make the baby stop crying. (Mother, 25-year-old, E3)

Sometimes I discuss with my husband, bring them to someone who can handle the illness, such as a TBA. She will massage my child. (Mother, 32-year-old, E1)

Access to, and experience of, child health services

Most of the mothers reported their current health services were adequate, and some even agreed that they provided a good service. However, there were some suggestions of inequality in the distribution and delivery of essential medicines, public health insurance (*Jamkesmas*) and health care to the community. The CHCs were reported to have been unresponsive in addressing long waiting times to receive health services and to have poor sanitary conditions, for example, unhygienic toilets.

Several women mentioned their house's distance to *Puskesmas* and a lack of health personnel availability, especially of doctors, as inadequacies in the health care service provision. The most

common response from mothers was that, on average, the distance to the closest government health facility was between 5 and 20 minutes, and that they used either a motorcycle taxi (*ojek*) or walked there. However, a few informants reported that they had to walk between 30 and 60 minutes:

...just half an hour, yeah walk, through short cut, yeah walk. (Mother, 39-year-old, E13)

If I walk, it takes me about one hour. (Mother, 41-year-old, E22)

...one hour for me to walk about 2 kilometres. (Mother, 31-year-old, E17)

Mothers from the more remote East, West and North regions were more likely to have had difficulties accessing *Puskesmas* during delivery and emergency treatment for childhood illness than those in the Central region. There were reports of a lack of awareness and fairness in the provision of health-related information, checks and facilities and in actively checking health, and reports that the information given by health personnel was only partially absorbed:

The village government who handles public health insurance matter is misinterpretating the condition in this place. In fact, this place also belongs to poor people. Those who haven't got public health insurance... It means the government is not fair enough. For Puskesmas service, I have to wait until two or three hours and then go back at three o'clock in the afternoon and then came home. The waiting time is too long... (Mother, 32-year-old, E1)

...my suggestion, we don't have posyandu [integrated health post] here, please make it here and also toilet. We need it. (Mother, 31-year-old, E17)

Most mothers kept the maternal and child health book, known as *Buku KIA*, in their home. However, some mothers said that their MCH book was held by a midwife or by health volunteers (*kader kesehatan*). Such cases are contrary to the recommended practice that MCH books should be kept by the mothers. One informant mentioned that she read the MCH book regularly in order to understand her children's health and survival:

Yes, even when I want to sleep, I read that book [MCH book] first. (Mother, 33-year-old, E2)

Some mothers reported that their infant or toddler had already received a complete set of immunisations, while others admitted that their children had incomplete immunisation. These

mothers were probed to understand the reasons for incomplete immunisation. However, most were either unable or unwilling to answer the question. The interviewers also validated an informant's answers by checking the MCH book and the children's health cards (*Kartu Menuju Sehat*). For mothers who experienced neonatal deaths, invariably there was no information in the MCH book about immunisation.

Contrary to common practice, one informant said that she had to pay a certain amount of money for checking her baby's weight, and this made her unwilling to visit child health services:

...and if we want to weigh our kids or for immunisation, we must pay a thousand rupiahs [equal with 0.08 US\$]. (Mother, 31-year-old, E17)

Some mothers criticised the delivery room conditions in *Puskesmas*. They felt uncomfortable during antenatal visits or about delivery in a room that only used curtains, which all sorts of people could easily open without permission and see inside. This made them feel dissatisfied with the CHC service:

Yes. Because when we are going to give birth, I am afraid people in my left or right side accidentally open the curtain. If the curtain is opened we feel so awkward. (Mother, 33-year-old, E6)

And also they open and close the door when we are giving birth, their kids also enter the antenatal room, the men too, we do not feel comfortable, please give a door for the antenatal room because when the midwife checked my tummy, people can just enter. So we don't feel comfortable. (Mother, 31-year-old, E17)

Early-age death experience

The women who had experienced one or more neonatal deaths had lower levels of utilisation of health services than those without neonatal deaths. A majority of the mothers with neonatal deaths had made only irregular visits to the CHC. Home delivery with TBAs was more common among mothers with newborn deaths than among those without newborn deaths, and most mothers who had experienced early-age death did not have access to *Jamkesmas*.

A lack of health knowledge was common. Most mothers who had experienced a neonatal death did not know the cause of death. Mothers tended to recognise their child's condition from signs

such as cough, flu, crying a lot or difficulty breathing. If such signs were observed, some mothers called or visited TBAs to massage the child. Others took their infants to *Puskesmas* or to hospital, which in most cases did not help, because they arrived there too late to save the child. Some women believed their infant had not had any health problems and had not received any explanation from the midwives or other health personnel as to why it had died:

*...I did not know, midwife never told me what kind of sickness happened to my baby.
(Mother, 24-year-old, E10)*

...I did not understand why my baby died. (Mother, 32-year-old, E7)

Several mothers were either unable or unwilling to provide information about the cause of death. Most mothers who experienced early-age death said that nothing unusual happened to their baby before and after delivery. They believed that the cause of death was a common sickness, such as flu or a fever. However, one informant reported her baby died because the baby was born with intestines outside her body, a condition known as *Gastroschisis* (birth defect). This baby was born at *Puskesmas* and referred to Ende District Hospital. Another mother's baby died because it drank her amniotic fluid, an explanation she eventually received from Ende hospital's health personnel, but had not been given earlier by the midwife. A third informant reported that her baby died because of diarrhoea after several days without any emergency treatment. She acknowledged her fault in not taking her baby to the closest health facility, which was due to her preference to use traditional medicines, such as red onions, for her baby. As a result, she arrived too late for the doctors at Ende District Hospital to save her child:

...just diarrhoea. Yes, more than three times a day. It started on Saturday until Tuesday. I did not bring my baby to Puskesmas. It was my negligence. Just diarrhoea, no cry. He still moved actively and had no blood in his faeces. I just rubbed his stomach with onions (Mother, 27-year-old, E30)

In several cases treatment at the health facility by the health personnel was received late. The next narrative shows a mother's experience of late action from midwives, because they had to wait for the doctor's instructions. Whilst for certain emergency situations midwives should wait for the

doctor's suggestions, in this case the baby's infusion fell off, a problem that is considered a basic matter that nurses can address without necessarily needing a doctor's instructions:

At dawn when I was sleeping the infusion fell from my baby's wrist, and then my husband, without waking me up, asked the help from the nurse to put back the infusion bottle. Unfortunately, they asked my husband to wait for the doctor. So my baby was without the infusion from five o'clock but the staff behaved as if nothing went wrong. I was very shocked when I saw my baby's face turned pale and her skin was so cold. Again I asked them to give her infusion but they just replied to me saying that I should put herbal oil to her. I rubbed her body with oil while my husband took hot water from the pot. I told them about the condition of my baby but they didn't reply. (Mother, 40-year-old, E32)

This informant also reported ignorance among the hospital nurses and their lack of skills in handling infusion:

I asked for help from a nurse who was on the night shift, she was about to leave the hospital at that time. I asked her because nobody wanted to help my baby. She came and rubbed my baby, and I asked her whether there was a doctor who could do something but she said the doctor would come after 8 am. We waited but the doctor didn't appear until after 8. When my baby's condition was getting worse, everybody called here and there, tried to give infusion to her but nothing worked. They tried for more than twenty times to give infusion but could not find the arteries. I asked them not to press my baby's body that way. I thought that time that if it was not possible to help her, I would give up because nobody cared for my baby, whose condition was bad without the infusion from dawn. (Mother, 40-year-old, E32)

Other mothers reported that after the delivery their baby was placed in an incubator for between two and seven days without any explanation being received from nurses or midwives. The unavailability of health personnel was also mentioned by some informants. One said that when she visited the closest *Puskesmas*, because her baby was in a serious condition, the *Puskesmas* health staff told her to go back home because there was no doctor available. This informant went to another health facility and similarly the doctor was not available:

...the medical staff said that the doctor was not available. The doctor went to Jakarta yesterday and the staff told me to go home. Then, I went home, and the motorcycle rider said that we had to go to other local hospital, because the doctor was available. When I arrived at the hospital's gate, the staff asked who was going to get a treatment. Then, I said my child. Then, the staff said they could not handle a kid because the doctor was not available as well. (Mother, 37-year-old, E15)

This quote suggests a strong effort was made by both the mother and her husband to save their baby. They decided to go to *Puskesmas W* and were instructed by the midwife to bring the baby to Ende District Hospital, despite the baby's serious illness without any precautionary treatment. Once they arrived at Ende hospital, one of the mother's parents had to call the paediatrician for an emergency treatment. Afterwards this mother said that the doctor felt very angry, because the referral given by the *Puskesmas W* midwife was inappropriate, and that the midwife should have first given adequate treatment to prevent further illness:

The doctor said the midwife was stupid, she should not admit her to Ende, given her critical condition. The doctor told that the midwife in Puskesmas W should give us a suggestion, so we did not have to go to Ende in the middle of the night because it was too dangerous for the baby's health. (Mother, 37-year-old, E15)

This informant experienced her baby's death at the hospital after several treatments administered by the doctors and the health personnel. No explanations were given about her baby's sickness from the previous *Puskesmas*; the only explanation was provided by the Ende hospital personnel. The baby died because of a brain inflammation, so-called *encephalitis*, which is caused by bacterial infection. Another quote suggests an informant felt really disappointed about doctor unavailability while her baby was in a serious condition. This informant suggested to the midwives that they administer early treatment to her baby:

...so we brought him to Puskesmas, and at that time we saw that the doctor wasn't there, so I said it was so sad that the doctor wasn't there, but because the midwives checked him, I said to them to prevent any dangerous thing about the mucus in his throat or tried to see his breath or his navel. (Mother, 31-year-old, E17)

A few informants showed fatalistic attitudes, saying that their baby died as part of God's destiny and they had surrendered it to God.

Not really, maybe it's just a destiny of the baby (laughing). God wanted to take my baby (laughing). (Mother, 28-year-old, E4)

At one until two o'clock in the morning, there was some white and green foam coming out from her mouth. I called my husband and said if God wanted my child to be like this, we had to surrender everything to Him. (Mother, 37-year-old, E15)

Family and community support for child health and survival

Most mothers agreed that during pregnancy their husband, relatives and mothers-in-law gave them full support. Several said that their family advised them to check their pregnancy at a health facility and gave them advice. Some also said that their husband preferred traditional medicine as the first treatment or called TBAs rather than the health facility during the pregnancy. The husbands provided a range of different forms of support, for example, reminding them to do activities with less work, providing money, giving motivation, praying for them, advising them not to take a bath at night but to eat nutritious food, and accompanying them to the health facility. As one mother reported:

...frequently my husband told me to go to the Puskesmas, check pregnancy regularly, walk carefully, take good care of my health, just like that. My husband also accompanied me, washed clothes, cooked but both my husband and family relatives made health decision. (Mother, 22-year-old, E14)

Most women agreed that their husband could be described as *suami siaga*, a term that means ‘always ready and aware at any time of delivery’. Almost all women reported that their husband held the power for making health decisions in the family and most only followed their husband’s decisions. However, some informants said that they always had opportunities for discussion with their husband when making health decisions. In the words of one mother:

Yes, my husband did not insist on having me to cook, wash, or other things. The important thing was that I had to take a rest. My husband and other family reminded me to go to Puskesmas. I went to Puskesmas with my husband. The decision was made together. (Mother, 33-year-old, E12)

Almost all mothers said they did not have the power to decide on care-seeking at health facilities, but that such decisions were made by fathers. A few infant deaths were reported to be a consequence of delays in care sought by husbands. Some responses indicated important sources of advice beyond health care personnel and family. For example, one informant stated that she learned more information about childhood survival from her neighbours than from the midwife,

while another informant reported the only up-to-date maternal and child health information received came from a health volunteer during the integrated health post service (*posyandu*):

...em, what, I got more information from my neighbours. They said that the midwife told them [the informant neighbours] to care the baby nicely, taking a bath, giving massage, like that. (Mother, 31-year-old, E17)

I haven't received any information about the child health. Sometimes health volunteer gives it every day. Every time I go to posyandu, she gives information and socialisation. (Mother, 31-year-old, E17)

2.4 Discussion

This study identifies a range of concerns relating to mothers' child health-related knowledge, health care accessibility and delivery, and attitudes of health care personnel, all of which may contribute to the continuation of relatively high child mortality rates in this underdeveloped district of Indonesia. Significant levels of use of traditional birth attendants and traditional remedies continue. Geographical and gender inequities and poor housing conditions further serve to promote adverse child health and survival outcomes.

The findings point to an ongoing need for improved health education for mothers. Almost all mothers reported that they had not received enough information during their antenatal visits and childbirth process from midwives or other health personnel. In several newborn death cases, mothers did not know and were not informed of the cause of death. This points to a lack of information including counselling services given by the health staff (Andajani-Sutjahjo and Manderson 2004; Hoque et al. 2012; Phipps et al. 2009). The importance of education on the need for suitable housing conditions, particularly adequately ventilated kitchens, is apparent from the observations of this study. In some cases, mothers experienced difficulty in making health-care-seeking decisions, possibly to the detriment of the child's health or even survival, because they needed to gain their husband's approval for a course of action. Thus, fathers too have potentially important needs for child health information in this community where decision-making remains male dominated. A greater involvement of both the father and the mother in health education

programs has been found to increase the number of antenatal visits and change their health behaviour towards child health (Ellis et al. 2013; Mullany et al. 2007; Tweheyo et al. 2010).

Although a majority of the informants gave birth at health facilities with midwives, a significant minority gave birth at home with the assistance of a TBA. This is a concern in view of the much higher neonatal mortality risk associated with TBA-assisted home births (Djaja and Soemantri 2003; Shrestha 2010). This study demonstrates a range of reasons why some in the community still favour using TBAs to help with the birth process, with financial difficulties, midwife unavailability, midwives' lack of professionalism, distance issues and TBAs being family members or respected elders in the community, being some of the reasons why mothers do not deliver with midwives at the closest health facility. This pattern is consistent with studies in West Java Province and Kendari and Cirebon districts (Anggorodi 2009; Titaley et al. 2010). This present study identifies education on the free availability of midwife services as a measure that should reduce the reliance on TBA-assisted delivery. It also illustrates how TBAs not only help the mother with the delivery but also help to take care of both mother and baby after the birth.

The Indonesian Ministry of Health has recommended that all district health offices should try to improve the ongoing partnership between midwives and TBAs, including provision of training, in order to reduce neonatal and maternal mortality (Ministry of Health 2012). The responses to this study indicate a need for village midwives to improve their basic skills and knowledge, for example, first-aid during birth complications, in order to improve quality of care (D'Ambruoso et al. 2009; Makowiecka et al. 2008). This study also provides examples of cases in which mothers had not received any information from midwives or other health personnel regarding early-age illnesses that resulted in death. Increasing midwives' professionalism, including encouraging them to continue communicating actively with mothers and to use more appropriate approaches, could also improve mothers' satisfaction with health services and child survival (Halldorsdottir and Karlsdottir 2011). This study shows a need for midwives at all levels of the health services to be

encouraged to provide a more professional, caring service (Aune et al. 2013; Dahlberg and Aune 2013; Hatt et al. 2007; Kashanian et al. 2010).

Geographic inequity is a substantial challenge for reducing early-age deaths (Laksono and Rachmawati 2013). Problems with distance to the closest health facility, the inequitable provision of midwives and the distribution of public health insurance, shown by this study, indicate that the current MNCH programs in Ende district fail not only in providing universal health coverage, but also in reaching the socially disadvantaged population in this community. Mothers from the more rural North, East and West regions are experiencing particular difficulties with childbirth and child health (MNCH) service utilisation. For example, some mothers from these areas were unable to check their pregnancy or visit or deliver at a health facility because of the distance involved or a lack of transport (Gabrysch and Campbell 2009). Such differences in access to health facilities could help to explain early-age mortality differences between regions in Ende, particularly for the socioeconomically disadvantaged sub-populations (Pardosi et al. 2011; Starfield 2007; Victora et al. 2003). The responses recorded in this study demonstrate cases in which the absence of midwives or other related health personnel has contributed to neonatal deaths. This indicates problems with the distribution of midwives and other health personnel, particularly shortages in areas outside Ende capital city, and, possibly, a lack of motivation on their part (EDHO 2012; Makowiecka et al. 2008; Manalu et al. 2005; Ronsmans et al. 2001).

Another aspect of geographic inequity illustrated by this study is the unequal distribution of the free public health insurance scheme, known as *Jamkesmas*. A few mothers from the North and West regions reported that they had not received a *Jamkesmas* card. As a result, these mothers still had to pay to access MNCH services, which is particularly difficult for mothers with irregular incomes. The informants' responses and the observations of their housing conditions suggest that these mothers were generally from poor households who would face particular difficulties paying out-of-pocket costs. In order to minimise this geographic inequity, there is a need to give priority

to targeting *Jamkesmas* at poor, rural mothers with low education levels to decrease the health status gap and improve child health and survival (Utomo et al. 2011).

As elsewhere in Indonesia, in Ende there are local customs, norms and traditions that serve to perpetuate gender inequity relating to women's social positions and power in the community (Laksono and Rachmawati 2013; NIHRD 2012; Wamala and Ågren 2002). Almost all mothers in the rural areas and most of those in the urban area in this study had experienced difficulty making health-care-seeking decisions, due to a dependency on their husband. That almost all the mothers do not work outside the home and farm may undermine their bargaining power with their husband. Improving mother's education levels has been shown to increase the utilisation of health care services and decrease gender inequity in decision-making (Beegle et al. 2001; Cui et al. 2010; Sen and Östlin 2008). Thus, improving women's education and empowering women more broadly could assist the improvement of child health and survival in this underdeveloped district of Indonesia (Abu-Ghaida and Klasen 2004; Connell 2012; Duflo 2011; Pardosi et al. 2011; Raven et al. 2015; Singh et al. 2013).

Whilst the in-depth and open-ended approach used in this study succeeds in identifying a range of new insights into child health and survival influences in Ende district, a number of limitations are inherent in such qualitative approaches. Firstly, caution should be used in generalising the results to the wider population of Ende, due to the small size of the purposive sample. Further research administering closed questions to a larger sample of mothers is needed to provide more robust statistical inferences. Secondly, inference from the results of this study in Ende to some other parts of Indonesia should be treated with caution, given the atypical characteristics of this underdeveloped, overwhelmingly rural and predominantly Catholic district. Whilst it collected data on mothers' pregnancy, delivery and early-age survival experiences, the study did not seek to explore the experiences of midwives or of other health personnel. Further research is needed to assess the practical issues faced in delivering health education and child health services, particularly in remote areas of Indonesia.

In conclusion, this study identifies pressing needs for child health education of mothers, improvements to the knowledge and professionalism of midwives and health personnel, measures to address the geographical inequity in the access to health services and personnel, especially midwives, and the free public health insurance scheme and gender inequity in this underdeveloped district of Indonesia.

2.5 Contributors

Jerico Franciscus Pardosi wrote the manuscripts, performed data analyses and interpretations and acted as a corresponding author (80% of the work). Nick Parr supervised the development of manuscripts, edited and assisted in manuscripts evaluation and provided some substantive suggestions (10% of the work). Salut Muhidin helped to edit and evaluate the manuscripts (10% of the work).

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Chapter 3 Fathers and Infant Health and Survival in a Rural District of Eastern Indonesia

Abstract. Studies have shown that child survival can be greater when fathers are more highly involved in infant care than when they are less involved. This paper investigates fathers' and paternal grandmothers' knowledge and experiences relating to infants' survival in a rural district of Indonesia, a context for which such information is lacking. Twenty fathers or replacement relatives participated in-depth interviews. Most had only very limited knowledge of the danger signs of childhood illness. None of participants had received child health-related information from local health personnel. Male-dominated forms of decision-making in relation to infant health care are the norm. Inadequacies in the child health services, such as difficulties in accessing health facilities, health personnel unavailability and discomfort during delivery remain as challenges. Fathers appear to rely largely on their wives for their infant health and survival knowledge and have little involvement with their infants. They see their roles in terms of providing economic support and basic care for their infants. Grandmothers are seen as a major source of health information by fathers, but have limited knowledge of infant survival. The findings point a need for child health promotion programs and campaigns, including the safe motherhood program, to include fathers as well as mothers, in order to increase their awareness of infant survival and involvement in infant raising, and to persuade them to allow mothers greater scope to make child health-seeking decisions, especially when children require emergency treatment.

Keywords: Fathers · Grandmothers · infant survival · infant health · mortality · Indonesia

3.1 Introduction

This paper investigates fathers' involvement in improving their infants' survival in Ende, a mostly rural district of Indonesia. Although there have been concerted efforts promoting child survival programs and policies, child mortality remains a major global challenge, and 3 million neonatal deaths occur globally each year (Bhutta et al. 2014; Lawn et al. 2010). Child mortality in Indonesia is decreasing but still relatively high: the neonatal, infant and under-five mortality rates decreased from 30, 62 and 84 deaths per 1,000 live births in 1990 to 15, 26 and 31 deaths per 1,000 live births respectively in 2012 (UNICEF 2013).

Since 1988, the Indonesian government has implemented the "Safe Motherhood Initiative" and the "Mother Friendly Movement" (*Gerakan Sayang Ibu*), to reduce maternal deaths and child deaths by more equally distributing trained midwives between villages and increasing community participation in Maternal and Child Health (MCH) programs (Shefner-Rogers and Sood 2004). The government has made concerted efforts to increase the involvement of mothers in child health programs. However, relatively little attention has been given to involving fathers or other family members, such as grandmothers, in child health education programs, in contrast to several other developing countries (Dudgeon and Inhorn 2004; Mullany et al. 2007; Roth and Mbizvo 2001). In 1999 the Indonesian Ministry of Health launched an initiative, the so-called *Alert Husband (Suami SIAGA)* program, in order to ensure their wives have safe pregnancies and childbirths (Shefner-Rogers and Sood 2004). However, this movement focused primarily on fathers' involvement before childbirth and provided less direction on how fathers should be involved in assisting the infant's physical and psychological growth. Several studies in developing countries have shown a need for increasing fathers' involvement in maternal health care such as antenatal visits which known to provide greater health outcomes not only for their wives but also their infant survival than when they are less involved (Beegle et al. 2001; Blaney et al. 2015; Mullany et al. 2007; Roth and Mbizvo 2001; Titaley et al. 2010). Thus there is a pressing need for research which could inform programs in Indonesia

about the reasons for and potential solutions to fathers' lack of involvement in child health.

Fathers' involvement during pregnancy and after delivery has been found by a number of studies to be an important source of support and assistance for mothers and to improve their children's health and survival (Beegle et al. 2001; Z. Hill et al. 2004; Hodnett et al. 2013; Shefner-Rogers and Sood 2004; Tweheyo et al. 2010; Umami and Puspitasari 2007). Half of the studies using multivariate analysis reviewed by Sear and Coall (2011) found fathers were a significant influence on child survival in pre-transitional societies. However the authors also suggest that fathers' impact on child well-being becomes more important with progress through the demographic transition. Thus the importance of involving fathers in child health may increase over time in countries such as Indonesia.

The literature for more developed countries (MDCs) have emphasized the influence of fathers' availability, motivations, and involvement in the direct care of their children's physical and psychological growth (Bolzan et al. 2005; Goodsell and Meldrum 2010; Parke 2000). For low- and middle-income countries, fathers' involvement tends to be greatest during and after pregnancy, and that fathers tend to make the final decisions on their wives' delivery care and maternal health (Becker et al. 2006; Beegle et al. 2001; Lee 1999; Mullany 2006; Shefner-Rogers and Sood 2004). Historically and in pre-transitional societies fathers' have been found mostly to provide only economic support for their children's development rather than being involved more widely and directly (Lamb 2000; Sear and Coall 2011). However, fathers' involvement with their children has generally increased and changed in its nature over time (Lamb 2000). The increasing importance of monitoring, understanding and increasing fathers' involvement in health education and antenatal care and its potential to improve health outcomes for their wives' and infants' health is recognised in the literature (Carroli et al. 2001; Dudgeon and Inhorn 2004; Mullany et al. 2007; Ninio and Rinott 1988; Sarkadi et al. 2008).

In developing countries, grandmothers are seen by fathers and mothers to be important advisors and caregivers during pregnancy, childbirth, and childhood illness, and they have been found to increase child survival by providing direct care and support to their grandchildren on a daily basis (Aubel 2012; Bender and McCann 2000; Mumtaz 2005). They also play important roles in assisting mothers, especially first-time mothers, for example, with infant feeding, bathing, household domestic work, and therefore would influence their grandchildren's health and survival (Aubel et al. 2004). Grandmothers have been found to positively influence the length of breastfeeding and other infant feeding practices, for example, by providing eggs, red meat and milk for their grandchildren (Blaney et al. 2015; Inayati et al. 2012). In addition, elders' involvement including grandparents' involvement in health decision-making is customary in many developing countries (Aubel and Sihalathavong 2001; Kerr et al. 2008).

For Indonesia, the existing studies on fathers of young children have tended to focus their involvement during pregnancy and delivery and their influences on maternal health and child nutrition, and have largely ignored their other roles and responsibilities relating to ensuring health and survival after the child has been born (Beegle et al. 2001; Shefner-Rogers and Sood 2004; Umami and Puspitasari 2007). Only a few studies have considered the infant survival-related benefits of grandparents' roles during pregnancy and delivery, such as helping mothers with their household duties, advising on nutrition, and assisting with feeding grandchildren (Bentley et al. 2003; Gryboski 1996; Hafidz 2007; Simkhada et al. 2010). There is a lack of studies both for fathers' influences on infant survival and for grandmothers' influences on infant survival for rural contexts. Hence, the aim of this study is to investigate fathers' and grandmothers' perceptions and knowledge of infant health and survival, their involvement in ensuring infant survival, and their personal experiences of infant deaths in a rural district of Indonesia.

3.2 Methods

In-depth interviews were conducted to explore fathers' and grandmothers' knowledge, provision of support and experiences related to infant health, survival and death, and to understand their roles and responsibilities for health-related decision making (Coast et al. 2009). Before conducting the interview, each participant received an explanation of the study's purpose and procedures. Ethical clearance was obtained from the author's University and the Indonesian Ministry of Health Ethics Committee (see Appendices C and D).

3.2.1 Sampling method

For sampling purposes Ende district was divided into four regions: the North, South, East and West regions. The sub-districts of these regions with highest and the lowest under-five mortality were selected as interview locations, based on Ende District Health Office (EDHO) data between 2010 and 2012. Nangapanda, Ende Timur, Wolojita and Wewaria were the sub-districts with the highest under-five mortality, while Maukaro, Ndona, Ndori and Detusoko were the sub-districts with the lowest child mortality. Of these, only Ende Timur is located in an urban area.

A purposive sampling procedure was applied to select the father participants. This involved, firstly, selecting mothers who had had at least one child in the last five years prior to the study's data collection, with equal numbers of mothers with child deaths and mothers with no experience of child deaths. In the selection of mothers with experience of child deaths, priority was given to selecting those with the most recent child deaths, in order to minimise recall bias. The aim was also to collect data from the mothers' husbands (henceforth "fathers"). However, in the event of a father being unavailable or unwilling to participate, interviews were sought from other family members, invariably the children's grandmothers. The selection of the mother and father informants from each of the selected sub-districts was made using the birth register book obtained from a local midwife coordinator (known as *Bidan Koordinator*) from the community health centre (CHC) (so-called *Puskesmas*).

All the targeted mothers were successfully interviewed. This article focuses primarily on the fathers' interviews. For the fathers, 15 informants were interviewed in-depth. Fifteen more fathers were absent working in the farm, at sea, or visiting their relatives in the cities, and two fathers declined to be interviewed. Where the father was unavailable or unwilling to be interviewed a grandfather or a grandmother was then approached. None of grandfathers were willing to be interviewed. Five paternal grandmothers were interviewed as replacements for unavailable fathers. Thus total sample size of the fathers (including replacements) was 20 informants.

3.2.3 Research questions

The aim of this research is to identify and evaluate the extent of fathers' knowledge of infant health and survival influences, their experiences and views on child health service performance, their involvement in ensuring infant survival, and to illustrate their personal experiences of infant deaths in a rural district of Indonesia.

3.2.4 Data collection and analysis

The fieldwork of this study was administered in February and August 2013. This included interviewer training, contacting potential informants, interviewing the fathers and grandmothers, transcription and translation. The interviews were conducted in May 2013. After that, the data analysis was conducted over nine months (August 2013-April 2014). Two local interviewers were recruited from EDHO. The interviews were conducted using the local language and *Bahasa Indonesia*, and took place in the participant's house (see Appendix E). The interviews lasted up to 25 minutes with an average of 15 minutes.

During the in-depth interviews participating fathers were asked about their roles and responsibilities during pregnancy, the delivery process and after delivery. The interviews explored fathers' understanding of infant basic illness signs, including the danger signs, their health-seeking behaviour and the process of health-related decision-making during a child's illness. The fathers were asked about their roles and responsibilities relating to infant care,

including questions relating to their children's food. Respondents with a history of infant deaths were probed to share their experiences before and during the death and were asked about their knowledge of critical signs of illness, such as lethargy, convulsions, difficulty breathing and high fever. Similar questions were addressed to the grandmothers (see Appendix G). After the interview, the recorded files were fully transcribed into *Bahasa Indonesia*. However, local terms in the native language were retained. The transcriptions were then translated into *English*. All the transcriptions and translations were validated by the research team.

Anonymous codes were assigned to informants to protect their identities. A content and thematic analysis was conducted to identify which words or sentences were repeatedly or frequently mentioned by the informants. Patterns and themes were identified, and quotes were selected in order to illustrate the patterns and themes (Hansen 2006). Triangulation was conducted by using EDHO annual reports between 2008 and 2013 in order to improve the validity of this study.

3.3 Results

Table 3.1. Demographic characteristics of the participating fathers and their wives, Ende District 2013

Characteristics	<i>n</i>	Percentage %
Place of residence		
Urban	1	6.7
Rural	14	93.3
Father's Age (years)		
18-24	0	0.0
25-29	4	26.7
30-34	5	33.3
35-39	5	33.3
40-44	1	6.7
≥45	0	0.0
Father's Education		
Primary School	5	33.3
Junior high school	5	33.3
Senior high school	4	26.7
Academy/University	1	6.7
Wife's Education		
Primary School	5	33.3
Junior high school	5	33.3
Senior high school	2	13.3
Academy/University	3	20.0
Father's Occupation		
Fisherman	3	20.0
Farmer	9	60.0
Private worker	0	0.0
Government employee	1	6.7
Other	2	13.3
Wife's Occupation		
Fisherman	0	0.0
Farmer	1	6.7
Private worker	0	0.0
Government employee	1	6.7
Housewives	13	86.7
Place of delivery		
Home	4	17.4
Community Health Centre	9	39.1
Hospital	10	43.5
Child death experience		
Yes	6	40.0
No	9	60.0

Source: Pardosi et al. 2015

Almost all the fathers lived in the rural areas, and most (60%) were farmers. All of their wives were housewives (86.7%), except for one government employee and one farmer. For a majority of both the fathers and their wives, the highest education was either primary or junior high school. A higher percentage of wives (20%) than husbands (7%) had graduated from an academy or a university.

All five grandmothers who participated in this study had only primary school education, and all were aged between 55 and 65 years. The most common places of delivery of the children were community health centres (CHCs) and the local hospital. However, four children were delivered at home. Seven out of the fifteen fathers were first-time fathers. Six fathers had experienced an infant death in the previous five years, including four first-time fathers. All but one of the deaths were neonatal deaths.

Table 3.2. Major categories and key themes

Infant health-related knowledge	Pregnancy and delivery support	Infant survival experiences
Fathers' knowledge of infant health and survival	Fathers' support during pregnancy and delivery	Infant death experience
Grandmothers' knowledge of infant health and survival	Grandmothers' support during pregnancy and delivery	Health services performance
Fathers' social support and sources of child health information		Decision-making for infant survival

Source: The fathers' interviews data 2013 (e.g collected by Pardosi)

Three major categories of fathers' and grandmothers' discussion emerged from the responses were: infant health-related knowledge, pregnancy and delivery support, and infant survival experiences. These were subdivided into the following eight key themes (see Table 3.2).

Fathers' knowledge of infant health and survival

Most of the fathers displayed only a rudimentary knowledge of the determinants of infant health and survival. The knowledge shown was mostly a very simplistic awareness of the basic need for nutrition and hygiene. For example, a few participants mentioned the importance of

nutritious food and hygiene for infants when asked to name the determinants of child health and to define a healthy baby, as illustrated by the following quotes:

We have to fulfil the needs of the children, clean environment, and also have to take care of their foods and drinks to fulfil their nutritional needs. (26-year-old, F4, F=father)

To grow healthy, we should care for children, give them nutritious foods and care for their health. (31-year-old, F5)

It depends on how the parents take care of their baby and the food hygiene. (39-year-old, F6)

The first-time fathers showed an even more limited knowledge of infant health and survival than the other fathers. A majority of the fathers who had experienced an infant death perceived infant health and survival influences largely in terms of feeding, and bathing their children. The following examples show how participants expressed their understanding:

I do not know anything about it. No, I do not know about it. I am busy working [fisherman]. (35-year-old, F2)

Yes, I know about nurturing children well, giving healthy food, bathing the child in the right way, they should take a bath in the morning then have breakfast before going to school. (39-year-old, F6)

I have never heard about child survival. I am busy working in my farm every day and I have never received any information about that from Puskesmas staff. (32-year-old, F8)

When asked to what they understood the signs of childhood illness to be, a majority of the fathers identified only a limited range of basic signs, for example diarrhoea, high fever, pallor and lethargy:

... the hazard signs, I knew. For example, if the child got diarrhoea, it is dangerous. Dengue fever is also serious for the baby. But it is normal if it was only flu or cough. Yea, it is just ordinary sickness. It is based on my experience. (50-year-old, F9)

Yes, I know. If my child doesn't want to play or is no longer laughing, those are the symptoms that my child is getting ill. Cough and flu are also symptoms that my child is getting ill. (25-year-old, F3)

Not really much, at least some signs for baby and toddler if they are not in good condition, for example pale, weak or having a high fever. (37-year-old, F1)

The lack of knowledge of signs of illness was particularly evident among the fathers who had experienced infant deaths. For example, one mentioned only a pale face as a way of determining his child's sickness and another identified vomit as a danger sign of his baby. Another linked his lack of such knowledge to his reliance on his wife's knowledge:

Red blotches (rashes) and if his face looked pale, oh I mean that he is sick. (36-year-old, F13)

I know. If the baby is sick and vomit, we have to bring the baby to Puskesmas. (29-year-old, F12)

I don't really understand about the dangerous symptoms for baby and toddler, but mostly my wife knows it better than me. (39-year-old, F6)

None of the informants had received any child health information from local health staff, such as midwives or nurses. Hardly any of the fathers identified other important child illness signs described in the Ministry of Health MCH book, such as convulsions, difficulty breathing, or wheezing. One informant said he identified his child's sickness by using his instinct and from his child frequent crying, as opposed to from conventional child illness signs:

I do not know much about children, but if I see something in the child I know that something has happened. If he is sick, something happened in his body, it is just by instinct, I know that something wrong. Also, if he cries too much even while urinating, that's all I know. (34-year-old, F15)

When fathers who had not experienced an infant death were asked what they would do if their child showed hazard signs of illness, such as high fever, only a few respondents indicated that they would take their child immediately to the local CHC. One participant would ask his wife about his child condition before taking the child to health facility while another participant reported he gave money to his wife to take the child to *Puskesmas* as follows:

I would ask my wife when the first time this child got fever, because I do not always stay at home. After that, we brought her to either Puskesmas or local hospital. (37-year-old, F1)

I give the money (to my wife) to buy the medicine for my child. It was my wife who brought the child to community health centre if my child got sick (25-year-old, F3).

None of the fathers who had experienced neonatal deaths were able to provide information in relation to what they would do if their child were sick, even after probing. This may be because they were busy working on their farm or at sea and mostly relied on their wives for taking their infant to Puskesmas when they were sick:

I am busy all day working on the farm. I told my wife to take care of the children. If something happens to my child, my wife does not have to wait for me to go to Puskesmas. She will tell me when I am back. I am not angry about it. (27-year-old, F10)

If my children got sick, my wife will bring them to Puskesmas. We made effort as what we can do. (32-year-old, F7)

Grandmothers' knowledge of infant health and survival determinants

All except one of the grandmothers in this study showed very little knowledge of the determinants of infant health and survival, even after probing. When asked, most showed only a simple awareness that the mother should give the baby food and milk in order to keep the baby healthy, as illustrated by the following quotes:

I know nothing but that the mother must give breastfeed milk to the baby (56-year-old, GM1, GM=grandmother)

Just take care of the children and give them food. (57-year-old, GM2)

I only know that children must be kept and fed well to grow healthy by their parents. (59-year-old, GM3)

None of the grandmothers mentioned important basic signs of infant illness in response to a question on the signs of childhood illness. Two stated that they knew nothing about child health and survival, and others reported never having received any information about the determinants of child survival from health staff. When asked what parents should do to maintain their child's health and survival, only one grandmother responded, even after probing. This participant saw a need for both modern medicines and traditional remedies, specifically massage, when a grandchild is sick:

To grow healthy, a baby must be kept and taken care of. If my grandchild shows signs of sickness, I ask the parents to ask for medicines in Puskesmas and after that

I massage the baby with oil. If the baby has a high fever, I massage the baby with onion oil. (63-year-old, GM5)

Despite the Indonesian government's "Safe Motherhood Initiative", none of the grandmothers had received any information from a CHC about the signs of childhood sickness. When asked, only high fever was mentioned as a sign of childhood illness. One grandmother added that, if she saw any signs of high fever in her grandchild, such as diarrhoea or difficulty in breathing, she took the child to a health facility, such as a CHC, to receive emergency treatment, while another grandmother said the grandchild should be taken to the CHC without delay:

If I see some 'bad' symptoms and signs, I carry my grandchild to the hospital [Puskesmas], and ask for medicines from the doctor or midwife. (63-year-old, GM5)

I know, if he is sick, we must bring him [grandchild] straight to the hospital [Puskesmas], and sleep inside the mosquito net. (59-year-old, GM3)

The baby will die if we do not take care of him, if we do not go to the hospital [Puskesmas] faster when the baby will get diarrhoea with high fever and difficulty in breathing. (57-year-old, GM2)

The value of breastfeeding was recognised by most grandmothers as an important form of feeding for infants. Almost all the grandmothers agreed that breast milk is better for the baby than formula milk, as illustrated by the response from the following informant:

Just giving the breast milk, not formula milk. To give breast milk, more healthy right! (59-year-old, GM3)

Fathers' support during pregnancy and delivery

The fathers reported giving a range of forms of support to their wives during pregnancy, including: providing food, helping with the housework, reminding their wives to have enough rest, and accompanying them to a health facility. Those who already had more than one child provided care for the other children, as shown by the following quotes:

Buying and giving her fruits and giving her money to go to Puskesmas, reminding her not to go outside, especially at night. (35-year-old, F2)

I have six children, so based on my experience of those six children, after her third month of pregnancy, she did not work. I took care of the house and kids. I did not let her do hard work in the house or on the farm. (50-year-old, F9)

A majority of the fathers reported accompanying their wives during delivery at *Puskesmas*, although others did not want to respond when asked about their involvement during delivery, even after probing with other questions. The fathers reported that post-delivery they recommended their wives to eat nutritious food and breastfeed their baby, and prayed for the mother and the baby. This is shown by the following two responses:

I always accompanied her to Puskesmas or hospital. I accompanied her when she was in labour. I brought her immediately to the doctor. After the birth, I always reminded her to take a rest and while she was resting, I took care of the children. Besides, I always tried to give her and my children healthy food, such as vegetables. I gave them money as they needed it. (26-year-old, F4)

I accompanied her. We were always together. When she gave birth, we went together from home to the place of birth. Our family also gave similar support. I have an adopted child. After delivery, I took care of him. I gave everything he needed. I also fed him. (36-year-old, F13)

I went together with my wife. During my wife's delivery, I prepared the transportation (oto) and accompanied her in Puskesmas (31-year-old, F5)

Grandmothers' support during pregnancy and delivery

The grandmothers described a range of ways in which they acted as a source of advice and support during their daughter-in-law's pregnancies and deliveries. All the participating grandmothers advised their pregnant daughters-in-law to drink regularly, eat plenty of vegetables, and rest well and not work too hard. A majority emphasised to their daughter-in-law the importance of checking the pregnancy at the local CHC. Two respondents reported the forms of support they provided as follows:

Remind her to eat more, take care of herself, have a good sleep and go to Puskesmas. (56-year-old, GM1)

Yes, I helped her when she was pregnant. I told her not to work hard. We went together to Puskesmas. (62-year-old, GM4)

I gave her meals. I also gave banana, cassava, water, rice and vegetables when she was pregnant. (57-year-old, GM2)

Some of the grandmothers were aware of the importance of taking their daughter-in-law to the local CHC or contacting the local midwife at the place of delivery and one reported taking the initiative of calling the village midwife even after her daughter-in-law had given birth at home:

I asked 'ibu bidan' [village midwife] to come and check on her health and the baby because she had already given birth. It had already happened. I also massaged her. (63-year-old, GM5)

We went together to Puskesmas, we slept together while waiting for her childbirth. I waited in Puskesmas until the baby was born. (62-year-old, GM4)

However, other grandmothers were unaware of the importance of taking their daughter-in-law to the local CHC as the place of delivery or contacting the local midwife. A few participants reported that after the delivery they had prepared food and cared for their daughter-in-law and grandchildren. Two said:

I cooked food for her, I said, 'Do not be late to eat and drink,' and that all was for her health. I also massaged her, cleaned her body and gave her medicines. (63-year-old, GM5)

The baby was given a bath by me. After the baby grew older, I also fed him. (62-year-old, GM4)

The persistence of traditional beliefs, customs and use of traditional remedies was apparent among the grandmothers. For example, one forbade her daughter-in-law to go out at night and also to take a bath at night. This informant believed that pregnant women doing activities at night is a taboo in the community, and believed that pregnant women doing outdoor activities at night, such as going to other people's houses, is unusual and could harm their pregnancy:

I told her not to go out at night and to take a bath only in the afternoon not at night. People say it is a taboo. (57-year-old, GM2)

One of the traditional remedies used was massage. The following quote documents a grandmother providing this practice to her daughter-in-law, and also shows that such a practice is not necessarily an alternative to the use of modern health facilities:

If she got sick, I massaged her, and I told her to go to Puskesmas after the massage to check her health. (63-year-old, GM5)

Infant death experience

During the interview, all the fathers and the grandmothers who had experienced infant death were asked about the infant death event and to share about what led to the death. However, all the fathers and the grandmothers who had experienced infant deaths displayed only very limited knowledge of child survival influences, and were unable to identify the cause of their infant death when asked about the factor. Only two of the fathers and none of the grandmothers were willing to share their experience of their child or grandchild's death even after probing. One father expressed his frustration at what had happened to his son at the local CHC. He had not received any explanation from the local doctor about the cause of the sickness from which his son died:

We checked him on Saturday because he cried in the afternoon, he cried and I was confused. We had him checked by a doctor, and the doctor said nothing bad happened, but he cried again. He cried for three or four hours on Saturday afternoon. He stopped and slept until the morning, and on Sunday at 1pm he started crying again and died after that. (32-year-old, F7)

This participant also added that his child's death had occurred even though the parents had always fulfilled the baby's basic needs:

We already give all they [children] need including the baby, we make effort, we brought the child to the Puskesmas, but he died and what can I do now. It has already happened. (32-year-old, F7)

Another respondent reported a case where the child died in hospital but also reported having wanted to take the baby home because he believed the child's condition was critical. This case illustrates a preference for the home as the place of death and this preference may have both cultural and financial motivations, which may also adversely affect the baby's survival:

For the dead baby, in Ende on that day I had informed her [his wife] that we had to go and should not spend the night here [hospital], because I saw the signs in his hand, the blood didn't flow, his face went black. I informed her, the signs in

the baby was not good, so we had to go home tomorrow. They asked me not to leave the hospital, but my heart said that we had to go home. (32-year-old, F8)

Child health services performance

A majority of the respondents felt satisfied with the quality of care given during delivery and after the birth. They believed *Puskesmas* was the appropriate choice for the place of delivery, because of its adequate facilities. Nevertheless, a few respondents expressed disappointment with the local CHC service's performance, because of the discomfort they experienced during delivery, such as the unavailability of staff when their child was in a critical condition, or a lack of provision of midwives or nurses in their village.

One father explained that his decision to have his child born at home, rather than at a CHC, arose from his dissatisfaction with the CHC's facilities experienced during a previous birth, while another reported resorting to using traditional medicines because of the long distance to travel between home and the closest health facility:

My first child was born in hospital [Puskesmas]. My second child was born in another district CHC, but I disliked the service. The place was too open, so the new nurses, seven to eight were in the room, so I was afraid that my wife got trauma, so I said to give birth to our second child at home. (32-year-old, F7)

This respondent also expressed disappointment with the community health service's performance. This informant took his daughter to the local CHC, only to find no health staff were available to help her:

We used to live in a city before but now we live in the village. My wife and I took my daughter to Puskesmas when she got sick. We made the best effort as we could, but the people in Puskesmas were not there. So difficult to find them. (32-year-old, F7)

Another father identified the need for more health staff to be available to prevent child deaths in his village:

But, the nurses or midwives should be ready to be placed in the villages. So, it would become much better for mother and child in my village. (34-year-old, F14)

Lack of access to health facilities was presented as a reason for using traditional medicines by the following father:

We are living far from the hospital [local CHC] and the health service was very difficult to get and reach, so we used traditional medicines for my children, like the leaves, and we did like what our grandparents did. (50-year-old, F9)

Decision-making for infant health and survival

In Ende final decisions of child health issues tend to be made by the fathers. However, a majority of the participating fathers, both those with experiences of infant death and those without such experience, reported that they consulted their wife before making the final decisions on their children's health problems. Two informants reported:

Yes, I do. My wife and I decide which one is the best way and it does not depend on me. We made a decision based on the best choice. (39-year-old, F6)

For child health, my wife does not have to wait for me, because child health is an important thing. Husband and wife should make decisions together, but when my child has health problems, she should handle it. (37-year-old, F1)

Some of these fathers attributed their willingness to share their power with their wife to the fact that they spent less time in childrearing. They accepted that their wives had more knowledge and experience of dealing with children's illnesses:

Sometimes my wife made the decision. She does not have to wait. She usually makes the decision and tells me when I am home. (27-year-old, F10)

For health, it is not all in my hands. Why? As the head of this family, I will not make decisions by myself, we just use the best way. About my children's health, their mother knew better than me, I just kept an eye on my children once I came home, so the decision is not absolutely mine. (34-year-old, F15)

When my children got sick, my wife should not wait for me because health is important. (37-year-old, F1)

Some fathers, disproportionately first time fathers stated they generally made their child health-related decisions without asking for their wife's agreement:

I was responsible for making the final decision of my child illness before my wife went to Puskesmas. (36-year-old, F13)

I make the decision for my wife and my children's health. (26-year-old, F4)

All the grandmothers reported that child health-related decisions were made by the child's father. One grandmother said that she had told her daughter-in-law to talk first to her husband and also to her parents-in-law, if her child felt sick, before taking the child to a CHC:

My daughter-in-law should talk first to her husband and me. Her husband would make the final decision. (59-year-old, GM3)

However, another grandmother reported that she told her daughter-in-law to take her child immediately to the local CHC if her grandchild showed signs of illness without waiting for the father's decision. She also said that if the father had money, he should give the money to his wife in order to take the child immediately to a *Puskesmas*:

...just went even though the father was not there. Just brought him to be checked, no need to wait for his father. If we see that the child is sick, we just bring him to Puskesmas. That is what I told to her. I told my son that if he has money, he should use it to pay for a motorcycle taxi, so-called ojek, or if not, just walk. (57-year-old, GM2)

Fathers' social support and sources of health information

Almost all the participating fathers had experienced a lack of provision of information from local health staff and a lack of assistance in regard to infant health and survival from the local community. Most participants reported that they had never received an invitation from a village midwife to attend the health promotion program. However, a few mentioned other sources of information and support. For example, one reported receiving child health information from the radio, while another received information from the mass media:

If a counselling session about it [child health] was being held, they never invited husbands. They [village midwives] only invited wives. Husbands just supported them. (37-year-old, F1)

No, I do not know about child health and survival because I've never got any education related to it. Yes, I have heard from the radio. Healthy baby means...it depends on how parents take care of the baby and the food hygiene. (35-year-old, F2)

I do, recently there were news about child survival on television, radio, or something. They said that it always happened that the mother and baby died, but now the government gave attention but currently they have decreased their attention. (34-year-old, F14)

Grandparents (i.e. parents-in-law) and neighbours were mentioned by a few fathers as sources of health information, especially for advice relating to their child's illness. As one put it:

We discuss it; we are family so we want the best for our child. But, sometimes we had so many problems, so my neighbours and parents gave us some advice. (32-year-old, F7)

Second-hand accounts of child deaths were also identified as an important form of information. In the words of one informant:

I got the information like ... that a baby was born and then died in the womb; there was also news about baby died after birth. There was a baby who was abandoned by its mother because she did not have a husband. Hmm, it is important for us as husbands to know it because it is for our children's health. (34-year-old, F15)

3.4 Discussion

This paper illustrates the inadequate knowledge among fathers relating to the causes of and practices affecting infant health and survival, their lack of involvement in direct infant care, the male-dominated forms of decision-making in relation to infant health care, and the issues identified by fathers relating to the inadequate quality of child health services in a rural district of Indonesia. The findings suggest fathers appear to rely largely on their wives in relation to their infant health and survival knowledge, tend to have little involvement with their infant, and that their influence is generally a matter of providing economic support and basic care for their infants. Despite the limitations of their of child health and survival knowledge, paternal grandmothers are seen by fathers as an important source of health information.

The very limited knowledge of the danger signs of childhood illness, found among fathers, especially those who had experienced a child death, could have fatal consequences. For example it could lead to delays in infants being taken to health facilities to receive necessary

treatment for illnesses, and thus to infant deaths (Pembe et al. 2009). The findings also show that first time fathers have an especially limited understanding of infant health issues. Mothers in Ende tend to have more child health knowledge than fathers (Pardosi et al. 2015). Our findings point to a pressing need to involve fathers, especially rural fathers, in child health education through child health promotion by local CHCs and other health staff, starting with antenatal services. Such education should include basic coverage relating to childhood illness, such as what the danger signs are and how to respond when they are observed. There is also a clear need for more information to be provided to fathers by midwives and other health staff (Emma and Susanne 2009; Harvey et al. 2013; Kululanga et al. 2012).

Fathers' involvement in health education programs during pregnancy and from early childhood onwards has been shown to not only improve the fathers' knowledge of child health and the care-seeking and other practices to address it, but also to improve the mothers' health, the childbirth outcomes, and the children's health, growth and development (Februhartanty et al. 2006; Z. Hill et al. 2004; Shefner-Rogers and Sood 2004; Teitler 2001; Tohotoa et al. 2009). This study illustrates fathers' lack of involvement in direct infant care in Ende. Clearly it is necessary for health education not only to improve fathers' knowledge of child health care but also to motivate higher levels of paternal involvement in infant health care.

Our study presents cases where a lack of health awareness leads fathers to seek child health information from the mass media (Mullany et al. 2007). Exposure of fathers to maternal and child health-related information by radio, television or other forms of mass media may improve early-age survival outcomes and could also affect the utilisation of child health facilities (Gabrysch and Campbell 2009; Stephenson et al. 2006). Our findings point to a need for the media to publicise child health education activities to fathers and for the publicity to help to make them feel they would be welcome if they were to attend. In addition, the local District Health Office could use local media, particularly radio, to promote child health-related

information, especially information needed to address the child health knowledge gaps of fathers, shown by the findings of this study.

The findings suggest that fathers tend to be more involved in providing support and assistance during pregnancy rather than during delivery and in the care of the newborn children. In Indonesia husbands are allowed to accompany their wives during childbirth. For caesarean sections, it depends on the doctor (Ministry of Health, 2013). However, only a minority of the fathers accompanied their wives during labour and continuously give support to their wife after delivery, and few were extensively involved in their caring for the newborn child (Ministry of Health 2013, 2010). This could indicate fathers having a lack of awareness of their potential influence on childbirth outcomes (Sapkota et al. 2012).

Grandmothers are important sources of advice to both fathers and mothers and important sources of care for infants. However the limited evidence from this study is that, with the exception of recognition of the value of breastfeeding, grandmothers lack of knowledge relating to infant health and survival (Aubel 2012). This lack of knowledge may be partly attributable to local health staff not involving grandmothers in health education programs and local CHC staff not providing grandmothers with child health-related information (Lee and Garvin 2003). Several studies have suggested involving grandmothers in health education programs by using an approach aligned with traditional social institutions in the local community may have positive effects on child survival probabilities (Aubel 2012; Aubel and Sihalathavong 2001; Hawkes 2004; Kerr et al. 2008; Sear and Mace 2008).

Compared to fathers, grandmothers have more significant roles and responsibilities during pregnancy, childbearing, and children's early years (Gupta et al. 2015). Our study presents examples of grandmothers' lack of child health awareness and adherence to traditions. It may be that grandmothers rely on their past experiences as a parent to inform their daughters-in-law in relation to child health and survival. In view of the continuing importance of grandmothers as sources of care for children, there is a pressing need to address their lack of up-to-date child

health awareness (Aubel 2012; Gupta et al. 2015; Jansen 2006). That grandmothers are considered by fathers to be key sources of child health-related advice may provide further indication of the shortcomings of fathers' child health-related knowledge.

Our findings highlight a need to improve the quality of child health care provided by local CHCs. Problems of discomfort during delivery, midwife or nurse unavailability, and a wider lack of health staff, poor quality of care at local CHCs and difficulty in accessing health facilities, unprofessional attitudes among health staff and a lack of provision of information by doctors and other health staff are evident (Adair et al. 2012; Pardosi et al. 2015). These issues need to be addressed by the local district health office through health care services by increasing the provision of village midwives and related health personnel, conducting regular training on child and newborn care for rural health staff, and renovating CHC health facilities such as delivery rooms to increase the utilization of child health services among rural populations (Althabe et al. 2008; Carlo et al. 2010; Donnay 2000; Emma and Susanne 2009).

The findings of this study show the male domination of child health-care-seeking decisions, despite fathers' inadequate knowledge of child health and illness, their fathers' often being away working on farms or at sea, and more general lesser involvement in child raising (Pardosi et al. 2015). It is evident that several fathers in this study made health-decisions without asking their wives' opinions. Enhanced infant survival outcomes could be achieved if fathers were more willing to share their power before making decisions on infant care (Becker et al. 2006; Beegle et al. 2001; Danforth et al. 2009). This could be done by educating husbands in rural communities through local MCH promotion programs, such as the safe motherhood program or health awareness campaigns, about infant health and its danger signs, and incorporating advice on the value of involving their wives in child health-seeking decisions and allowing them to make decisions without consulting their husband when a child requires emergency treatment (Donnay 2000; Kwambai et al. 2013; Roth and Mbizvo 2001).

Despite the male-domination of infant care decision-making, a few grandmothers reported taking the initiative for seeking urgent care for their grandchildren's illness without asking permission from the fathers. This may indicate that fathers respect for their mothers' seniority and experience of caring for sick children (Aubel 2012; Mumtaz and Salway 2007). A few grandmothers in our study still administered traditional remedies for their grandchildren's illnesses (Bakshi et al. 2013; Engmann et al. 2013). The findings point to a need for local governments to increase the involvement of grandmothers in child health interventions in order to increase their awareness of infant survival issues, and improving their infant health practices (Aubel et al. 2004; Beiersmann et al. 2007; Kerr et al. 2008).

Our study indicates a lack of willingness among fathers and grandmothers to share their infant death experiences. This may be because the death of an infant is a traumatic event. However the lack of social support provided to deal with grief and the failure by health care providers to supply information to the family regarding the causes of their infant's death may have contributed to the unwillingness or inability of fathers and grandmothers to discuss the infant deaths (Aho et al. 2009; Pardosi et al. 2015). Thus there may be a need to improve health staff communication skills to provide more information to for fathers and to assist them to deal with grief (Aho et al. 2009; Bosticco and Thompson 2005; Romesberg 2004).

In view of the small size samples of fathers and paternal grandmothers and the substantial and potentially biased non response, caution is needed in making inference to the wider population. In addition, the birth and death registration in this rural district of Indonesia is incomplete. Thus the sample frame used could potentially generate a biased sample of births and deaths in rural villages (Burke et al. 2011; Pardosi et al. 2011). Despite these limitations, the findings of this study have the potential to add to the evidence on fathers' influences and knowledge of infant health and survival in the Indonesian context.

Fathers should be seen as having the potential to be an important complement to the mother in ensuring infant survival by providing the needed support for a safe birth and for the survival

of the child (Sayer et al. 2004). It is important both to increase the involvement of fathers, particularly rural fathers, in the wellbeing of their children through health education programs, and to strengthen the mothers' decision making powers relating to the health and survival of their children in Ende district.

3.5 Contributors

Jerico Franciscus Pardosi wrote the manuscripts, performed data analyses and interpretations and acted as a corresponding author (80% of the work). Nick Parr supervised the development of manuscripts, edited and assisted in manuscripts evaluation and provided some substantive suggestions (10% of the work). Salut Muhidin helped to edit and evaluate the manuscripts (10% of the work).

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Chapter 4 Local Government and Community Leaders' Perspectives on Child Health and Mortality and Inequity Issues in Rural Eastern Indonesia

Abstract. Since 2001 a decentralisation policy has increased the responsibility placed on local government for improving child health in Indonesia. This paper explores local government and community leaders' perspectives on child health in a rural district in Indonesia, using a qualitative approach. The issues probed relate to health personnel skills and motivation, service availability, the influence of traditional beliefs, and health care and gender inequity. The participants identify weak leadership, inefficient health management, and inadequate child health budgets as important issues. The lack of health staff in rural areas is seen as the reason for promoting the use of traditional birth attendants. Midwifery graduates and village midwives are perceived as lacking motivation to work in rural areas. Some local traditions are seen as detrimental to child health. Husbands provide little support to their wives. These results highlight the need for a harmonization and alignment of the efforts of local government agencies and local community leaders to address child health care and gender inequity issues.

Keywords: Child health · child mortality · inequity · health services · community ·
Indonesia

4.1 Introduction

Indonesia has been struggling to reduce its neonatal, infant and under-five deaths in order to meet the fourth Millennium Development Goals by 2015. In 2012, the levels were still above the average of the South-East Asia region (Bhutta et al. 2010; Lawn et al. 2010; UNICEF 2013). Despite the implementation of a series of universal health-related programs and the prioritisation of child health and survival as national policies, child mortality rates still vary considerably between districts and sub-districts in Indonesia (Acuin et al. 2011; UNDP 2011; Victora et al. 2003; Yinger and Ransom 2003).

Both inadequacies in health care access and delivery and the persistence of traditional beliefs continue to adversely affect child health and survival in Indonesia. Shortages of health care workers (HCWs) and child health services in rural and remote areas, such as antenatal, perinatal and postnatal care, have been found to have adverse consequences for birth outcomes and infant survival (Adair et al. 2012; Frankenberg et al. 2005). Partly as a result of their difficulties in accessing health facilities and midwives and partly due to traditional beliefs, many rural women in Indonesia continue to use traditional birth attendants (TBAs), rather than local midwives (Agus and Horiuchi 2012a; Agus et al. 2012b; Pardosi et al. 2015; Titaley et al. 2010).

There is also geographical inequity in accessing obstetric care and in the distribution of health care insurance within Indonesia (Acuin et al. 2011; Hidayat et al. 2004). Inadequate skills and knowledge among health staff relating to delivery and care for newborns, such as the required support to provide during labour, hygiene during delivery, and the provision of late treatment care for newborns, is another important health care delivery issue, and this issue has been found to adversely affect child health and survival (Ensor et al. 2009; Hatt et al. 2007; Hennessy et al. 2006). Local customs and community traditions, which are not scientifically-proven, have continued to affect perceptions and practices related to child health and survival. For example, there are local norms which forbid pregnant women from going out at night, going

to the river, bathing at night, and slaughtering animals (NIHRD 2012; Wulandari and Whelan 2011).

Gender disparities in roles and responsibilities within the household have been found to affect child survival in less developed countries. Women, especially those with low socio-economic status, tend to experience a greater burden of housework than their husbands, and this issue limits their involvement in health-seeking decision-making and knowledge of children's health and survival influences (Bhutta et al. 2004; Duflo 2011; Victora et al. 2003). In contrast, higher socio-economic status women with greater opportunities to make health-seeking decisions for their children and a greater control of household economic resources have been found to have higher rates of utilisation of child health care services and child survival (Maitra 2004).

Women in rural Indonesia tend to have less power than men in pregnancy and child health decision-making, and this is detrimental to infant health and survival (Beegle et al. 2001; Pardosi et al. 2015; Speizer et al. 2005). Unplanned pregnancy has been found to be associated with neonatal and maternal death and low birth weight (Lawn et al. 2009; Singh et al. 2010; Yanikkerem et al. 2013). In Indonesia, a lack of commitment from local government agencies, a lack of program dissemination, and an unequal distribution of free family planning services are major challenges to reducing the number of unplanned pregnancies in the population faced by the National Family Planning Coordinating Board (BAPPENAS 2009, 2010).

Historically, the Indonesian Ministry of Health was the main child health policymaker, with local governments acting as recipients of the central government policy (Lieberman et al. 2005). However, since 2001 local governments have been given an increased responsibility for managing their own local health policies (Kristiansen and Santoso 2006). Despite this decentralisation, significant disparities between areas in health status and inequities in health coverage have persisted (Baird et al. 2011; Poerwanto et al. 2003; Trisnantoro et al. 2010; B. Utomo et al. 2011). Moreover, despite their increased autonomy, district health systems in

Indonesia have continued to face problems relating to their accountability in managing local health budgets and changing from a preventive paradigm to a curative paradigm (Heywood and Choi 2010; Kristiansen and Santoso 2006). Since leadership and governance are critical building blocks to ensuring effective health services, and particularly in view of the increasingly important role of district government leadership in providing child health services, understanding local governments' roles and responsibilities and their partnerships with local communities has become important for international organisations which are concerned about the improvement of standards and equity in child health in developing countries such as Indonesia (Asante et al. 2012; Daly et al. 2003; Farnsworth et al. 2014; WHO 2007, 2008).

Increasing local community involvement has also become an important part of the district health system's approach to reducing child mortality in Less Developed Countries. Community leaders mobilising local people to use health facilities and the building of partnerships between local community leaders and local governments have been found to increase public participation in local child health programs, to improve maternal and child health, and to prevent early-age deaths, especially for poorer populations (Gwatkin et al. 2004; Haines et al. 2007; Kerber et al. 2007; Rosato et al. 2008). However, a study in West Java Province found a lack of understanding of and support for primary health service issues among local community leaders. Thus, there is a need for an improved understanding of local community leaders' perceptions of, and their involvements in, child health and survival programs (Titaley et al. 2010).

Despite their increased importance in child health policy implementation, to date there has been a shortage of studies in Indonesia which explore local government and community leaders' views of child survival issues and their roles and responsibilities in child health programs, and a shortage of studies on their perceptions of how health and gender inequity issues affect child survival in their communities at the district level. This study aims to address this gap by (1) identifying local government and community leaders' perspectives on child health, mortality

and inequity issues, and (2) examining their understanding of their roles and responsibilities relating to reducing child deaths and improving gender and health care equity.

National and local child health programs and policy

The local government and community leader participants in this study were actively involved in implementing a range of national, provincial and local child health programs and policies. At the national level, the government has implemented a range of programs which aimed at reducing maternal and child deaths. One of the major initiatives, introduced in 1988, was a village midwife program, known as *bidan desa*, involving distributing 50,000 midwives to rural areas (Hatt et al. 2007; Shefner-Rogers and Sood 2004; Shrestha 2010; Trisnantoro et al. 2010). In 1997, the Integrated Management of Childhood Illness (IMCI) policy, involving 8,000 community health workers, which aimed at providing primary care for improving children health, was introduced (Trisnantoro et al. 2010). In 2004, Indonesia launched a health insurance scheme for the poorer populations, known as '*Jaminan Kesehatan Masyarakat*' (Jamkesmas).

However, a lack of coverage of the rural population has become a major challenge for the implementation of this program (Harimurti et al. 2013; Simmonds and Hort 2013). In 2011, the government launched a universal benefit scheme, known as *Jaminan Persalinan* (Jampersal), which allowed every pregnant woman to deliver free of charge at health facilities and aimed to reduce neonatal deaths. However, since 2014 the program has been integrated into a new health insurance scheme, known as Social Security Organising Body (BPJS).

At the provincial level, in 2009 the East Nusa Tenggara government launched a strategy for saving lives and improving maternal health through its Maternal and Child Health (MCH) Revolution program ('*Revolusi Kesehatan Ibu dan Anak*'). This program aimed to improve the quality of health care services and, more importantly, to ensure women could deliver at appropriate health facilities. It also aimed to increase the number of adequate health facilities,

raise the number of women who deliver at a health facility, and improve the quality of post-natal family planning services (NTT Provincial Health Office 2012).

Since 2010, Ende district government legislated a provincial MCH revolution program and implemented a community mobilisation system (2H2), which monitored pregnant women 2 days before and 2 days after delivery. Community awareness of the MCH program and involvement in this mobilisation program were seen as being critical to the success of MCH Revolution (EDHO 2013).

4.2 Methods

4.2.1 Research participants

Focus group discussions (FGDs) were conducted to identify local government and community leaders' knowledge and perspectives on child health and survival and related inequity issues, including their roles and responsibilities. Thirteen participants were involved in two separate focus group discussions. Eight participants were from Ende local government departments and five were community leaders. Purposive sampling was conducted to select participants in this study based on the following criteria: a) being between 18 to 65 years old, b) currently holding a position as a supervisor or higher either in the Ende District Health Office (EDHO), a Social and Women's Empowerment local government agency or a local community organisation, and c) having experiences related to Ende children's health and survival programs and policies. The participants were chosen to have similar levels of seniority in their respective local government and community hierarchies in order that they could share their views free from the influence of superiors. A field supervisor from EDHO was selected to organise the focus group discussions (FGDs).

4.2.3 Data collection

The focus group discussions were conducted separately in the local language of *Bahasa Indonesia* in May 2013. Prior to the discussion, each participant received an explanation of the

study objectives and was asked to complete a consent form (see Appendix F). Participants discussed the current child mortality situation in Ende district, their roles and responsibilities for reducing child mortality, their perspectives on, and understanding and knowledge of child survival programs as well as the policies for Ende district (see Appendix H). All group participants were audio-recorded.

4.2.4 Data analysis

All recorded files were transcribed into *Bahasa Indonesia* and all the transcriptions were translated into *English*. Before coding, anonymous codes were applied for all informants to protect their identities. Semantic content analysis was applied to provide the frequencies with which words or sentences that were mentioned by the participants in the form of matrix (Stewart et al. 2006).

A content analysis identified similar patterns and themes supported by relevant quotes from selected participants, and interpretations were developed based on the patterns and major themes. For triangulation, the EDHO Annual Health Profile between 2008 and 2013 was used for internal validity purposes. Ethical clearance for this study was obtained from the author's university and from the National Institute of Health Research and Development (NIHRD), Indonesian Ministry of Health Research Ethics Committees (see Appendices C and D).

4.3 Results

Table 4.1 presents the characteristics of participants from the government and community groups. The participants from the government group included six EDHO supervisors from different health units, one participant from the local women's empowerment district agency, and one from the local child protection district agency. The community group consisted of one Ende Alert Village (so-called *Desa Siaga*) representative, one *Puskesmas* (community health centre or CHC) partnership supervisor, a local maternity clinic supervisor (a catholic sister), a community engagement supervisor, and a member of the local women's group. Almost all

participants were married, and a majority had graduated from college or university. The following are ten key themes identified from the FGDs.

Table 4.1. The focus group discussion participant characteristics

Characteristics	Government group (G)	Community group (C)
Number of participants	8	5
Sex		
<i>Male</i>	2	2
<i>Female</i>	6	3
Marital status		
<i>Married</i>	8	4
<i>Single</i>	0	1
Highest education		
<i>Junior high school or below</i>	-	-
<i>Senior high school</i>	1	2
<i>Academy/University</i>	7	3

Health care inequity issues related to child mortality

Most of the participants indicated that there have been inequities in the provision of health care services, with the rural and remote areas being disadvantaged. The lack of health staff in these areas was seen as a major issue. A majority of the participants reported that many remote villages had a shortage or even a complete absence of midwives or other childbirth-related health staff. It was reported that some health staff did not always stay in their village. A few participants expressed concern that midwives and nurses were unwilling to be placed in rural and remote areas. Hence, some CHCs had a surplus of midwives or nurses while others did not:

...medical staff are still very limited in villages. Most of the staff uncontrollably prefer staying in Ende town to the villages. They just come for three of six working days. This fact consequently has a bad impact on the management of health care services to the villagers. Many health care problems there are left unsolved, including those experienced by pregnant women, who are supposed to be handled as soon as possible. (G5, G=Government)

Actually the provision of health staff in Ende district has been sufficient because in this region the ratio of the supply and demand of the staff is equal. However, the distribution to all areas is not fair because most of the staff avoid working at remote places. As long as they have good relationships with their leaders, they can easily choose to work in the places they want to. It is not surprising that we find too many nurses and midwives in certain Puskesmas, while other Puskesmas do not have midwives and nurses. (C1, C=Community)

Drug unavailability at some CHCs and village health posts was seen as another factor affecting the geographic inequality of child survival, as illustrated by the following quote from a participant of the government group:

Medicine is another problem... but it is still difficult to solve the problem concerned if there is not enough medicine there. Many Puskesmas, pustu [community health sub-centre], and polindes [village maternity post] are still in lack of medicines... it is difficult for us to help them if the medicine is not appropriate. This happens in Ende district... the problem of late distribution of medicines in this district lasts for four to five months almost every year. (G2)

Health staff skills and performance

Most of the participants indicated that there were problems with child health care personnel skills and performance. A majority reported examples of midwives or nurses who refused to serve their patients despite their arrival in the middle of the night or after operational hours. There were reports of favouritism and of unwillingness to help by village midwives and nurses:

Mostly, those patients who have a close relationship with midwife will get priority in the service. The midwife will come to serve them soon, even at midnight. On the other hand, those who do not have close relationships with midwives will not be handled easily. Some midwives even tell a lie that they are not available at the moment of need, just because they do not want to help the patients. This is a real and factual condition here, and many patients have experienced this. (G5)

It is about how to handle a patient with heart. In addition, her [midwife] humanity sense is also questionable. It is so very insensitive to refuse handling a sick patient just because it is not during the office hours. Moreover, she is also a woman, who should prioritise humanity in service. (G4)

Several participants expressed disappointment with the attitudes of young graduates, who they saw as being financially motivated and lacking the motivation to work in remote areas:

Our children nowadays do not take medical or nursing schools based on their talent. The reason why they choose those fields is that they think graduates of health schools have a greater chance to get jobs upon graduation. There are a lot of jobs available; civil servants, in clinics, or wherever, the jobs are available. (G8)

When we see from the human resources point of view, we find that the staff, both trained and untrained, have not paid serious attention to this particular condition... civil servants tend to focus more on financial benefits; they will be hesitant to serve people if there is no money given to them. (C2)

One participant suggested that this was because many midwifery or nursing schools were run primarily as businesses rather than as preparation programs for their graduates with the essential skills required to serve in the CHCs or other health facilities:

Nowadays, many new midwifery and nursing schools have been built, I think mostly with the aim of profit making, so most of the graduates are not qualified... they may be good at competence, but many are because of money. It is very different when they help patients directly. In short, they need more practice and skills... we issue a policy, which requires all health care staff to have training prior to working in the society. (G1)

The need of health information

Most of the participants from both groups suggested that there is a need for more health information to be provided by midwives and other related health personnel. A few suggested that this could be seen as an indirect cause of child deaths:

What I have followed and witnessed so far, the main cause of the deaths of babies or toddlers in this regency lies in the hands of health care staff... that the midwives and nurses and other health staff should have provided families, especially pregnant women, with adequate information about baby care starting from the beginning of the pregnancy. (C2)

There is minimal information about infectious diseases, which may lead to death given to the family. The health care workers do not provide adequate information to the families. That's all what I can say about this problem. (G3)

We [Ende district health office] need to support them at least by giving adequate information, so that they know how to live a healthy life. More than that, they can also plan for health programs to keep their family, especially their children healthy. (G1)

The importance of parents having adequate child health and survival knowledge and mothers regularly checking their pregnancy or child's health was emphasised by a few participants, while another pointed to mothers' lack of attention to and ignorance of the symptoms of illness as a causes of child death:

I think the death of the baby should be detected earlier... parents should have known about this. When the pregnancy is in its early periods, mothers should actively check the condition of the fetus and detect the possible problems that may exist and have got the proper ways to anticipate it. (G7)

In many cases mothers tend to ignore children's sickness. They only take their children to the hospital or clinic when the condition of the babies or toddlers is critical... mothers here do not give full attention to their children's health. (G2)

Use of traditional birth attendants

The continued use of traditional birth attendants (TBAs), especially in rural and remote areas, was seen as an indirect determinant of child deaths by some members of the community group. A lack of economic resources and the persistence of traditional beliefs were the main reasons identified for the continued use of TBAs. The following quotes illustrate the importance they attached to economic considerations:

The majority of people in the village prefer to deliver babies at home, in the village because it is more practical and economical. It is practical because... if they deliver the babies at clinics, they should pay certain amount of money for staying there and health care, while there is no specific financial preparation for the birth. (C4)

Economic status has its influence from its society. The example of economic status is about traditional birth attendants. In the NTT Maternal and Child Health Revolution program we have forbidden [that] the pregnant women to consult their pregnancy with traditional birth attendants. (C1)

TBAs were considered by the participants to be health volunteers who should not therefore assist deliveries at home. One expressed disappointment with the local district health office's actions to reduce the use of TBA in rural villages:

...traditional birth attendants are partners for village midwives. Their duty is to take the women at term to deliver babies at the nearest Puskesmas. Also, it is common in practice here that TBAs are forbidden to help the birth process at small and limited health centres in the villages. Instead, they should recommend taking the women to the Puskesmas. (C2)

In the program of revolution for Health of Mother and Child... forbidden for pregnant women to consult their pregnancy with a traditional birth attendant... what the health office has done to minimise the existence of the traditional birth attendant. (C1)

Gender inequity issues related to child health and mortality

Women's lack of involvement in decision-making, especially health-seeking decisions was seen by most participants as a gender inequity issue. The participants thought women should have been given more responsibility for decision-making by their husbands during pregnancy and after delivery. Women were perceived by most participants as facing difficulties in making decisions, especially pregnancy-related decisions and health-seeking decisions:

Decisions on when to get pregnant... when to visit clinics or other health care facilities, and what kinds of food to consume are still very weak. A good example is about food, the good ones are given to the husband or elderly people, while the pregnant woman only gets the left over. (G8)

For example, she will ask for agreement from her husband and family to take the sick toddler to the clinic. She cannot decide herself because she has no power to do so. Besides, the fact that some families still do not have any knowledge about health care sometimes brings fatal situations. Their innocence may cause child deaths. (G1)

Why should we [women] take part in the program if our aspiration is not heard, let alone accommodated? This is women's aspiration. On the one hand, we are required to participate in health care program; on the other hand our opinions or suggestions are not accommodated. (C5)

Husbands were portrayed as providing little support to their wives, and rarely accompanying them to health facilities. This was seen as contributing to women lacking awareness of their children's illnesses and their own health needs, as illustrated by the following participants' explanations:

The reason for the death of the child is because the heavy burden given to the women or mothers... women or mothers still have to do a lot of work at home, ranging from doing the household work, taking care of husband, cooking, and when they are with baby they must also feed their toddlers, or when are pregnant, they must also check their condition at clinics or hospital. This heavy amount of work deprives the women/mothers from taking care of their babies or toddlers... according to the standards from the health office. (G4)

In fact, those poor women are required to watch their cows at pastures, even though they are pregnant. Of course, they suffer a lot and some even die because of these heavy burdens. For example, they had accidents such as tripping over stones while pulling cows' rope. Their physical health conditions are ignored because their husband and big families force them to work hard even though they are pregnant. (C5)

Many husbands did not accompany their wives to have the pregnancy checked in the Puskesmas. Women... do not pay attention to the development of their fetus in each stage of the pregnancy. They do not take care about the health of their fetus and themselves. (C4)

Some participants pointed to husbands lacking understanding of the need to provide healthy and nutritious food to their wives during pregnancy, to the detriment of the baby's health. One described it in this way:

We know that actually the nutrition of a pregnant woman should be fulfilled right from its early time. However, if the husband does not have a good perception and comprehension of the health of his pregnant wife, no good things can be done. He is supposed to arrange the correct consumption habits of his wife and child... this

is closely related to behaviour and habits, not at the level of the style yet. I thought... which gives women smaller portions than their husbands. (C5)

Another participant reported a disturbing case in which the husband did not want his wife to deliver at the CHC and this decision led to the death of his baby. After the child's death, the head of the village and sub-district suggested that the father should take his wife to the hospital, but he rejected the idea because he was afraid that no one would care of his dog:

There was a woman of 43 years old who got pregnant. Her baby was alive before delivery. Since her hemoglobin was very low, the woman was advised to deliver at the nearest Puskesmas. However, her husband strongly rejected the advice. He didn't allow his wife to deliver the baby at the Puskesmas and his wife finally delivered the baby at home... the baby was dead when it was born... in the Puskesmas we suggested taking her to the hospital to get blood transfusion. Everybody in the village strongly persuaded the husband to take his wife to the hospital ... the reason was so illogical and ridiculous. He was worried about his dog; no one would take care of his dog if he had to accompany his wife in the hospital. (G1)

Other participants reported husbands' having misconceptions about the supplementary feeding program for infants, which provides children under-five with eggs through the *Posyandu* (integrated health post). They saw a strong need to promote this infant feeding program to fathers:

When babies or toddlers are taken to the Posyandu by their mothers, they will get supplementary food like eggs and take the food home. Unfortunately, at home the eggs are not consumed by the kids but...It is their fathers who finish the eggs taken from the Posyandu. (C5)

We give supplementary food for toddlers, but their fathers or older siblings also consume the food, and in the long run the toddlers remain in the condition of malnutrition. (G7)

In addition, a preference for sons was identified as a gender-related issue by a few participants:

*When the babies are born, the culture in most of the regions here [Ende] tends to distinguish male children from female. For example, upon the birth of a baby there is a saying: **ko ata, toko ata, toko kita** (this baby is not ours, if it is a baby girl, because when she becomes an adult, she will get married and follow her husband's family) or (this is ours, if it is a baby boy, because when he becomes an adult, he will get married and remains in his big family or clan). (C5)*

Unplanned pregnancy among young women

A few participants linked unplanned pregnancy among women, especially young women, to the number of infant deaths. If the spacing between children was 'too close', or pregnancy occurred 'too old' and 'too often', it would not only harm the mothers' health but also their birth outcomes. Furthermore, women with unplanned pregnancies were seen as less prepared in terms of knowledge and the capacity to care for a child:

The majority of pregnancies in our society are not planned... we even witnessed how a mother was not ready or planned to control the pregnancy, or she did not have baby's clothes when delivering the baby. Everything seems to happen suddenly, no prior preparation at all, so the baby died because the mother had no preparation at all, just brought their body to the clinic. (G5)

Pregnant women with poor nutrition and also with chronic energy deficiency are increasing from year to year. Mostly this condition is caused by lack of attention and care due to the misconception of the society, which assumes that pregnancy is natural for every woman; hence, there is no need to make special preparation for it. (G8)

One participant emphasised the need for young women to understand the impact of unplanned pregnancy on infant deaths:

It is urgent to promote health care to female children ever since they are ten years old. We cannot wait until the time when they are pregnant some day and give them information about the importance of healthy life. So far we only focus on the pregnancy, breastfeeding, and baby or toddler care until five years of age. Admittedly [urban] teenagers in this era know more information about sex than we did. (G6)

Challenging issues for reducing child mortality and improving child health

Challenges facing government and community organisations to reduce child deaths in Ende district and their roles and responsibilities in addressing these challenges emerged as a theme in the discussions. In the government group, most participants stated that reducing child deaths is not only the responsibility of the local District Health Office. The main challenge seen by this group was changing family and community knowledge, attitudes and practices through continuous maternal and child health (MCH) intervention programs. They saw collaboration between local agencies and a strong political agenda to support health care promotion as integral to this process. The need to change from a curative paradigm to a health promotion and

prevention paradigm was seen as important for Ende district and as having family financial benefits:

I think health care promotion should be increased. Yes, it is about promotion and counselling to people and to society. Honestly, so far health care promotion has been put as the very last priority. It just began to be prioritised recently. (G6)

Health care promotion... because when they have good understanding about health care, families will have proper concept and can make good plans. For example, if one of their family members gets a particular disease, they know what step to do. If they cannot overcome the problem themselves, at least they know where to contact for further help... when they do not have adequate information and knowledge; they will just stay at home with nothing to do to take proper steps for handling their own family members who are sick. (G1)

I think that health care promotion is urgent. Promotion is important in order to make people know about health care information. It is common that we prefer people hospitalised and use the provided medicine rather than preventing the sickness by promotion. More money is spent on curing diseases rather than preventing them.... People can use the cost for health care for their children's school tuition or building their house. (G5)

One participant emphasised the importance of targeted health care services and the need for continuous health promotion programs. Another expressed concerns about the lack of commitment from health staff to providing quality health care services to the poor population:

I think we should prepare and plan the target of our services with proper timetables. In addition, we should also prepare for the continuous promotion and socialisation programs. (G2)

In my opinion, it's all about commitment. Are we as health care staff willing to serve poor people?... there won't be any problems if we willingly and honestly serve, care, and help those people with their limited financial and educational backgrounds. If they are still under-qualified in terms of human resources, what should we do to make them more qualified?... that everything depends on our own commitment with our job. (G5)

The involvement and collaboration with of other agencies was considered essential to reducing child deaths and improving mothers' status, especially for underdeveloped villages.

For example, as described by the following participants:

However, participation from other sectors of life is also important in this case. Sectors like agriculture, women empowerment, and transportation also play important roles to enhance healthy villages. Women empowerment sector, for example, is expected to give great contributions to increase women's status. Transportation sector does play an

important role because poor transportation (roads in this case) will also influence the process for transporting patients from a village to health care centres. (G1)

If we are really willing to solve this problem [child deaths in Ende], the first thing to consider is collaboration. Yes, collaboration. Health office cannot claim that it is the single fighter, so it will struggle itself because it definitely can't. (C1)

This participant stated that participation by all community members is required in order to minimise health inequity issues. Even though the local government provided the community with health insurance, the insurance scheme has not been distributed equally to the whole population. Another participant pointed to the low quality of service provided to those with community health insurance:

Health insurance and birth insurance cannot guarantee that all the people in the society are willing to take part and the insurance itself is not aimed to serve all of them. For example, Posyandu has its own budget and it is for health affairs (silent), so people will assume that this is health office's business and they have nothing to do with the program. Actually, the program of Posyandu needs participation from all elements in the society, and it is actually the main factor in the program. Otherwise, the idea of equity is only rhetoric. (C1)

Delivery insurance seems to be not working at all in this case because they prefer serving patients with cash payment to those with the insurance cards. This is quite different from our services in the private sector. For us serving patients seriously is a must, so we don't focus on financial benefits. (C2)

Budget allocation for maternal and child health programs

Most of the participants from the community group saw a lack of political and budgetary support from the local government as a major challenge to reducing child deaths, as exemplified by the following quotes:

Budget should be available. However, as stated by another participant, if the program is just a "project", and indeed so far this is just a project in the development of this region and NTT province in general, this is just a program, which means that by the end of the project, community's behaviours will return to the previous habits. (C5)

It certainly includes budgeting because we plan the budget here on the table without knowing [silent] the real situation of the society. We only know the situation here but not in the real society. I am saying this based on my two-year experience, and I have seen no transparency. Without transparency we cannot obtain the proposed outcomes. I may say this issue is just a 'project', yes just a 'project'. Oops, I am sorry for saying this, but this is from my viewpoint as purely an advocate, purely from an independent organization. Yes, this is just a 'project', and the more the budget, the more people are drawn to the project and once the

project is finished, they will go back as usual, so they only pursued the project. (C1)

One participant pointed to a need for *DPRD* Ende (the Ende District House of Representatives) to give greater scrutiny to the proposed district health budget and the priority given to maternal and child health programs:

We all know that the problem of infant mortality is so communal and complex that we should find the best solution together. That's why I think we should oversee the budget and ask for the participation of the District House of Representatives to take control and watch the decision makers to accommodate the programs which support the health of mothers and children. So, it requires the participation of all parties and budget. (C5)

This participant expressed disappointment with members of parliament giving a low priority to the health needs of women and children in the local budget:

Members of parliament should ask themselves to what extent they had evaluated the community [needs being met] and motivated the local stakeholders on what to do, so the budget can be allocated appropriately. However, if the parliament members just behave as bosses at the top and they do not want to experience people's pain, it's useless. I have often protested in the parliament that there should be enough budgets for women empowerment, for the health of mothers and children. There should be vivid figures ... how many per cent are allocated. Well, it all goes back to their mentality. (C5)

Community participation for child survival

A majority of the community group participants saw active community participation in health programs as important to increasing child survival. One shared their successful experience of reducing the number of child deaths in their village by involving community members in helping pregnant women to deliver at the closest health facility and setting up a database:

Since the establishment of Desa Siaga [Alert Village] on 25 June until now, we haven't found any single case of baby/toddler death there. This is because we pay full attention to the vision and mission of the Ministry of Health, which promotes self-enhanced society for healthy life, serving for healthy people. We have initiated a database collection for pregnant women; encourage pregnant women to have regular check-ups for pregnancy at Posyandu [integrated village health post]. We also suggest taking their baby/toddler to the Posyandu in order to be examined for any problems of malnutrition in babies/toddlers. (C3)

Another participant reported that, despite the lack of financial support from the local government, the community had managed to fund and build a waiting house near to a CHC

(Rumah Tunggu). This waiting house was built to enable pregnant women to stay a few days before full term rather than to face the choice between arduous travel to deliver at the CHC or home delivery:

Initially we have proposed the budget to EDHO, but they did not accept our proposed budget for building waiting house...we have built a waiting house for women at term with a very good management and the budget is by the people themselves, not from the fund of non-governmental organisations or government. The budget is from the Village Income and Village Expense Budget. For your information, the program is now a pilot project. (C1)

Local traditions and beliefs during pregnancy and after delivery

The participants described a range of local ceremonies and traditions that continue to exist, mostly in the rural and remote areas, for women during and after delivery. A pregnant woman is required by tradition to confess her mistakes during pregnancy to her husband, neighbours, parents and parents-in-law, usually during the last trimester of pregnancy. It is believed that if women follow this tradition, the delivery process will be free from problems. The main problem participants saw being associated with this tradition was that if pregnant women had to travel long distances to their relatives' home, there may be adverse consequences for their health and their child's survival. Mothers often had to travel to mountainous areas or to other islands using public transportation on damaged roads, as described in the following quote:

At that time... she was required to follow a traditional ceremony, in which she had to apologise to her in-laws (parents and brother or sister) and everybody lives together with her. According to their belief, the birth problem faced by this woman was caused by a curse because of her faults to those people before. She had to follow the procedure in order to be able to deliver the baby. I just could not imagine... she should apologise live in distant regions. It takes time to make them come to forgive this poor woman. (G1)

For so many times... everybody surrounding her will require her to apologise to people to whom she once made mistakes. In particular critical situations, she is even forced to talk honestly about her pregnancy and tell everybody who the baby's father is, for example. This habit is still practised and has become a culture here after the woman apologises and confesses her mistakes or secret of her pregnancy, probably because of psychological stress and fear, all of her muscles become stiff. After she has shared her problems or secrets that she has hidden so far, and told everything honestly, the birth process becomes easy. So... the habits and culture create psychological stress and tension to the woman, and once she is relieved. (C2)

After the delivery, women and their babies are by tradition not allowed to go out from their house unless they have held the ceremony known as *Wa'u Nata* or *Ra Ndawa*, involving sacrificing animals, usually pigs. The participants expressed concerns with this prohibition on movement because it might prevent the mother from seeking postnatal care or using child health services:

After delivering a baby, woman/mother is not allowed to go out of the house before this ceremony is held. She is only allowed to do so if Wa'u Nata has been conducted. There is no excuse for the woman to step out from the house for whatever the reason is, even when she is sick unless the Wa'u Nata ceremony is held... the baby is not allowed to be taken to the Posyandu [integrated village health post] for body weighing or other health care services. If the family or parents have slaughtered animals like pigs for the ceremony. Then, both the mother and the baby are released from the prohibitions... also are allowed to visit health care centres or meet the health care staff ... and this culture is still practised there. (G8)

After the baby is born, there is a tradition called "Ra Ndawa", which requires the family to slaughter a big pig for the rite. You see, it is very contradictory. Before the birth, the family doesn't have any money to pay for the birth, but slaughtering a big (of course expensive) is quite affordable for the family, even though economically the mother is poor. (C4)

Some regions of Ende were reported to have food prohibitions for women during pregnancy and after delivery:

According to local people's belief, consuming fish or meat will make the breast milk smell fishy. Hence, pregnant women are only allowed to consume corn. It lasts for up to three months, and then the women are allowed to consume normal food. (C2)

I got this experience when I worked at a CHC near the Ende coast. There was a prohibition on breastfeeding woman to consume rice. She was not allowed to eat rice and eggs. They said that if she ate eggs, her baby would get an ulcer, and also when the baby sucked mom's nipple, it smelt fishy. In addition, we were not allowed to eat barley in our family. (G2)

The last statement indicates that local people may be more concerned about this local belief than with ensuring mothers' and children's health wellbeing. These local beliefs and traditions are stronger in rural and remote areas and may adversely influence children's health and survival.

4.4 Discussion

The government and community group discussions identify a range of health service delivery issues may increase the risk of child mortality, especially in rural and remote areas. The issues identified relate to health personnel skills and motivation, service availability, health care inequity and gender inequity, and the persistent influence of traditional beliefs in this underdeveloped district of Indonesia.

The participants suggested that there is a need for increased promotion of child health to rural families and a need to distribute more midwives with adequate child health skills to rural and remote areas. However, the range of solutions they suggested appears to be only partial, and tend to be specific to their own roles and sectors, rather than involving collaboration between the government agencies and community leaders and organisations.

A need to provide regular training on integrated maternal and child health to midwives is apparent. There are concerns about new midwife graduates possessing inadequate skills and knowledge in child health and survival, which were attributed to low quality teaching at recently-established midwifery or nursing schools. To tackle this issue, local governments should monitor and evaluate midwifery and nursing schools' curricula to ensure that maternal and child health care issues, especially those facing rural and remote areas, are covered adequately. Local governments should also work with the Indonesian Ministry of Health and Ministry of Education to conduct accreditation of these schools (Ministry of Education and Culture 2011).

Young graduates and village midwives are seen as lacking motivation to work in rural and remote areas, due to the added financial rewards from working in urban areas (Makowiecka et al. 2008). It is important for local governments to provide incentives for those who are willing to work in remote villages or areas with geographical challenges in order to improve the quality of child health care provision (Dickson et al. 2014; Ensor et al. 2009; Henderson and Tulloch 2008; Prytherch et al. 2013). Another potential solution would be the provision of career support

to village midwives from both local and central governments, especially for those who have been working many years and possibly also for volunteers (BAPPENAS 2005). Many village midwives work on a temporary contract or a voluntary basis, and in many cases they have done so over many years. Enhancing their opportunities to transfer to permanent status may improve their morale and motivation to deliver better child health services (BAPPENAS 2005).

The responses from the community group demonstrate that the use of TBA services continues in rural and remote areas, and this needs to be addressed by local governments by improving the quality of health services provided by midwives (Makowiecka et al. 2008; Pardosi et al. 2015). The community participants were concerned about the lack of effort by local governments to improve their partnerships with local TBAs. The Indonesian Ministry of Health (2012) has recommended involving TBAs in health volunteer training and that TBAs should not primarily be responsible for pregnant women during delivery.

The responses from the community group show their concerns for rural women experiencing the absence of midwives in assisting with their child health problems after travelling long distances to the closest health facility (Gabrysch and Campbell 2009; O'Donnell 2007). A few community informants suggested there is a need to provide new health facilities in rural and remote areas, despite of their challenging geographical conditions. Pardosi et al. (2015) found rural mothers also see a need for closer health facilities, such as *Puskesmas Pembantu* (community health sub-centre) or village health posts (*Pos Kesehatan Desa*). This would require increased collaboration between local governments and provincial and national governments, and prioritisation of the expansion of rural primary care services (Kruk et al. 2010).

The focus group discussions highlight gender inequity issues in this district of Indonesia. Women's lack of participation in decision-making in general and in child health-seeking and pregnancy decision-making in particular were identified as concerns (Gipson et al. 2008; Tsui et al. 2010). The responses from the government group also suggest rural husbands should be

encouraged to share and to provide more opportunities for their wives to make decisions regarding their children's health (Hodnett et al. 2013; Shefner-Rogers and Sood 2004). While gender inequity was identified as a problem by the participants, it was notable that none put forward solutions as to how best to promote attitudinal and related health behavioural change.

Enhancing the education of both fathers and their wives about child health and survival influences and increasing their involvement in health education and seeking decision-making would enable them to prevent early-age illnesses or deaths, as suggested by a majority of the community informants and some government participants (Mwambete and Joseph 2010; Tweheyo et al. 2010). There is a need for continuous dissemination about local child-feeding programs to fathers in order to address misconceptions about these programs, which lead to their children and pregnant wives having inadequate nutrition, as suggested by both government and community participants (Holmes et al. 2010; Piwoz et al. 2003). A greater involvement of local community leaders in the child health programs may stimulate the spread of information about child health to rural communities in general and rural husbands in particular, considering the high levels of esteem they command (Ki-Moon 2010; Nair et al. 2010).

Helping to prevent unplanned pregnancy, especially among older and younger women, by the provision of information on family planning and reproductive health by village midwives through the national '*empat terlalu*' (too young, too old, too often and too close) program, as mentioned by most informants of this study, also could reduce the risk of neonatal and maternal deaths (Lawn et al. 2009; Ministry of Health 2010; Mullany 2006; Singh et al. 2010; Speizer et al. 2005; I. Utomo et al. 2014; Yanikkerem et al. 2013).

As elsewhere in Indonesia, local traditions and food prohibitions related to childbirth continue to exist especially in rural and remote areas of Ende district (Suryawati 2007). This indicates the need for continuous health promotion and local interventions especially in rural communities, which have strong traditional values in order to improve the people's understanding and knowledge of child health (Z. Hill et al. 2004; Victora et al. 2003).

Our findings indicate inadequate district budgets for child health and an unequal distribution of health insurance as major concerns. This reflects the low priority given by the local district health office and elected representatives to improving coverage of the disadvantaged population, and points to a need for local government to increase their political commitment to and budgets for child health (Acuin et al. 2011; Ensor and Cooper 2004; Haws et al. 2007; La Vincente et al. 2013; B. Utomo et al. 2011). The responses from some community participants point to a need to involve local community leaders in planning local government health budgets and increasing local budget transparency and government accountability (Ki-Moon 2010). Furthermore, the local governments should also tackle the gender inequity issues by implementing gender-responsive planning and budgeting (GRPB), by allocating more resources for maternal and child health in rural communities, as recommended by community participants (Ki-Moon 2010; Noerdin 2014).

Both the community leaders and the local government officials identified inadequate collaboration as an issue. However, their perceptions of the needs for collaboration differed notably. The community leader participants demonstrated their awareness of the need for and their willingness to be involved in village child health programs by starting a local *waiting house* ('rumah tunggu').initiative, which supports pregnant women who live in distant villages to deliver at a health facility by residing a few days before and after delivery in a house that is close to the *Puskesmas* (Eckermann and Deodato 2008; Lassi et al. 2010). Their comments indicate that it is necessary for local governments to develop collaboration with local community leaders and show a greater appreciation of community efforts. These strategies have been proven to be effective ways of promoting behavioural change and reducing child mortality even with limited resources (Farnsworth et al. 2014; Martines et al. 2005). In contrast, the local government participants pointed to a lack of coordination between the local district health office and other local government agencies and to inefficiencies in the local maternal and child health programs.

This study has illustrated local governments' lack of understanding and their implementation of their roles and responsibilities relating to reducing infant and child deaths in Ende district, and has generated new insights into gender and health care inequity issues and the problems of health care services performance by village midwives in this district of Eastern Indonesia. In view of the small sample size, caution should be exercised when generalising the results to a wider population of government officials and community leaders. In addition, some of the findings may not apply to districts with different characteristics to Ende.

4.5 Conclusion

This study identifies a pressing need for Ende local governments to improve the quality of rural primary health care, increase the distribution of midwives in rural and remote areas, and increase the involvement of local community leaders in district health programs. More actions by local government agencies in continuous collaboration and shared leadership with local community leaders in order to address health care and gender inequity issues are needed to improve child health and survival in this predominantly rural area of Eastern Indonesia.

4.6 Contributors

Jerico Franciscus Pardosi wrote the manuscripts, performed data analyses and interpretations and acted as a corresponding author (80% of the work). Nick Parr supervised the development of manuscripts, edited and assisted in manuscripts evaluation and provided some substantive suggestions (10% of the work). Salut Muhidin helped to edit and evaluate the manuscripts (10% of the work).

4.7 Acknowledgements

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Chapter 5 Conclusion

5.1 Introduction

This thesis examines early-age health, survival and inequity issues in a rural Eastern district in Indonesia. This concluding chapter presents the summary of main findings in Section 5.2. In Section 5.3, the policy implications of the thesis for governments, communities and families are elaborated and specific recommendations for reducing early-age deaths and related inequity issues, especially for rural and remote areas, are presented. The contributions of this thesis to current knowledge are addressed in Section 5.4. Section 5.5 discusses the limitations of this study and its recommendations for future directions of research relating to child survival and inequity issues in Indonesia. Finally, Section 5.6 focuses the personal evaluations and reflections of this thesis.

5.2 Summary of Main Findings

All findings are derived from previous chapters. Chapter 2 analyses the results from in-depth interviews addressing mothers' pregnancy, delivery and early-age survival experiences, including inequity issues in health service delivery and gender issues. A similar approach was also applied on fathers and grandmothers in the study reported in Chapter 3, which explores fathers' and grandmothers' knowledge, support and experiences related to infant health, survival, death and health-related decision-making within their family. In Chapter 4, focus group discussions (FGDs) were administered to local community leaders and government officials to identify their perspectives on child health, mortality and inequity issues such as gender and health care. Focus group discussions were conducted to understand local government officials and community leaders' roles and responsibilities in reducing child deaths and improving infant survival, and the results are presented. The following part summarises the most significant findings from Chapters 2, 3 and 4.

The key themes in Chapter 2 are mothers' pregnancy and delivery experiences, health personnel's attitudes, mothers' knowledge of child health and determinants of survival, health-seeking behaviour, child health services, early-age death experience, and family and community support.

Most of the mothers were found to be unable to identify basic childhood illness signs. Only very few mothers had received sufficient information relating to their pregnancy from CHC midwife during antenatal and postnatal visits. Hence, almost all mothers reported a need for more information to be provided on child health from the village midwife or the midwife at the local CHC. Most mothers with neonatal deaths did not know the danger signs of infant illness, including the cause of their infant's death. The mothers had not received any information from health personnel (doctor, midwives or nurses) relating to their child's death. This implies a problem with the implementation of health education for mothers by midwives and other related health staff during antenatal or postnatal visits and infant treatments.

The findings indicate inappropriate or discomforting attitudes of midwives towards mothers during pregnancy and, especially, during delivery. The responses recorded from mothers demonstrate cases in which the absence of midwives or other health personnel has contributed to neonatal deaths, particularly those from the East, West and North regions where difficulties in accessing local child health services during their child's illnesses or delivery complications were experienced. A few mothers from the North and West regions had not received a *Jamkesmas card*. As a result, these mothers still had to pay to access maternal, neonatal and child health (MNCH), which is particularly difficult for mothers with irregular incomes.

A few of the mothers reported that village midwives did not live in their village or *Puskesmas*. As a result, the mothers who had childbirth at home favoured TBAs rather than the village midwife as their birth attendants. These responses illustrate how TBAs not only help the mother with the delivery but also provide fee-free assistance to take care of both mother and baby after birth and that TBAs are available 24/7, in contrast to the village midwife.

The interviewed mothers received a range of different forms of support from their husbands during their pregnancy. Nevertheless, difficulty in making health-seeking decisions for their child was experienced by mothers in rural and remote areas. Only a small number of mothers had the opportunity to discuss decisions about their child's illness with their husbands. It is notable that mothers without early-age deaths had received more support from their husbands not only during pregnancy and delivery but also after-delivery than those with early-age deaths.

Chapter 3 demonstrates fathers' and paternal grandmothers' knowledge and experiences relating to infant health and survival and the support given to mothers during pregnancy, delivery and child raising by applying in-depth interviews. The key themes are fathers' and grandmothers' knowledge of infant health and survival, fathers' social support and sources of child health information, fathers' and grandmothers' support during pregnancy and delivery, infant death experiences, health services performance and decision-making for infant survival.

The fathers showed only a very simple knowledge of the determinants of infant health and survival, such as providing enough food. The four fathers interviewed, who had experienced an infant death and were first-time fathers, displayed an even more limited knowledge of infant health than the other fathers. Almost all the fathers did not know the danger signs of infant illnesses. Compared to the mothers (*Chapter 2*), the fathers in this study had even less basic knowledge of childhood illness and its dangers signs. None of the fathers interviewed had received health information from local health staff concerning infant health and survival. This points to a need for publicising local child health education activities to fathers to increase their involvement in ensuring infant health and survival.

The fathers in this study tended to make the final decisions on their infant's health issues, despite their limited knowledge of infant health and their less involvement in caring their infant than that of their wives. The results from *Chapter 3* indicate that several first-time fathers made decisions about their infant's illnesses without asking for their wife's opinions. Hardly any fathers had received any invitations from their village midwife to attend the local health

promotion program. This indicates a need to educate fathers through local child health activities so that they will agree to allow their wives to make health decisions without consulting them, especially in emergency situations.

The reports from Chapter 3 show grandmothers to be a major source of health information for fathers, despite their inadequate knowledge of infant health and survival. Moreover, the findings show the greater importance of grandmothers compared to fathers in providing support and assistance for mothers during pregnancy, childbirth and breastfeeding. This implies a need for midwives and other local CHC health staff to involve grandmothers in local child health interventions.

Low quality care services such as health personnel unavailability, discomfort during delivery and long distances to the closest CHC are still a challenge, according to rural fathers and grandmothers, supporting the evidence provided by mothers in Chapter 2. This indicates a need to provide better quality rural health care services by increasing the distribution of midwives to rural and remote areas and renovating birth facility conditions at health centres.

Chapter 4 examines two group discussions (FGDs), one with five local community leaders and the other with eight government officials, to understand their perspectives, knowledge and opinions relating to Ende's child mortality situation, including the implementation of their roles and responsibilities in reducing child deaths and implementing child health policies. In both FGDs, all participants had experiences related to Ende's child health and survival programs and policies. The key themes are health care inequity issues related to child mortality, health staff skills and performance, the need for health information, use of traditional birth attendants, gender inequity issues related to child mortality, unplanned pregnancy among young women, challenging issues related to child health and mortality, budget allocations for child health programs, community participation in improving child survival, and local traditions and beliefs relating to during and after delivery.

The results demonstrate that the use of TBA services continues, mostly in the rural and remote areas. This finding is consistent with those from rural mothers (Chapter 2) and fathers (Chapter 3). The community participants felt disappointed with the lack of effort made by EDHO to reduce the number of TBAs in rural and remote villages.

Several informants from the community group also reported an absence or shortage of midwives in rural and remote villages as an issue. This finding is consistent with the results of Chapter 2 and 3 and points to a need to enhance the quality of health services provided by midwives and their distribution to rural and remote villages.

There is a need for increasing child health promotion relating to early-age health and survival in rural and remote areas in local CHCs, as was stated by most of the community and government participants reported in Chapters 2 and 3. Several community respondents and a few government participants perceived the lack of child health information from midwives to be an indirect cause of infant death. Unplanned pregnancy in rural areas was seen by the government participants as another cause of infant deaths which was associated with inadequate health care promotion by midwives and other health staff to women, especially young women.

The responses from the community and government groups demonstrate that a range of local traditions related to childbirth continue to exist among rural families and that this requires local interventions in the form of continuous health promotion to expand rural communities understanding and knowledge of child health practices.

The results from both groups illustrate that young midwife graduates are seen as lacking skills and knowledge in relation to child health and survival, due to low quality of teaching at newly-established midwifery or nursing schools. Young graduates and village midwives are perceived as lacking motivation to work in rural and remote areas, because of the added financial rewards from working in urban areas.

Women's lack of participation in decision-making for their pregnancy and child health was observed by most of the government and community participants. The findings suggest a need

to educate both fathers and mothers relating to child health and survival to prevent early-age deaths. Fathers were portrayed by several government and community informants as providing little support to their wives and having limited knowledge of child health and survival. Unfortunately, none of community and government participants put forward solutions to promote husbands' health behavioural change towards their wives and their children's health.

The findings from the community participants indicate inadequate district budgets for child health and an unequal distribution of health insurance as a major concern. The responses from several community participants point to a need to involve local community leaders in planning local health budgets. Both groups of participants suggest partial solutions relating to child survival and mortality issues and tend to be specific only to their own roles and sectors with less collaboration with other sectors or community organisations. This indicates a need for collaboration and sharing leadership between government agencies and local community leaders in reducing child mortality especially for disadvantaged populations.

Comparing the findings from all interviewed participants (mothers, fathers, grandmothers, local community leaders and local government agencies), a number of common and contrasting themes are evident. The common themes are related to the low quality of health services provided by midwives and local CHCs to rural and remote regions, the limited knowledge of child health and survival among fathers and mothers as a result of a lack of health education and promotion effort by EDHO, maldistribution of midwives and other-related health personnel, and gender inequity as a cause of rural women's difficulty in decision-making for their infant's health.

The mothers reported having their husband's full support during delivery, including having him accompany them to the health facility. However several fathers did not want to respond about their involvement during their child's delivery. Most of the mothers reported that their husband held the health decision-making power, and did not provide enough opportunity to the mother to be involved in the decision-making, whereas the fathers indicated that they asked

their wives' opinions before making final decisions. Furthermore, several fathers said they provided opportunities for their wives to make their child health decisions without having to wait for their approval.

A majority of the fathers who had an infant death experience did not provide detailed information about their infant death, even after probing. In contrast the mothers who had infant death experience were willing to share their stories.

Key themes such as unplanned pregnancy among young women, budget allocation for maternal and child health program, and issues related to the lack of coordination between and within local government agencies and its alignment with local community leaders were only found among local government in the findings of Chapter 4. Moreover, despite the initiatives taken by local community leaders in providing *waiting houses* as shown in Chapter 4, neither the father nor the mother informants reported having received any support from their local community leaders relating to infant health and survival.

5.3 Policy Implications for Government and Community Leaders

This thesis suggests key policy implications for reducing early-age mortality and tackling gender and health care inequity issues in a rural district of Indonesia. The following implications are suggested for governments and community leaders.

The overall findings suggest a need for central government in collaboration with local governments to redevelop the national child health policy by focusing not only on mothers during antenatal visits and delivery, but also on post-natal visits. The results obtained from the mothers in Chapter 2 and from the fathers and grandmothers in Chapter 3 indicate a need for providing more post-natal services to ensure newborn survival among rural families. Most of the cases of early-age death in this study demonstrate its connection with poor quality of care services for newborn experienced by the mothers and fathers of this study.

In view of the poor quality of child health services in rural and remote areas, a majority of all the groups of participants (mothers, fathers/grandmothers, community leaders and

government officials) share a view of the need for village midwives and other health personnel relating to maternal and child health services to improve their basic skills and knowledge in order to improve the quality of care during antenatal and post-natal visits. Both central and district governments should provide regular training on integrated maternal and child health for midwives or other related health personnel for delivering better child health services for rural population.

A lack of midwives in rural and remote areas is evident. As a result, rural mothers tend to prefer using TBAs rather than village midwives during their pregnancy, delivery or even after delivery, as indicated in Chapters 2 and 4. It is essential for local governments to build on-going partnership between TBAs and midwives by involving TBAs as health volunteers. Furthermore, the local district health office needs to address this issue by increasing the distribution of village midwives and related health staff to rural and remote areas while at the same time enhancing the ability of village midwives, especially those who have been working many years, to transfer their status to permanent employees. This could improve their morale and motivation to deliver professional caring services in rural and remote areas.

The evidence in Chapter 4 also points to a specific need for local and provincial governments to monitor and evaluate midwifery or nursing schools curricula in order to meet the skills and competencies needed as a midwife or other-related health staff to improve the quality of health services to rural population.

Some of the evidence from Chapters 2 and 3 suggests the Indonesian Ministry of Health in collaboration with the East Nusa Tenggara provincial office and Ende District government should assess the condition of health centre facilities, especially birth-related facilities, in rural and remote areas, and indicates a need for renovating health centres birth-related facilities.

More importantly, this thesis identifies pressing need for improving child health education to be provided to mothers, fathers and grandmothers, as mentioned in Chapters 2 and 3. In particular, basic information relating to childhood illness and its danger signs should be

provided by midwives or related health personnel, because such knowledge has been found to be very limited among the mothers, fathers and grandmothers in this study. The findings of Chapter 3 suggest a need for local governments to increase the involvement of grandmothers in child health interventions in order to increase their awareness of infant survival issues and infant health services.

In regards to infant death experience, the evidence from the mothers and fathers indicates a lack of support provided to deal with grief and failure by health care providers to supply information to the family regarding the causes of their infant's death. This may have contributed to the unwillingness of fathers as well as grandmothers to discuss their experience of infant deaths. Hence, there may be a need to improve the communication skills of health staff so that they can provide information to mothers and fathers, and to assist them to deal with their loss and grief.

It is important to invite fathers to local child health promotion programs and campaigns to increase their awareness of infant survival and involvement in infant raising, including their participation in the local safe motherhood programs. This would allow mothers to participate more in child health-seeking decision or even make decisions without consulting their husbands, especially when a child requires emergency treatment. There is a need to promote maternal and child health to first-time fathers, most of whom have limited knowledge of infant health and survival, as reported in Chapter 3. Local government agencies in collaboration with local community leaders should develop reproductive health education for young couples to promote essential health information relating to pregnancy, delivery and early-age health care, and to reduce the number of unplanned pregnancies, as argued by government and community respondents.

Widening the public insurance distribution, especially for poorer mothers is recommended to tackle geographical inequities in health care services and to increase early-age survival in

Ende district. The current situation appears to be far from the expectations of the *Revolusi KIA* program in Ende District.

In relation to gender and health care inequity issues among rural mothers and fathers, the findings in Chapter 4 suggest the need for a harmonization and alignment of the efforts of local government agencies and local community leaders. Continuous communication and participation between the local district health office and other local government agencies along with local community leaders relating to the local maternal and child health programs would be essential to improve child health and survival in rural areas.

The discussions between the government and community leaders indicate the need for continuous health promotion and local interventions, especially for rural communities that still have strong traditional values, to increase the understanding and knowledge of child health in the community. The evidence from the mothers and fathers suggests greater involvement of their local community leaders in child health programs is needed to send the information concerning child health more broadly to rural communities in general and rural husbands in particular.

The local community initiatives of establishing waiting house (*rumah tunggu*) demonstrates the awareness and willingness of local community leaders to participate in the MCH revolution program, the so-called 2H2 (2 days before and 2 days after delivery), to ensure pregnant women to give birth at a health facility. This community-based activity could be implemented at other CHCs, especially for those pregnant women who had to travel long distances to reach the closest health facility, as mentioned in Chapters 2 and 4.

The findings from rural mothers indicate their difficulties in making child health decisions, which are mostly made by their husbands despite their husbands' inadequate knowledge of child health and illness, their being often away working on farms or at sea, and their lesser involvement in infant raising, similar to the findings from the interviewed fathers and grandmothers. This illustrates the importance of involving their wives in health-seeking

decisions to prevent delays in treatment or delays in accessing the closest health facility. Fathers should also provide support and assistance not only during pregnancy but also during delivery and in the care of newborn children. For grandmothers, there is an urgent need for local governments to address their lack of up-to-date child health awareness by involving them in child health interventions to increase their awareness of infant survival.

5.4 Contributions to Knowledge

This thesis explores key challenges related to early-age health, survival and inequity issues in a district in Indonesia using various subgroups within the population. The principal contributions of this thesis are:

1. The provision of up-to-date evidence-based research in regards to this geographical context and in the context of the new decentralised policies, which indicates the pressing need for early-age health education for rural mothers, fathers, grandmothers, and local community leaders in Eastern Indonesia. Existing studies, as outlined in previous chapters, have focussed more on the national or the Western Indonesian context, and were conducted prior to or during the early stage of implemented of the decentralisation policy. Previous literature has shown that health personnel provided less time on promoting essential information for pregnant women during antenatal care visits and the lesser participation of fathers and other extended family members. This thesis identifies key information that should be included in child health education, specifically for basic childhood illness signs, including the danger signs, about which the mother and father respondents showed very limited knowledge, as reported in Chapters 2 and 3. Furthermore, the findings illustrate the lack of effort by midwives and local CHCs to promote child health education to mothers, fathers and grandmothers, which has also been shown by several studies mentioned in Section 1.2 and Chapter 4.
2. This thesis contributes to filling the gap in knowledge for understanding early-age health care service and health care inequity issues at the district level in the Eastern part

of Indonesia. The existing literature on child health in Indonesia, as noted in Section 1.2 and Chapters 2-4, mostly emphasises the poor quality of care during the period of pregnancy and delivery. There is prior limited knowledge about post-natal care services, including the problems faced by the poor, especially for those living in rural and remote areas. This research demonstrates key child health service delivery issues at the sub-national level, especially for rural populations, and identifies the need to improve midwives and health personnel professionalism as a critical issue in addressing health care inequality related to access to rural health care services.

3. This thesis is the most up-to-date known study conducted in the rural Eastern part of Indonesia to specifically explore the demand side factors based on mothers' and fathers' first-hand accounts of early-age death experiences. Previous studies tended to focus on understanding infant deaths using the supply side factors, such as poor quality of care during pregnancy and childbirth, difficulty in accessing health facilities, poor quality of obstetric care to maternal mortality and low utilization of antenatal care visits (see Section 1.2, Chapters 2 and 3). Few studies in Indonesia have explored the first-hand accounts of infant mortality based on families' and communities' perspectives and women's pregnancy and delivery experiences, including their health-seeking behaviours. This thesis provides specific insights which could assist increasing the provision and quality of rural primary health care services, especially for infants in critical conditions, based on the informants' accounts of their experiences. Coverage of these important topics is scarce or lacking in the existing Indonesian literature on early-age health and survival.
4. This present study identifies specific findings about rural fathers' involvement with infant health through their personal accounts and experiences. Most existing studies in Indonesia have focused on examining mothers' roles and responsibilities relating to child survival, and little attention has been given to those of fathers. This thesis offers

direction on how fathers and grandmothers can contribute to preventing early-age deaths by developing the formulation of child health education and related-policies for families for districts with similar characteristics (mostly rural and Catholic) as Ende district.

5. This thesis confirms that gender inequity issues continue to exist in Ende district, East Nusa Tenggara province, as was evident from the previous literature relate to earlier periods. The findings illustrate specific gender inequity issues facing rural mothers which constrain their participation in decision-making about their infant's illnesses and lead to difficulties in their delivery and child health care. Husbands are portrayed by the government and local community informants as providing little support to their wife during delivery and in the care of newborn children.
6. This thesis demonstrates the potential importance of local community engagement in reducing early-age deaths in rural population. The "*rumah tunggu*" (waiting house) initiative from local community leaders in Ende district is an example of how the involvement and participation of community leaders can contribute to the prevention of early-age deaths, even without funding from local government. The evidence outlined in Chapter 4 contributes to the understanding of local community leaders' roles in reducing early-age deaths and inequity issues at health care facility. Reasonably few previous studies on Indonesia have focused on the influence of local community leaders in local child health programmes, including their perceptions of infant health and survival.
7. This thesis provides evidence of the continuation of strong traditional values and practices and their influences on pregnancy and delivery in a community in Ende district. As illustrated in Chapter 1, pregnant women and new mothers are not allowed to consume certain foods and have to perform traditional ceremonies in which a pregnant mother has to travel long distances to confess her mistakes to her parents and parents-in-law before childbirth. These local traditions may adversely influence

children's health and survival. Yet, the results of this study indicate the lack of intervention by the local government to address these issues.

8. This thesis demonstrates a range of reasons why some in the community still favour using TBAs to help with the birth process, including; financial difficulties, midwives' lack of professionalism, midwife unavailability, and TBAs being family members or respected elders in the community. This is consistent with previous research conducted in Western Indonesia. Nevertheless, the mothers' accounts of pregnancy and delivery experiences related with TBAs provide valuable insights into a rural health system that is not functioning effectively and efficiently to prevent newborn deaths a rural Eastern Indonesian context.
9. This thesis demonstrates independent critical power through proposing key policy directions for local and national governments as well as local community leaders based on the evidence from different groups of respondents (see Section 5.3). The findings of this study suggest potential solutions to assist the local stakeholders and policy makers in Indonesia in shaping up the new Sustainable Development Goals (SDGs) for rural regions, such as Ende district. In particular, the qualitative findings from local government employees and community leaders indicate a pressing need for increasing continuous collaboration and shared leadership in a society where traditional norms and values are strong.

5.5 Limitations and Future Directions

This thesis provides insights into early-age health, survival, gender and health care inequity issues among mothers, fathers, grandmothers, local community leaders and local government agencies in rural district of Indonesia particularly Ende district. It highlights the inadequate knowledge of early-age health, child health service problems in rural and remote areas, problems associated with the implementation of current child health policies and programs especially for disadvantaged populations, fathers' lesser involvement in infant raising, and the

lack of coordination between local government agencies and local community leaders as issues which may influence early-age health and survival in a rural Eastern district of Indonesia.

However, this study is not without its limitations. Firstly, generalising the findings of this thesis to a wider population will require caution due to the small sample size. Secondly, inferences from the findings of this study conducted in Ende district, an underdeveloped, overwhelmingly rural and predominantly Catholic district to some other parts of Indonesia with differing characteristics should be interpreted with caution. Thirdly, this study did not include midwives or other related health personnel as participants. This is mainly because this thesis aimed to understand the demand side barriers and experiences relating to early-age health and survival, rather than the supply side. Whilst midwives and other-related health personnel are key players in early-age health and survival, there is an urgent need to address not only the supply side (health personnel and health system performance) but also the demand side which includes the mothers the fathers, relatives and local community leaders in relation to early-age health and survival,. Furthermore, at a global level, there has been a change of intervention focus by strengthening the district health system and addressing the demand side to achieve equitable and accessible health care services for reducing maternal and child deaths (Freedman et al. 2007; O'Donnell 2007). Ensor and Cooper (2004) argue the importance of identifying the social and cultural value demand-side barriers to increasing the accessibility of health care services in the community. This concern is also illustrated by Houweling et al (2007) who stresses that cultural factors affecting mothers should be considered for developing professional maternity care. Therefore, further research could increase the number of participants to represent a wider population by administering large scale sample surveys to provide more robust statistical inferences. In addition, obtaining information and insights from health staff (for instance village midwife known as *Bidan* Desa) would be vitally important for future research relating to early-age health and survival as well as inequity issues at the sub-national level.

5.6 Evaluations and Reflections

The qualitative approach was useful to understand the early-age health, survival and inequity issues in the population and in the particular research setting of Ende district. The qualitative approach has provided fascinating findings for a rural Eastern Indonesian context relating to early-age health and well-being. This approach was an appropriate method to help my understanding the “why” questions relating to early-age health, survival and inequity issues that would complement the existing evidence for Eastern Indonesia.

It was unfortunate that the research participation rate among fathers was quite low (60 per cent), despite all the efforts made by the interviewers, the local officials and I during the fieldwork. The low participation rate in this study could lead to non-response bias and reduced the sample size and the rigour of this research. Therefore, particular caution is needed in making inference of the fathers’ findings to the wider population. I conducted a multiple coding process, triangulation and also discussion with the research team and several researchers from the Indonesian Ministry of Health for validity and reliability purposes (e.g. check the reliability of the response pattern and the quality of information obtained from all participants).

I would highly recommend anyone who would take a similar approach for a PhD level project to prepare your sample selection carefully because the foundation for qualitative research is not about generalizing your findings but essentially for obtaining in-depth and rich information that would answer the research questions of your thesis. Therefore, I would suggest involving local officials in selecting your key informants. The local officials who assisted this identifying the key informants for the in-depth interviews and focus group discussions also provided local guides and transportation to the selected villages during data collection, which saved time and stress.

Two local personnel from Ende District Health Office (EDHO) were involved as interviewers and another two as transcribers of the interview data. Prior to data collection, I conducted qualitative training for EDHO staff to increase their capacity to understand

qualitative studies. The Head of EDHO appreciated the value of this qualitative study for evaluating EDHO local staff performance in delivering better rural health care services and the quality of rural health care services relating to pregnant women, mothers and children. For that reason, I still continue to communicate with the local officials about my research findings.

Were I to consider including other types of informants in this study, I would definitely include village midwives, nurses and other health personnel relating to children's health care services to provide more complete evidence on early-age health, survival and inequity issues in Ende district. The main reason for not including the health personnel was to focus on getting more in-depth information from the demand side rather than the supply side.

The findings from the local government officials who have roles and responsibilities in reducing infant mortality provided interesting evidence, particularly on health services performance and the availability of health personnel in rural and remote villages. The findings from local government officials indicate the poor quality of rural health services and gender and health care inequity issues which also reported by the mothers, the fathers and the grandmothers. Furthermore, the information obtained from the mothers suggested possible solutions for the local government officials particularly to improving primary health services for poor families and also increasing their collaboration with other government agencies and local community leaders.

I must admit that Chapter 4 is my favourite article of this thesis. Basically, the focus group discussion (FGD) is the recommended technique to examine the policy-makers knowledge and their program implementation by comparing with local community institutions as long as you selecting a homogenous participant (e.g. same level seniority). I would suggest for anyone who would conduct a group discussion to select a moderator who had experience in leading a FGD and adequate knowledge on early-age health, survival and inequity issues. This is mainly to ensure the quality of the discussion and also the depth of the information that will be obtained

from each participant. Therefore, I decided to lead the group discussions after realising that the field work supervisor did not have adequate skills and knowledge in leading a FGD.

Considering the short period time frame of my fieldwork, I would recommend having a much longer period at the research site, between 3 and 5 months, specifically for conducting in-depth interviews in order to obtain more depth information and also to provide more opportunity to observe the study participants and their communities (see also Sub Section 3.2.4).

In regards to the in-depth interviews, at least one week's training should be enough to prepare the interviewers for conducting an interview. I realised that the first day of the data collection was not entirely successful in terms of obtaining details from the informants. As a result, I checked and listened to the recordings every day to maintain the quality of the interviews. It is also recommended to have an evaluation after completing the interviews with the interviewers to ensure the quality of the data. Although full transcription of the interview data is not compulsory, I suggest doing so because I have learned so many things by reading the complete transcription for all interviews. It was a painful process but meaningful to enriching my data analysis. I received support from a professional translator who assisted the translation process from local language to Bahasa Indonesia and English. It should be noted that involving local interviewers is worthwhile in a region which has a distinctive traditional culture such as Ende district, especially for acquiring the depth of informants' experience and their perspectives relating to infant health and survival. For example, several mothers of this study used their local language in the interview. I found that these mothers have provided more depth information about their pregnancy, delivery and child death experience than those using *Bahasa Indonesia*. By using the local language, it also allowed the mothers to speak relax and felt close with the local interviewers.

I spent 6 months on field work and nearly one year on the data analysis (Chapter 2, 3 and 4). Both of these activities have really tested my physical and mental conditions. While doing so, I have tried to prevent my own expectations and experiences influencing the data collection and

analysis process. The best way to avoid my own personal beliefs and experiences influencing this type of study was to involve the research team and other researchers and also comparing the findings with the existing evidence as part of triangulation process.

I found that a pilot project of my qualitative instruments in different locations (e.g. Jakarta and Sydney) with similar targeted interview participants provided useful insights for the development of the thesis questionnaires. In fact, there were several changes to the interview key questions as a result of the pilot experience.

I would recommend to anyone who will be doing a qualitative method to prepare your analysis framework while collecting your data during field-work. This would help ensure your coding process was sufficient in terms of time efficiency. I have also learned to take notes during the field work which could provide additional information to assist the interpretation of the findings. I highly recommended you make your own observations about the participants' house, the whole interview and FGD process, the quality of interviewers, the transcriptions and the translations.

Lastly, considering the appropriate framework would be the most crucial part of your qualitative design. I did not regret for spending a lot of time reading many articles and books relating to my chosen theoretical framework. This has enabled me to formulate the qualitative instruments of this study and provide specific direction for interpreting the interviews data.

This study has shown key issues relating to early-age health and survival, gender and health care inequity at rural district in Indonesia, which require more priority and attention by various levels of government agencies to prevent early-age deaths at sub-national regions. An especially relevant issue is engaging fathers into infant raising by considering their potential influences on children's health and well-being.

Achieving success in reducing early-age deaths, gender and health care inequity issues at the sub-national level in Indonesia is not only about delivering local and national health policies and programs to all regions but also about increasing the access to early-age health-related

education and promotion for families and communities, empowering women for making decisions on health issues, as well as ensuring timely, acceptable and affordable quality of health care services, especially for rural and poor families. Thus, understanding Indonesia's locally-specific issues relating to child health and survival and implementing health interventions through collaboration between government agencies and community leaders can contribute to saving more of lives of early-age children, to whom the future belongs.

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Appendix A. Early-age mortality rates in Indonesia, IDHS 2002

Neonatal, postneonatal, infant, child, and under-five mortality rates for the 10-year period preceding the survey, by province, Indonesia 2002-2003

Province	Neonatal mortality (NN)	Postneonatal mortality (PNN) ¹	Infant mortality ($_1q_0$)	Child mortality ($_4q_1$)	Under-five mortality ($_5q_0$)
Sumatera					
North Sumatera	24	18	42	16	57
West Sumatera	28	19	48	12	59
Riau	26	17	43	18	60
Jambi	14	28	41	10	51
South Sumatera	19	12	30	19	49
Bengkulu	27	25	53	17	68
Lampung	24	31	55	10	64
Bangka-Belitung	28	15	43	4	47
Java					
DKI Jakarta	18	17	35	6	41
West Java	25	19	44	6	50
Central Java	19	17	36	8	44
DI Yogyakarta	17	3	20	4	23
East Java	28	14	43	10	52
Banten	16	21	38	19	56
Bali and Nusa Tenggara					
Bali	9	5	14	5	19
West Nusa Tenggara	24	51	74	31	103
East Nusa Tenggara	31	28	59	15	73
Kalimantan					
West Kalimantan	24	23	47	17	63
Central Kalimantan	22	18	40	8	47
South Kalimantan	23	22	45	12	57
East Kalimantan	20	22	42	9	50
Sulawesi					
North Sulawesi	16	9	25	9	33
Central Sulawesi	24	28	52	20	71
South Sulawesi	12	35	47	26	72
Southeast Sulawesi	36	31	67	27	92
Gorontalo	24	54	77	21	97

¹ Computed as the difference between the infant and neonatal mortality rates

Appendix B. Early-age mortality rates in Indonesia, IDHS 2012

Neonatal, postneonatal, infant, child, and under-five mortality rates for the 10-year period preceding the survey, by province, Indonesia 2012

Province	Neonatal mortality (NN)	Post-neonatal mortality (PNN) ¹	Infant mortality (₁ q ₀)	Child mortality (₄ q ₁)	Under-five mortality (₅ q ₀)
Sumatera					
Aceh	28	18	47	6	52
North Sumatera	26	14	40	15	54
West Sumatera	17	10	27	7	34
Riau	15	9	24	4	28
Jambi	16	18	34	3	36
South Sumatera	20	8	29	9	37
Bengkulu	21	8	29	7	35
Lampung	20	10	30	8	38
Bangka Belitung	20	7	27	6	32
Riau Islands	21	13	35	8	42
Java					
DKI Jakarta	15	7	22	10	31
West Java	17	13	30	9	38
Central Java	22	10	32	7	38
DI Yogyakarta	18	7	25	5	30
East Java	14	15	30	4	34
Banten	23	9	32	7	38
Bali and Nusa Tenggara					
Bali	18	11	29	4	33
West Nusa Tenggara	33	24	57	18	75
East Nusa Tenggara	26	19	45	14	58
Kalimantan					
West Kalimantan	18	13	31	6	37
Central Kalimantan	25	24	49	8	56
South Kalimantan	30	14	44	13	57
East Kalimantan	12	9	21	10	31
Sulawesi					
North Sulawesi	23	9	33	4	37
Central Sulawesi	26	32	58	28	85
South Sulawesi	13	12	25	13	37
Southeast Sulawesi	25	20	45	10	55
Gorontalo	26	41	67	11	78
West Sulawesi	26	34	60	11	70
Maluku and Papua					
Maluku	24	12	36	24	60
North Maluku	37	24	62	25	85
West Papua	35	39	74	38	109
Papua	27	27	54	64	115
Total	20	14	34	10	43

¹ Computed as the difference between the infant and neonatal mortality rates

Appendix C. Ethics approval from Macquarie University ethics committee



MACQUARIE
University

JERICO PARDOSI
<jerico.pardosi@students.mq.edu.au>

Approved- Ethics application- Parr (Ref No: 5201200938)

Ethics Secretariat <ethics.secretariat@mq.edu.au>

28 March 2013 at 11:24

To: Dr Nick Parr <nick.parr@mq.edu.au>

Cc: Dr Salut Muhidin <salut.muhidin@mq.edu.au>, Mr Jerry Franciscus Pardosi
<jerico.pardosi@students.mq.edu.au>

Dear Dr Parr

Re: "Health Inequity and Early Age Mortality in
Ende District, Indonesia" (Ethics Ref:
5201200938)

Thank you for your recent correspondence. Your
response has addressed the issues raised by the
Human Research Ethics Committee and you may now
commence your research.

This research meets the requirements of the National
Statement on Ethical Conduct in Human Research
(2007). The National Statement is available at the
following web site:

http://www.nhmrc.gov.au/_files_nhmrc/publications/

[attachments/e72.pdf](#). The following personnel are

authorised to conduct this research:

Dr Nick Parr
Dr Salut Muhidin
Mr Jerry Franciscus Pardosi

**NB. STUDENTS: IT IS YOUR RESPONSIBILITY TO KEEP A COPY
OF THIS APPROVAL EMAIL TO SUBMIT WITH YOUR THESIS.**

Please retain a copy of this email as this is your
official notification of final ethics approval.

Yours sincerely
Dr Karolyn White
Director of Research Ethics
Chair, Human Research Ethics Committee

Appendix D. Ethics approval from National Institute of Health Research and Development ethics committee



MINISTRY OF HEALTH
NATIONAL INSTITUTE
OF HEALTH RESEARCH AND DEVELOPMENT
Jalan Percetakan Negara No. 29 Jakarta 10560 Kotak Pos 1226
Telepon: (021) 4261088 Faksimile: (021) 4243933
E-mail: sesban@litbang.depkes.go.id, Website: <http://www.litbang.depkes.go.id>

ETHICAL APPROVAL FOR THE USE OF HUMAN SUBJECTS

No. : LB .02.01 / 5.2 / KE.101 / 2013

The Committee on Health Research Ethics of the National Institute of Health Research and Development, Indonesia Ministry of Health, after conducting review on the research protocol entitled :

"Health Inequity and Early Age Mortality in Ende District, East Nusa Tenggara Province, Indonesia"

submitted on : **February 6, 2013** by : **Jerico Franciscus Pardosi, MPH.**

has hereby declared that the above protocol whereby human subjects will be used, has been approved for implementation in duration as stated in the protocol.

Please note that this *ethical approval* is for the period of 1 year since approved date.

Should there be any modification and/or extension of the study, the Principal Investigator is required to resubmit the protocol for approval. The progress and final summary reports should be submitted to NIHRD ethics committee.

Jakarta, March 28, 2013

Committee of Health Research Ethics,
Chairperson,

Prof. Dr. M. Sudomo

Appendix E. Informed consent form for in-depth interview participants



Department of Marketing and Management
Faculty of Business and Economics
MACQUARIE UNIVERSITY NSW 2109
Phone: +61 (2) 98508570
Fax: +61 (2) 98506065
Email: nick.parr@mq.edu.au

Chief Investigator's / Supervisor's Name:
Nick Parr

Chief Investigator's / Supervisor's Title
Associate Professor

Information and Consent Form (*In-depth Interview*)

Name of Project:

Health Inequity and Early Age Mortality in Ende District, East Nusa Tenggara Province, Indonesia

You are invited to participate in a study of health inequity and child mortality in Ende district. The purpose of the study is to identify health inequity in early age mortality at the district level. The findings from this study will contribute to improved practices in tackling health inequity and to reducing early age mortality issues at the district level. In addition, it will contribute to the academic literature related to health inequity and early age mortality in developing countries.

The study is being conducted by Jerico Franciscus Pardosi (email: jerico.pardosi@mq.edu.au; phone numbers: +6281316712787, +61410150477) to meet the requirements of Doctor of Philosophy program at Macquarie University, under the supervision of A/Prof. Nick Parr and Dr. Salut Muhidin, Department of Marketing and Management, Macquarie University (emails: nick.parr@mq.edu.au and salut.muhidin@mq.edu.au).

If you decide to participate, you will be involved in an interview. The duration for the interview is about 60-90 minutes. The collected information will be related to your social perspectives, knowledge and understanding of child mortality and survival based on your own experience. During the interview, audio recording and photo equipment will be used. The photo of house's conditions will be used to complement the information on your life experience of child survival and/or child mortality. Both audio recording and photography process will only be used after obtaining your consent.

The only possible risk or discomfort is related with questions regarding child under-five death history. If you are uncomfortable discussing this topic or any other issue, you have freedom to halt the process and take time out or stop completely from the interview. If you do become distressed, the field supervisor will stop the interview and provide information regarding support services from the nearest community health centre (*Puskesmas*).

All information and personal details gathered in the course of the study will remain confidential. For the purpose of analysis, this study will only use an anonymous code for each participant without any specific information. There will be no information provided in the publications and presentations on this study that will lead to revealing the identity of participants (*except as required by law*). All respondents will receive a reward of AUD\$12 as part of your involvement.

All data will be retained for the minimum period of 5 years. The original recordings, photos and related documents will be stored and kept in a locked filing cabinet in the Chief investigator and Co-investigators office at Macquarie University. The cabinet is locked and all related electronic documents are password protected. A summary of the results of the data can be made available to you on request. Participants can send email to jerico.pardosi@mq.edu.au. The findings of this study will appear in academic journals, conference papers, and PhD thesis. There is no conflict of interest in this study.

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without adverse consequence.

I, _____ (*participant's name*) have read (*or, where appropriate, have had read to me*) and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

Participant's Name: _____
(Block letters)

Participant's Signature: _____ Date: _____

Investigator's Name: _____
(Block letters)

Investigator's Signature: _____ Date: _____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

(INVESTIGATOR'S [OR PARTICIPANT'S] COPY)

Appendix F. Informed consent form for focus group participants



Department of Marketing and Management
Faculty of Business and Economics
MACQUARIE UNIVERSITY NSW 2109
Phone: +61 (2) 98508570
Fax: +61 (2) 98506065
Email: nick.parr@mq.edu.au

Chief Investigator's / Supervisor's Name:
Nick Parr

Chief Investigator's / Supervisor's Title
Associate Professor

Information and Consent Form (*Focus Group*)

Name of Project:

Health Inequity and Early Age Mortality in Ende District, East Nusa Tenggara Province, Indonesia

You are invited to participate in a study of health inequity and child mortality in Ende district. The purpose of the study is to identify health inequity in early age mortality at the district level. The findings from this study will contribute to improved practices in tackling health inequity and to reducing early age mortality issues at the district level. In addition, it will contribute to the academic literature related to health inequity and early age mortality in developing countries.

The study is being conducted by Jerico Franciscus Pardosi (email: jerico.pardosi@mq.edu.au; phone numbers: +6281316712787, +61410150477) to meet the requirements of Doctor of Philosophy program at Macquarie University, under the supervision of A/Prof. Nick Parr and Dr. Salut Muhidin, Department of Marketing and Management, Macquarie University (emails: nick.parr@mq.edu.au and salut.muhidin@mq.edu.au).

If you decide to participate, you will be involved in a focus group discussion. The duration for the discussion is about 90-120 minutes. The information expected will be related to your perspectives and understanding on health inequity and early age mortality, current situation and evaluation of child survival program and its policy in Ende district. Audio recording process will only be used after obtaining your consent.

All information and personal details gathered in the course of the study will remain confidential. For the purpose of analysis, this study will only use an anonymous code for each participant without any specific information. There will be no information provided in the publications and presentations on this study that will lead to revealing the identity of participants (*except as required by law*). All respondents will receive a reward of AUD\$9 as part of your involvement.

All data will be retained for the minimum period of 5 years. The original recordings, photos and related documents will be stored and kept in a locked filing cabinet in the Chief investigator and Co-investigators office at Macquarie University. The cabinet is locked and all related electronic documents are password protected. A summary of the results of the data can be made available to you on request. Participants can send email to jerico.pardosi@mq.edu.au. The findings of this study will appear in academic journals, conference papers, and PhD thesis. There is no conflict of interest in this study.

Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time without having to give a reason and without adverse consequence.

I, _____ (*participant's name*) have read (*or, where appropriate, have had read to me*) and understand the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from further participation in the research at any time without consequence. I have been given a copy of this form to keep.

Participant's Name: _____
(Block letters)

Participant's Signature: _____ Date: _____

Investigator's Name: _____
(Block letters)

Investigator's Signature: _____ Date: _____

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

(INVESTIGATOR'S [OR PARTICIPANT'S] COPY)

Appendix G. In-depth interview questionnaire

**Health Inequity of Early Age Mortality in Ende District
In-depth Interview Questionnaire**

Confidential

I. IDENTIFICATION LOCATION			
1	Province		
2	District		
3	Subdistrict		
4	Villages		
5	Village classification	1. Urban 2. Rural	
6	Home Address	
7	Name of Informant	
8	Interview Date/..... /2013	
II. INFORMANT DETAILS			
1	Interviewer's Name	
2	Head of Household Name	
3	Informant's husband's ageyears	
4	Name of Informant	
5	How old were you at your last birthday?years	
6	Informant's highest education	1. No schooling 2. Ever attended primary 3. Graduated from primary	4. Graduated from Junior High School 5. Graduated from Senior High School 6. Graduated from Academy/University
7	Informant's husband highest education	1. No schooling 2. Ever attended primary 3. Graduated from primary	4. Graduated from Junior High School 5. Graduated from Senior High School 6. Graduated from Academy/University
8	Informant's main occupation	1. Not working 2. Labour 3. Farmer/Fisherman 4. Private worker	5. Government/Army 6. Entrepreneur 7. Retired 8. Others _____

9	If informant not working, what is your daily activity?	1. Farming 2. Selling 3. Active in organisation	4. Child carer 5. Others _____ —
10	Husband's main occupation	1. Not working 2. Labour 3. Farmer/Fisherman 4. Private worker	5. Government/Army 6. Entrepreneur 7. Retired 8. Others _____ —

III. BIRTH HISTORY

1	In the last five years (between 2008 and 2013), did you have any births?	1. Yes 2. No
2	In the last five years (between 2008 and 2013), did you have any stillbirths?	1. Yes 2. No
3	In the last five years (between 2008 and 2013), did you have any miscarriages?	1. Yes 2. No

IV. RETROSPECTIVE BIRTH HISTORY IN THE LAST FIVE YEARS (between 2008 AND 2013)

IV.1	IV.2	IV.3	IV.4	IV.5	IV.6	IV.7	IV.8	IV.9
What name was given to your (first/next baby)?	Were any of these births twins 1=SINGLE 2=TWINS	Is (NAME) a boy or a girl? 1= Boy 2= Girl	In what month and year was (NAME) born?	Is (NAME) still alive? 1= Yes 2= No If NO, please continue to IV.8	IF ALIVE: How old was (NAME) at his/her last birthday? RECORD AGE IN COMPLETED YEARS.	IF ALIVE: Is (NAME) living with you? 1= Yes 2= No Continue to IV.9	IF DEAD: How old was (NAME) when he/she died? IF 'less than 2 year', probe how many months old was (NAME)? RECORD: DAYS IF <1 month MONTH IF < 2 years YEARS IF ≥ 2 years	Were there any other live births between (NAME OF PREVIOUS BIRTH) and (NAME) including any children who died after birth? 1= Yes 2= No
1.	<input type="checkbox"/>	<input type="checkbox"/>	MONTH <input type="text"/> <input type="text"/> YEAR <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/>	DAYS ...1 <input type="text"/> <input type="text"/> MONTH..2 <input type="text"/> <input type="text"/> YEAR ...3 <input type="text"/> <input type="text"/>	<input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	MONTH <input type="text"/> <input type="text"/> YEAR <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/>	DAYS ...1 <input type="text"/> <input type="text"/> MONTH..2 <input type="text"/> <input type="text"/> YEAR ...3 <input type="text"/> <input type="text"/>	<input type="checkbox"/>
IV.1	IV.2	IV.3	IV.4	IV.5	IV.6	IV.7	IV.8	IV.9

What name was given to your (first/next baby)?	Were any of these births twins 1=SINGLE 2=TWINS	Is (NAME) a boy or a girl? 1= Boy 2= Girl	In what month and year was (NAME) born?	Is (NAME) still alive? 1= Yes 2= No If NO, please continue to IV.8	IF ALIVE: How old was (NAME) at his/her last birthday? RECORD AGE IN COMPLETED YEARS.	IF ALIVE: Is (NAME) living with you? 1= Yes 2= No Continue to IV.9	IF DEAD: How old was (NAME) when he/she died? IF 'less than 2 Year', probe how many months old was (NAME)? RECORD: DAYS IF <1 month MONTH IF < 2 years YEARS IF ≥ 2 years	Were there any other live births between (NAME OF PREVIOUS BIRTH) and (NAME) including any children who died after birth? 1= Yes 2= No
3.	<input type="checkbox"/>	<input type="checkbox"/>	MONTH □ □ YEAR □ □ □ □	<input type="checkbox"/>	□ □	<input type="checkbox"/>	DAYS ...1 □ □ MONTH..2 □ □ YEAR ...3 □ □	<input type="checkbox"/>
4.	<input type="checkbox"/>	<input type="checkbox"/>	MONTH □ □ YEAR □ □ □ □	<input type="checkbox"/>	□ □	<input type="checkbox"/>	DAYS ...1 □ □ MONTH..2 □ □ YEAR ...3 □ □	<input type="checkbox"/>
5.	<input type="checkbox"/>	<input type="checkbox"/>	MONTH □ □ YEAR □ □ □ □	<input type="checkbox"/>	□ □	<input type="checkbox"/>	DAYS ...1 □ □ MONTH..2 □ □ YEAR ...3 □ □	<input type="checkbox"/>

From Retrospective Birth History, write down total number of children born, live and dead between 2008 and 2013 ONLY. Check again the totals in the birth history questions.

Alive : □ □

Death: □ □

V. IN-DEPTH QUESTIONS FOR MOTHER/FAMILY

Now, I would like to ask you more details about any births you have had during the last five years.

Pregnancy and delivery history in the last five years,

1. Did you receive antenatal care during pregnancy in the last five years? If YES, who was responsible for giving the antenatal care? Where was the antenatal care provided? (probing for average visits for all pregnancy)
2. On average how many times did you visit a community health centres during your pregnancies? (Probe average visits for all pregnancy in the last five years)
3. Who assisted your deliveries (starting from the first until the last child)? Where did the delivery take place (starting from the first until the last child)? If NOT USING HEALTH FACILITY, ask similar questions and try to specify the reason for not selecting health facility?
4. Did your children aged under-5 experience any illnesses? If YES, what were the illnesses and where did you first seek advice or treatment?
5. Did you know the signs of illness of children under-5? If YES, could you mention the signs?
6. What kind of support did your family (husband and relatives) give to you during all your pregnancies and deliveries? Did you receive full support (probe for specific support for example attention, assistance, feeding the baby/child, financial support or neglected) from your family including for health decisions for all your children under-5? If YES, please describe.
7. After delivery, did you have to do any traditional ceremony? If YES, please describe. probe: are there sanctions if you do NOT participate, influence for mother and baby, the role of father, mother believes in traditional ceremonies, community involvement in traditional ceremonies)

Pregnancy and delivery history for the last child,

8. Did you receive antenatal care during your last pregnancy? If YES, who was responsible for giving the antenatal care? Where was the antenatal care provided? How many antenatal care visits did you have during your pregnancy?
9. How many times did you visit community health centres during your pregnancy? (Probe average visits for last birth in the last five years)
10. Who assisted your last delivery? Where did the delivery take place? If NOT USING HEALTH FACILITY, ask similar questions and try to specify the reason for not selecting health facility?
11. In your last pregnancy, were you referred to any other health facility? If YES, where is the referral health facility?
12. After your child was born, did someone check on his/her health? (If YES, who checked your baby?, if NOT, ask about the reasons)
13. Did your last child experience any illnesses? If YES, what were the illnesses and where did you first seek advice or treatment?
14. Did you know the signs of illness of children under-5? If YES, could you mention the signs?

15. What kind of support did your family (husband and relatives) give to you during all your pregnancy? Did you receive full support (probe for specific support for example attention, assistance, feeding the baby/child, financial support or neglected) from your family including for health decision for your child? If YES, please describe.
16. How about the food selection for your last child? What did you know about healthy and appropriate food for your last child? (to identify financial problems and probe types of foods usually given to baby/child)

For mothers who delivered by using traditional birth attendants (TBA) (any child in last five years),

17. How was your delivery process? Any problems? If YES, please describe. How was your child health?
18. Overall, what did you think about the service given by TBA?
19. How much did you have to pay for the service? (to compare with health facility cost)

Now, I would like to ask you more details about any child under-5 death experience you have had during your life in the last five years.

For mothers who have child under-5 death experience (any child in last 5 years), if NO child death go to Q25
(please use the same questions for asking each child under-5 death experience)

20. What did happen to your (NAME) baby/child under-5 that led to the death event? (probe: cause of death according to mother) Were there any health issues (informant might answer certain clinical problems and related health problems? Please tell us what happened during and after the delivery? (probe: what did happen before the baby/child die?)
21. What kind of support did your family (husband and relatives) give to you during that time? Please describe. Did you receive full support (probe for specific support for example attention, assistance, feeding the baby/child, financial support or neglected) from your family including for health decision for your child? If YES, please describe.
22. During your pregnancy, did you have any health concerns (including nutrition problems)? If YES, please describe.
23. How about the food selection for your child? What do you know about healthy and appropriate food for child under-5? (to identify financial problems and probe types of foods usually given to baby/child) (If possible ask about the baby/child under-5 height and weight)
24. After delivery, did you have to do any traditional ceremony? If YES, please describe. (probe: sanction if NOT participate, influence for mother and baby, the role of father, mother belief, community involvement)

Health care access and services,

25. Do you have health card/child health book? (ask them to show the health card or child health book they have)
26. Did all your children under-5 receive any vaccinations? (probe vaccination types, completeness and the place of vaccination and if possible ask for the child health book)
27. How long does it take from your home to reach the closest health care provider? (probe for distance (km), time (minutes/hours), mode of transportation).

28. Have you ever received any information about child survival? If YES, what information did you receive, from who and when?
29. In regards of health care provider, what do you think about the child health service given? Did you have any difficulties in accessing health care? (ask for possible financial problems or health decision)

Community and Government Support,

30. In the last five years, did you experience support in terms of attention and health decisions from your community and local governments? If YES, please describe.
31. Do you have any recommendation for the current child survival program and the community in your area?

For father/family relatives living in the same house

(Record relationship to informant's husband, mother, sister, brother etc.). If not father record reason for father's non-response (absent, dead, divorced/separated, refused etc.),

Name :

Relationship with informant :

Reason for father's non- response:

32. What do you know about child mortality and survival? (probe the importance, knowledge and understanding about child mortality and survival)
33. During pregnancy, in what ways did you support **informant**? During delivery, in what ways did you support **informant**? After delivery, in what ways did you support **informant**? (to identify the roles and responsibilities from father and relatives)
34. Did you know the signs of illness of children under-5? If YES, could you mention the signs? If NOT, have you ever received any information about child survival? If YES, what information did you receive, from who and when?
35. Did you discuss health decisions with **informant** and family? Who made the final decisions?

Appendix H. Focus group discussion guides



Department of Marketing and Management
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MACQUARIE UNIVERSITY NSW 2109

Health Inequity and Early Age Mortality in Ende District Focus Group Discussion (FGD) Guides

Total time for FGD= 90-120 minutes

Opening Script (10 minutes)

Please use the following script for FGD opening.

Good morning/afternoon. Thank you for coming to our group discussion today. My name is _____ and I will be facilitating today discussion accompanied by _____ that will be responsible for our discussion note taking and audio recording.

The purpose of our discussion is to understand your perspectives, opinions and also experience related to early age mortality. Today discussion has been prepared by the Principal investigator from Macquarie University, Australia and Ende District Health Office (EDHO). This discussion is part of a project entitled Health Inequity and Early Age Mortality in Ende District, Indonesia.

Today discussion is an important stage of the project that will lead to better understanding of policy leader's role in reducing health inequities of early age mortality in Ende district. This research aims to identify perspectives on child mortality, an area in which policy, community leaders and related child health program coordinators have essential role and responsibility for child survival policy. Your opinions, suggestions and comments will be very useful for our project in terms of information for formulating appropriate child survival policy at district level.

This study is voluntarily and if you agree to participate, then you will be asked to sign the informed consent. There will be no risk for you to involve in this study. On the other hand, all information that you will give during our discussion will be confidential.

(After all invited participants sign the inform consent, ask everyone to introduce them self by mentioning their name, organization and current position)

Please remember to mention the rule for FGD as the following:

- 1. This discussion should be open and honest*
- 2. All people should respects other people opinions*
- 3. All participants should have equal opportunity to give their ideas or opinions*
- 4. All information will be private and confidential (including your names, we will use other initial without directing to certain people)*

Current child mortality situation and program

1. What do you think about the current Ende child mortality situation? (previously in the opening already mentioned by co-investigator (Jerico Franciscus Pardosi) about facts and figures of Ende child mortality situation)
2. Do you agree with the facts on child mortality given previously? If NOT (ask about the arguments)
3. What do you think to be the significant causes of child mortality in Ende district?
4. What do you know about child survival program in Ende district?
5. What are the challenges for reducing child mortality based on your work unit?
6. What do you think about child mortality differences between subdistricts in Ende?

Role and responsibility for reducing child mortality

7. Does your office/community have any related program to child health? (ask for more details)
8. Does your office/community have any related program to child survival? (ask for more details)
9. Please explain briefly about your work unit roles and responsibilities related to child mortality or child health
10. How effective do you think about your work unit or community involvement in reducing child mortality?

Cultural issues related to early age mortality

11. Are there any traditions for mothers after delivery? If YES, please describe?(probe for sanction if NOT decide to involve, values in that tradition)

Health Inequity

12. What do you think about the distribution of child survival program in Ende district for the whole population?
13. Do you think that there are social justice and fairness issues related to early age mortality and child survival? What are the issues in your opinion?
14. What are the cultural issues related to early age mortality in Ende district?
15. For the disadvantaged populations, what do you think about specific policies and programs? Do you think it is important to give particular attention to poor populations?

Recommendation for Child Survival Policies and Programs in Ende District

16. Do you have any recommendation for child survival policies in Ende? If YES, what are your recommendations?
17. Are there any specific child survival policies related to your work or in the community?
18. Are there any specific child survival programs related to your work or in the community?
19. What do you recommend for reducing child mortality in Ende district based on your work unit responsibilities and your own suggestion?

Conclusion: *Facilitator must read the important conclusion and recommendation related to child survival program. Thank you for your participation.*

Appendix I. Example Case Studies

The selected case studies include the short story of health seeking behaviour during pregnancy, delivery and after delivery for one mother who had an infant death, a mother who did not have an infant death, and two fathers.

Mother-E30

(27 years old, Graduated from Senior High School, one child died during neonatal period)

When I was in my 7th month of pregnancy, I went to *Puskesmas* for antenatal visits. Before that period, I visited the Catholic Maternity Clinic twice for my antenatal care services. I did not check my pregnancy in the first trimester because my parents did not know that I was pregnant at that time so I was afraid to tell them at first. I did the pregnancy test after one month of my menstruation period. My baby was born at *Puskesmas* assisted by local midwives and accompanied by a traditional birth attendant (TBA). During my last trimester, I felt pain on my right abdomen so I asked TBA to come and she massaged me. I preferred *Puskesmas* as the place of delivery because *Puskesmas* has provided good services with complete facilities and its midwives ready to help my delivery process. My baby weight was 3.2 kilograms.

Unfortunately, I have never received home visit by the midwives after delivery. However, I visited *Puskesmas* twice because my baby had a cough and fever. My baby got influenza. My husband worked in Kalimantan but he often sent me money to buy formula milk and clothes for the baby. My baby only consumed breast milk for two weeks. The baby did not like my breast milk so I gave the baby formula milk.

The baby vomited more than three times a day. I did not bring my baby to *Puskesmas*. It was my negligence. The baby got it on Saturday. Just diarrhoea, no cry! I took my baby on Tuesday because *Puskesmas* was closed until Monday and the doctor was not available on Sunday. The baby still moved actively and had no blood in his faeces. I just rubbed my baby stomach with onions. My baby also got fever. I bought fever medicine for babies. I brought my baby to the hospital and my baby received oxygen and infusion. But, then my baby died.

Mother-E8

(22 years old, Graduated from Junior High School, has two children, no child death experience)

I went to *Puskesmas* by myself for all pregnancy. My first child was 5 times and the second one was 7 times for my antenatal visits with midwife. My first child was born in Ende local hospital and the second child was born in *Puskesmas*.

If my children got sick more than two days, I will take them to *Puskesmas*. If they got flu and cough, I usually give them lemon mixed with soy sauce with different quantity. The youngest will get half of spoon and the oldest will receive full spoon. My husband was kind to me. During pregnancy, he reminded me to take a rest, eat well and reminded me to go to *Puskesmas*. In some occasions he accompanied me to *Puskesmas*. Both my children have received immunization from *Puskesmas*.

We have a tradition known as *wa'u tanah*. After my first child went home from hospital, we usually made a welcoming event in our house. During that ceremony, the child was brought around the house and neighbourhood. But I did not do it for my second child. There is no sanction, it is just a tradition.

Father-F15

(34 years old, Graduated from Junior High School, has two children, no child death experience)

I do not know much about children, but if I see something in the child I know that something happens. If he is sick, something happened in his body, it is just instinct. I know that something wrong. Also, if he cries too much even while urinating, that's all I know. During my wife pregnancies, I supported her domestic duties.

For health in my household, it is not all in my hands. Why? As the head of this family, I will not take decisions by myself, we just use the best way. About my children's health, their mother knows better than me, I just watch out for my children once I came home, so the decision is not absolutely mine.

Father-F7

(32 years old, Graduated from Junior High School, has four children, one of them died during neonatal period)

I do not understand about children's health and wellbeing. For my youngest child, we already give all the baby need, we make effort, we brought the child to the *Puskesmas*, but he died and what can I do now. It has already happened.

I have never received any explanation from the doctor about the cause of my baby sickness. We checked him on Saturday, because he cried in the afternoon, he cried and I was confused. We had checked him by a doctor, and the doctor said nothing bad happened, but he cried again. He cried for three or four hours on Saturday afternoon. He stopped and slept until the morning and at the day on Sunday on 1pm he started to cry again and died after that.