

FINAL REPORT

RECOGNITION AND CARE-SEEKING OF MATERNAL AND NEWBORN COMPLICATIONS IN JAYAWIJAYA DISTRICT, PAPUA, INDONESIA: A QUALITATIVE STUDY

WAHANA VISI INDONESIA

Location included in study: Jayawijaya District, Papua Province, Indonesia

Date Completed: October 2015



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Research Team

The study was entitled "Translating Research into Action", TRAction, funded the by United States Agency for International Development (USAID) under cooperative agreement No. GHS-A-00-09-00015-00. The project team includes prime recipient, University Research Co., LLC (URC), Harvard University School of Public Health, and sub-recipients from other research organizations.

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ABBREVIATIONS

ANC	: Antenatal Care
CHW	: Community Health Worker
DHO	: District Health Officer
FGD	: Focus Group Discussions
IMR	: Infant Mortality Rate
MiP	: Malaria in Pregnancy
MMR	: Maternal Mortality Ratio
NGO	: Non- governmental organization
PHC	: Primary Health Center
PPH	: Postpartum Hemorrhage
REACH	: Reaching For Equity And Access For Child Health
U5	: Under Five
U5MR	: Under-five Mortality Rate
UNICEF	: United Nation Children's Fund
URC	: University Research Company
USAID	: United States Agency for International Development
WVI	: World Vision International
WVUS	: World Vision United States

EXECUTIVE SUMMARY

At the end of 2015, the global maternal mortality target remained evasive. Likewise, newborn mortality rates have been on a plateau after a decade, despite a substantial mortality decrease among children under five. Indonesia's progress on maternal health has slowed in recent years, with its maternal mortality ratio (MMR) remaining greater than 200 per 100,000 live births during the past decade. The country's present condition reflects a reduction in infant and under-five mortality; currently most of Indonesia's child deaths take place during the neonatal period. According to statistics prepared by aid organizations that work in Papua, the province's overall health status is the lowest of the country. There are no MMR data at the province and district level; however, analysis of the 2010 Indonesia national census produced an estimate that the MMR in Papua Province was 620 per 100,000, which is the highest of all provinces in Indonesia. The infant mortality rate in Papua Province is almost twice the national average. Jayawijaya District, the site of the present research, exhibits an infant mortality rate three times greater than the national average. An understanding of how local home caretakers recognize disease and of the community system that is in place to react to newborn and maternal emergencies is essential for the design of effective and feasible interventions. This study describes the recognition of maternal (postpartum bleeding) and newborn illness and respective care-seeking behaviors in Jayawijaya district, Indonesia.

We used a qualitative design to conduct the study at seven subdistricts in Jayawijaya District, Papua. Data were collected using in-depth interviews and focus group discussions (FGDs) with key informants, such as family members who accompanied sick newborns or mothers who experienced bleeding before the newborn or mother died. Interviews consisted of two cases of maternal deaths, five cases of mothers with postpartum hemorrhage, five with newborn illness, and five with newborn deaths.

Results showed that participants recognized bleeding as a sign of danger when present during labor and a sign of severity during the postpartum period. Severity of maternal illness was determined by visual observation by midwives and mostly based on previous experience. Recognition of danger signs among newborns was lacking and mainly performed by the mother. Care-seeking decisions were mostly dominated by husband in the case of maternal health, with a time interval of less than six hours. Most care was started at home by birth attendants, but the majority sought care outside of the home within the public system. Most maternal deaths were associated with delays in receiving appropriate treatment at public health facilities. In the case of newborns, the decision to seek care was dominated by the mother, with a time interval between illness recognition and decision to seek care greater than 24 hours, with the majority seeking care at home. Most newborn deaths were associated with delays in all three components: illness recognition, care-seeking, and receiving appropriate care.

Findings demonstrate interventions in Jayawijaya District to reduce maternal mortality will need to focus on quality improvement for maternal care at health facilities; to reduce newborn mortality, interventions should be designed to improve disease recognition at home, care-seeking, and quality of care.

INTRODUCTION

INTRODUCTION

A. BACKGROUND

GLOBAL PROBLEM

Significant progress has been made toward the achievement of the fourth and fifth United Nations Millennium Development Goals to reduce child and maternal mortality. However, considerable work still remains. Although the under-five child mortality rate has significantly decreased, the rate of neonatal mortality remains high, especially in low and middle income countries. Under-five child mortality has decreased from 12 million deaths per year in 1990 to 6.9 million deaths per year in 2011, whereas neonatal deaths have only decreased from 4.3 million to 2.9 million during the same time period and currently comprise more than 43% of under-five mortality.¹ Global maternal mortality has decreased from 440 deaths per 100,000 live births in 1990 to 240 deaths per 100,000 live births in 2010. This represents a 47% decline; however, this figure is still far below the 75% reduction target.

NATIONAL PROBLEM

Despite Indonesia's progress in reducing its under-five mortality rate (U5MR), 26 of Indonesia's 33 Provinces have higher U5MR than the national average of 44 deaths per 1,000 live births.²  **ie Papua Province, 75 per 1000 children under-five (U5) ie, which is 2.9 times greater than the national average.** According to recent estimates by United Nations Children's Fund (UNICEF), Papua's Jayawijaya District experienced U5 mortality in excess of 3.1 times the national average and 6% above the provincial average.³ The newborn mortality rate in the district of Jayawijaya is 2.7 times greater than the national average and 1.6 greater than the provincial level.³ Recent mortality studies have shown that most of these U5 mortalities in Jayawijaya District are related to pneumonia (47%) and diarrhea (21%).⁴ According to UNICEF, the rate of neonatal death in Indonesia has remained stable for the last two decades and accounts for about 30% of U5MR. These statistics show a great need to emphasize interventions that reduce neonatal deaths.⁵

The MMR in Indonesia was recorded as 359 maternal deaths per 100,000 live births during 2008–2012.² No MMR data are available for the province and district levels; however, analysis of the 2010 Indonesia national census produced MMR estimates for Papua Province of 620 per 100,000, which is the highest of all provinces of Indonesia.⁵ According to a United Nations Population Fund Indonesia report, major causes of maternal death are hemorrhage (28%), eclampsia (24%), sepsis (11%), abortion complication (6%), obstructed labor (5%), and others (26%). Many of these complications were not treated properly because of a lack of quality care.

Table 1 shows a comparison of the 2012 Indonesian mortality rates for the country, province, and district levels. Put simply, Jayawijaya District has higher rates than both the province and country as a whole.

Table 1: Maternal and Child Mortality Rates and Skilled Birth Attendance Coverage by District, Province, and Nation (Indonesia 2012)

	U5MR	IMR	MMR	Skilled Birth Attendance
Indonesia	40/1000*	32/1000*	359/100,000	83.1%*
Papua Province	115/1000*	54/1000*	620/100,000****	39.9%*
Jayawijaya District	122/1000**	86/1000**	N/A	36%**

*Indonesia Demographic Health Survey, 2012

MICS, UNICEF 2012; * REACH baseline survey; **** NIHRD, 2012

LOCAL PROBLEM

Jayawijaya District (Figure 1) has a population of 431,338 people in 32 subdistricts divided into 366 villages and approximately 16.6 people per square kilometer. A great majority of people who live in Jayawijaya District belong to the Dani ethnic and linguistic group. The Dani people live in small compounds known as osili or silimo. Each silimo is made up of men's houses (or honai) and a number of family houses (or ebai), all of which are situated around a communal courtyard and enclosed within a fence. Several married men typically occupy a silimo, along with their wives, children, and other relatives. With approximately 5,100 births per year, children in Jayawijaya District (particularly in the most marginalized communities) have the highest mortality risk in Papua Province. This area is isolated with no road links to the provincial capital and few roads within each subdistrict.

Figure 1: Study Location: Jayawijaya, Papua Province, Indonesia.



The communities in this area are in a state of social transition following recent sustained contact with the outside world and decentralization of funding management at the district and village level. Because of these factors, many traditional roles in society have been lost or changed at a very rapid pace. Women and children in these districts face many problems including low income, malnutrition, and poor health status with a high incidence of communicable diseases and low life expectancy.

Despite the advanced status of decentralization and efforts to improve access to health services in remote locations of Indonesia, access to basic health services has still remained low in such areas, including Jayawijaya District. World Vision's REACH project baseline data from 2010 showed that only 1 in 4 mothers received antenatal care (ANC) and only 15% of infants were delivered by a skilled birth attendant (2.3 times less than the national figures reported by Demographic Health Survey 2012, 2.7 times less than the provincial average, and 2.4 times less than the district average).⁶ Likewise, less than 2% of newborns had early breastfeeding (within one hour after birth), which is 19 times less than the district average reported by UNICEF. The majority of the population reached health facilities by walking an average of 30 minutes; however, 70% did not find an available health worker upon reaching the facility.⁶ Quality of care is challenged by insufficient skilled person-nel to deliver facility-based services, conduct outreach activities, and supervise community-based providers. Ruptures in supply chains are also common and may lead to a lack of rapid diagnostic tests, clean delivery kits, and necessary drugs.

To study these issues, World Vision participated in a multi-country implementation research project in collaboration with the National Institute of Health Research and Development, the Ministry of Health, and faculty of Public Health University of Indonesia (Indonesia TRAction Team), with support from the USAID-funded Translating Research into Action (TRAction) program.

B. RESEARCH QUESTION

The focus of this study was to identify, analyze, and describe illness recognition and care-seeking patterns across various contexts. As part of this project, World Vision, in collaboration with University Research Company (URC)/TR Action team, conducted a mixed-method case study to describe recognition and care-seeking behaviors related to maternal and newborn complications in the Jayawijaya District, Papua Province, Indonesia.

The research questions in this study are as follows:

1. What was the process of recognition of and decision-making for seeking treatment/care among the families of women who experienced postpartum hemorrhage (PPH) or maternal death regardless of birth location within the last six months?
2. What was the sequence of actions for seeking treatment/care among these families?
3. What was the process of recognition of and decision-making for seeking treatment/care among families of newborns who experienced an illness or died within the first 28 days of life regardless of birth location within the last six months?
4. What was the sequence of actions for seeking treatment/care among the families of these newborns?

C. METHODOLOGY

This study involved collection of qualitative data from families that had experienced a maternal or neonatal death and from families in which the woman had PPH or the newborn developed an illness within the last six months. The study documented the process and description related to the research questions in ten sub-districts and 15 villages in Jayawijaya District. The participants were five women with presumptive diagnosis of PPH plus two maternal deaths identified within the last six months in community and at health facilities. Additionally, the study also included five newborns with severe illness and four newborn deaths within the last six months in the community and at health facilities.

Because the research in this study involved human participants, institutional review board clearance was obtained from the Expert Committee on Research and Research Ethics from the Public Health University of Indonesia to approve the

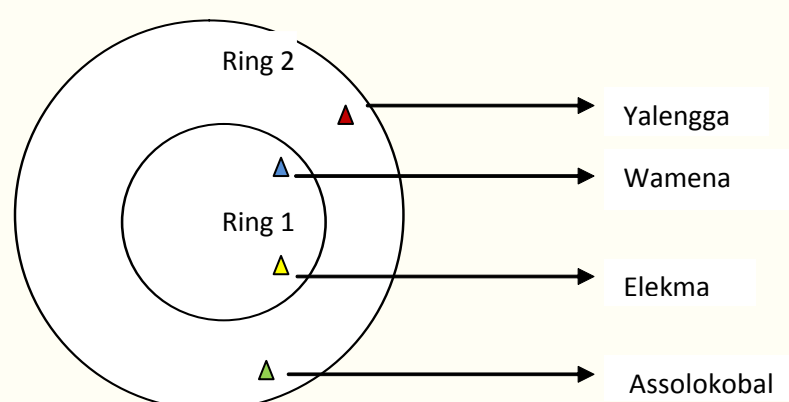
procedures as ethical. This approval was effective during the research period of this study (April 2015–April 2016). To further the ethical soundness of this study, informed verbal consent was received before the start of every interview.

SELECTION PROCESS

To capture a sufficient number of maternal and newborn illness and deaths for the study, the research team focused on case identification from within the inner city (Ring 1 of Figure 2, approximately within 5 km from the district town/Wamena City). If the minimum number of samples could not be located, the contingency plans were as follows:

1. Expand the time period to include the maternal and/or newborn deaths in the last one year.
2. Expand the areas to include subdistricts in Ring 2, approximately 5–10 km from the city.

Figure 2. Classification of Area Study



To estimate the number of maternal and neonatal deaths in the area, routine district health information systems were used to find the information. However, because HISs are very weak in the district, the number of actual deaths were likely underestimated. To illustrate this problem, a mortality study conducted in 2013 used a listing method that identified 80 under-five deaths in 53 villages, whereas the routine HIS only identified 21 under-five deaths in the district (128 villages) for the same year.⁴ Because of this discrepancy, the **pres-ent** study used the district estimates for neonatal deaths and provincial estimates for maternal deaths. In 2011, the neonatal mortality rate in the district was estimated at 36 per 1,000 live births,⁴ and the maternal mortality ratio in the Papua Province was estimated at 620 per 100,000 live births.⁵ With a total population of 51,590 in Ring 1, the estimated number of births in the target population is 1,267 per year. Therefore, the estimated number of neonatal deaths is 22 neonatal deaths in 6 months and the estimated number of **mater-nal** deaths is four maternal deaths in six months. Data sources used to identify and locate cases included hospital records, Primary Health Center (PHC) centers records, midwives records, CHW records, community-based leader records (religious and others), and community-based screening. See Table 2.

Table 2: Sources Contacted to Locate Cases Included in the Study

Case	Sources
Newborn survivors	• Hospital records • Primary health center records • CHWs records • Midwives records

Newborn deaths	• Hospital records • Primary health center records • CHWs records • Midwives records • Mortality data at the community level as evidenced by church leaders' and village government records
Women with PPH	• Hospital records • Primary health center records • Village midwives' records • Community screening as evidenced by community-based PPH screening tools
Maternal deaths	• Hospital records • DHO/Primary health center records • Village midwives records • Community screening as evidenced by community based PPH screening tools • Mortality data at the community level as evidenced by church leaders' and village government records

DATA COLLECTION

After cases were identified, illness narratives were taken. These illness narratives consisted of stories and interpretations of the illness (or death) by those who had the illness as well as others (such as family and other care-takers) who were present during that time. These illness narratives were taken with the aim of gaining the perspective of those who were interviewed while giving them a voice and granting them the dignity of being heard. Interviews were conducted in villages in the Jayawijaya District during a period of two months in 2015. We conducted all interviews in the local language. We asked participants to describe their ideas and **experiences** about the process of recognition of illness, decision-making, and the care-seeking pattern for maternal and newborn complications.

Four separate illness narrative interview guides were used for this study: one each for excessive maternal bleeding, newborn illnesses, maternal deaths, and newborn deaths. Structure and content were very similar among the guides. Recognition questions included inquiries about how mothers and other caregivers recognized symptoms, how they determined symptom severity, and what they believed were the causes of the illness. Decision-making questions consisted of who the main decision-makers were, the factors considered in decision-making, and the amount of time it took to seek care. Finally, questions about care-seeking patterns asked about the type of care sought, the sequence of care sought, how long it took to get care, and the level of satisfaction with the care received. Additional questions were asked regarding influence of the illness experience and suggestions for future interventions. At the end of each interview, an event timeline was completed.

A time-by-event matrix instrument was developed to facilitate the recording of the illness narratives. The instrument depicted the recording of textual responses by specific group members that detailed the circumstances surrounding the event and any factors associated with the identification of and response to the event. The matrix included a record of decision-making processes, preferred types of treatment/care, and the perceived quality of the barriers to seeking care. Informants' demographic and social characteristics also were captured.

After interviews were completed, the research team developed debriefings. Recordings were transcribed verbatim. Some cases in which local dialects were used were translated into Indonesian. Coding of these transcripts was performed based on a codebook developed by the TRAction team (Appendix G). The coding process used the Nvivo qualitative analysis software both in Indonesian and English. The coding results produced were based on the type of cases (maternal death, maternal illness, neonatal death, and neonatal illness) and were used as a reference to create a matrix based on the determined variables. The debriefings and transcripts were then reviewed by researchers and consultants. These reviewers provided feedback to the research team with instruction to clarify any unclear information, to re-interview selected respondents to gather additional information, and to suggest improvement for future data collection. All final transcripts were translated into English and given a unique identification. We organized each theme or topic into larger categories with various subthemes, which constituted the foundation of synthesizing and conceptualizing the relationships among the data.

ACTIVITIES COMPLETED

ACTIVITIES COMPLETED

A. LITERATURE REVIEW

EFFECTIVE INTERVENTIONS

As outlined in the WHO Partnership for Maternal, Newborn and Child Health's 7 list of 56 evidence-based essential interventions to reduce maternal, newborn, and child mortality, reductions in maternal and newborn mortality require access to quality and respectful skilled care, mostly at the facility level.⁸ However, because of a variety of sociocultural and other reasons, women and families often delay access to skilled care when maternal/newborn complications arise.

Identification of potentially life-threatening complications as well as timely and appropriate care-seeking is essential to increase use of skilled care. In 1994, Thaddeus and Maine developed the Three Delays model, which organizes barriers to identification and care-seeking for maternal complications into three categories: 1) delay in deciding to seek care; 2) delay in reaching a facility; and 3) delay in receiving quality care. This framework also has been successfully applied to newborn health.⁷ The first delay includes both recognition of complications and the decision to seek care. For both women and newborns, improvement in the availability of skilled care will not effectively reduce maternal and neonatal mortality unless attention is also paid to the quality of the services provided and families know when, where, and how to access the required care and are appropriately supported to act on this knowledge.⁹ This Three Delays model has been used both to develop and evaluate maternal/newborn programs. However, there is a lack of systematic evidence as to how women and families identify maternal/newborn complications; the factors behind decision-making to seek care; and the role of cultural beliefs as drivers of individual decisions, perceptions, ideas and behavior. This area needs more exploration to understand both the facilitators and the barriers that drive decisions at the family and community levels.

BARRIERS TO SEEKING SKILLED CARE

Many well-known barriers, such as financial constraints, distance to facilities, and poor quality of care and provider skills, may interfere with the decision to seek skilled care. Psychosocial factors, including cultural beliefs, practices, and customary rules for family decision-making, also have been found to influence identification of illness and appropriate care-seeking actions for both maternal complications and newborn illness.

The following list describes common barriers to skilled care:

- Challenges in recognizing symptoms that indicate a potentially life-threatening complication or uncertainty about when the severity of a condition may require skilled care. This includes lack of understanding about when normal maternal symptoms progress to life-threatening conditions (such as postpartum bleeding or long labor) as well as difficulties in recognizing nonspecific symptoms of newborn illness (lethargy, inability to suckle).^{10–14}

- Culturally shared beliefs, such as cultural restrictions on movement outside the home that limit facility-based care-seeking, fatalism about newborn survival, the outlook that pregnancy and pregnancy related complications are natural and part of the birthing process, and issues of shyness and fear relative to pregnancy.^{10,12,15–22}
- Perceptions regarding the effectiveness and overall quality of care available from skilled health providers at local health centers.
- Preference for care from traditional providers or family members and traditional home remedies.^{10,12,15,17,19, 20,22–30}
- Limited decision-making power among women, often associated with low education of both the **moth-er** and other authority figures, such as traditional birth attendants, husbands, women, and mothers.^{11,16,22,24,30–32}
- Changing social norms that may influence recognition and care seeking, for example, macro-level changes in socioeconomic status and maternal education.

Most available research that describes factors that influence appropriate care-seeking has focused on the barriers, whereas little research has investigated factors that support appropriate care-seeking behavior beyond identification of specific symptoms or family demographic characteristics (i.e., education, income, etc.) that are associated with more care seeking behavior.^{33–39} In addition, it is important to consider the **inter-action** between available services and potential beneficiaries at multiple levels, from family to household to community to facility.

CONTEXTUAL QUANTITATIVE DATA OF THE STUDY AREAS

The data in Table 3 were gathered from the REACH Project end-line survey (conducted in 51 villages in May 2013), the Jayawijaya DHO Report, the Jayawijaya Statistics 2013, the Indonesian Demographic Health Survey 2012, and the Basic Health Survey 2013 to gain greater understanding of the context.

Table 3: Contextual Quantitative Data and Source of Information

Data	Source of Information
Context of health system and program: • # of districts/communities • Structure and functionality of health system including formal, informal as well public/private providers of care • Structure of local governance • Socioeconomic Status	• REACH Project endline survey • Jayawijaya Statistics 2013
Population/demographic: • Estimated # women of reproductive age in study area • Estimated # of pregnancies and deliveries per year • # of maternal deaths (per year) and by cause • # of newborn deaths (per year) and by cause	• Jayawijaya Statistics 2013 • DHO report

Coverage data on the following indicators: • % of women with at least one ANC from a skilled provider • % of women with at least four ANC visits • % of women whose last delivery was attended by a skilled provider • % of women whose last delivery was conducted in a health facility	• REACH Project endline survey
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B. NETWORKING/RELATIONSHIP-BUILDING AND MEETINGS WITH PARTNERS/STAKEHOLDERS

As part of efforts to smoothe the process of the study, the research team coordinated with several government agencies, NGOs, and organizations at the community level. Some of the activities were as follows:

- Ethical clearance: The ethical process of the proposals was reviewed by the Ethical Clearance research Board at the University of Indonesia.
- Research permit letter: Permissions for the research were obtained from the Ministry of Internal Affairs.
- Induction meeting: This process was conducted to socialize the research activities with related institutions in Jayawijaya District, such as the district hospital, primary health center, health academic, community and religious leaders, and CHWs. The induction meeting was held prior to data collection.
- FGDs with community and religious leaders: To obtain a picture of maternal and child health issues, this event was attended by a pastor/shepherd, the village head, DHO staff, and CHWs.
- FGD and in-depth interview with midwives and DHO staff: To obtain a picture of maternal and child health issues related to the Jayawijaya area.
- Qualitative analysis data workshop: Performed to involve the health staff as a part of the data analysis process. The activity also was intended to confirm the research findings.

C. DISSEMINATION ACTIVITIES

Dissemination activities will be conducted at both the local and national level. The purpose of the dissemination will be to share the results of USAID TRAction with local, district, provincial, and national stakeholders; to share the research methodology with key partners (Ministry of Health, universities, NGOs, etc.); and to provide feedback on national and local level plans to reduce maternal and neonatal deaths. Local dissemination will be conducted as part of the Maternal and Child Health Symposium in Wamena city during the month of November, 2015. The local dissemination seminar will be a one-day event focused on sharing the findings and the methodology of the TRAction project along with other health projects being implemented in Jayawijaya, including the Infant & Young Child Feeding, Community-Based Integrated Management of Childhood Illness, and Community Based Total Sanitation .

The national level dissemination will be a four-day event. The first day will focus on lessons learned from TRAction and other USAID-funded projects in Papua, such as Kinerja Papua, UNICEF ACHIEVE, and Malaria in Pregnancy (MiP). The Kinerja Papua program, implemented by RTI International, supports provincial- and district-level governments in improving health and education service delivery in four districts in Papua Province. The UNICEF ACHIEVE and MiP program aim to improve province- and district-level health policies and facility management of integrated maternal, newborn, child health, and MiP programs and is particularly intended to reach remote communities in eastern Indonesia, including Papua and West Papua Provinces. The three remaining days of the dissemination will focus on sharing the methodology with part-ners and stakeholders.

D. PUBLICATIONS DEVELOPED

In complying with contractual products, one draft document has been submitted for publication.

RESULTS OF ANALYSES

RESULTS OF ANALYSES

We conducted 24 small group interviews with a total of 61 individuals and 3 individual interviews (two CHWs and one district health officer) over a period of two months (April and May 2015). We initially planned to interview husbands separately, but during the instrument field testing, we found that the communities do not allow questions about personal/family matters asked only of the mother without her husband present. Moreover, instrument pretesting revealed that the husband's involvement during the interview could enrich the information shared; in some cases, the husband even encouraged the mother to share her information. The illness narrative group interview therefore included the husbands. Field data collection identified that husbands' presence did not significantly hinder the mothers' sharing of information. We initially planned to conduct focus group discussions with CHWs, midwives, and religious and community leaders. However, because the number of participants who attended was less than four persons, we decided to have a small-group discussion with midwives and religious and community leaders. The group discussion with CHWs was changed to in-depth interview because the CHWs came at different times.

A. MATERNAL ILLNESS AND DEATH CASES

RECOGNITION OF POSTPARTUM HEMORRHAGE

The results of the study showed that within the study participants' community culture, bleeding was generally seen as a sign of danger when present during the labor and deliver access and was considered a sign of severity during the postpartum period. The severity of maternal illness was determined by visual observation of symptoms, such as the amount of blood that seeped during a short period of time. In addition to bleeding, symptoms of retained placenta also were easily recognizable. Knowledge about the recognition of all symptoms was related to birth attendants' previous experience assisting births, previous exposure to health information, and whether the mother had received antenatal care(ANC).

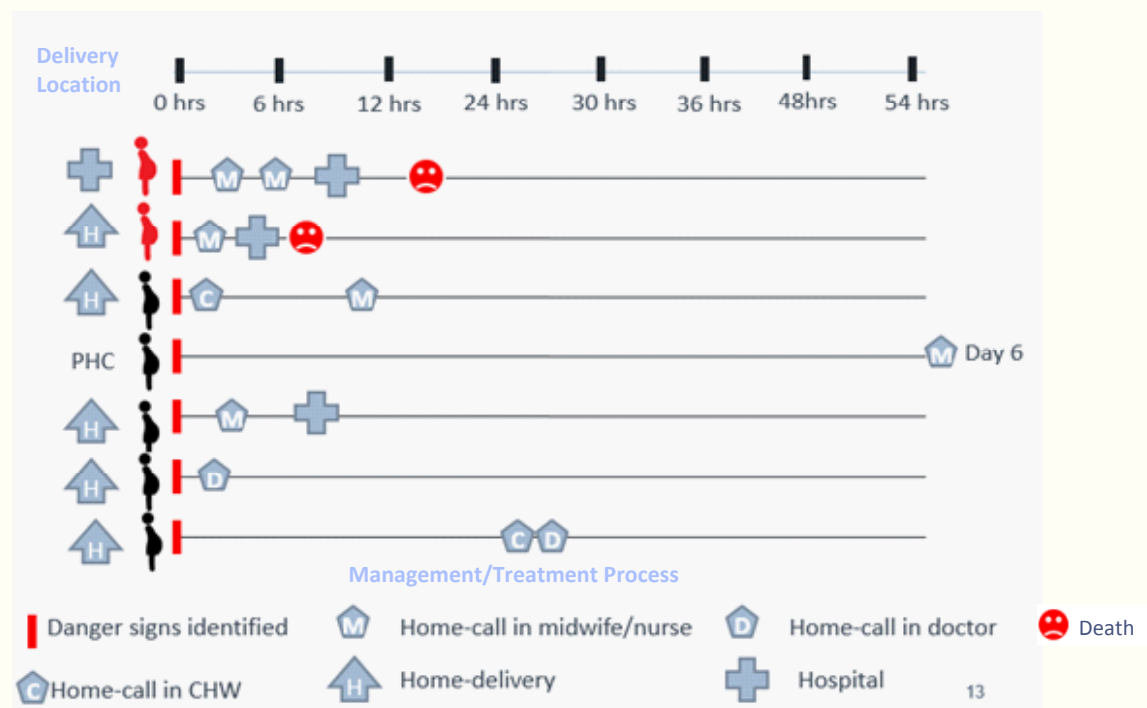
Causes of maternal bleeding were generally attributed to cultural factors, such as the belief that past mistakes affect the birthing process, as well as the placenta's ("baby brother" or kakak in local terms) responsibility for bleeding. Culture also played a part in the creation of barriers. One common barrier to recognition of symptoms had to do with social customs, such as regulations on dwelling. Because men and women lived in different honai, and men/husbands were not allowed to be with their wives in the same honai during the delivery process, delays in symptom recognition and decision-making sometimes occurred.

CARE-SEEKING

In the communities included in the study, the decision to seek care lies predominantly with the husband. As the husband is considered the person most responsible for his wife's health, he is generally the key decision-maker when determining the response to the appearance of symptoms. The maternal uncle also plays a major role in the decision-making process. Typically, the uncle's suggestions and/or views are

given greater regard than those of other family members. Because this society believes that female elders in the family are to assist deliveries, these women also at times were involved in decision-making. On average, the interval between symptom recognition and the decision to seek care in the home was less than six hours, whereas the interval to reach care outside of the home was often greater than six hours (see Figure 3). Rapid decision-making usually occurred when visible symptoms of bleeding began to appear. Other decision-making influences included the support of family and the husband's awareness of the wife's pregnancy history. For example, if a pregnant wife had problems during pregnancy (e.g., anemia) with previous births, the husband was more responsive in making decisions to seek help. Other influences included **cul-tural** matters. In some cases, the incidence of maternal illness and death triggered conflict between families and could contribute in some cases to intertribal warfare. To avoid this, the husband's family was typically quick to take action. In general, there was no significant lag time between the decision-making stage and the process of seeking help/finding treatment.

Figure 3: Timeline Maternal Cases



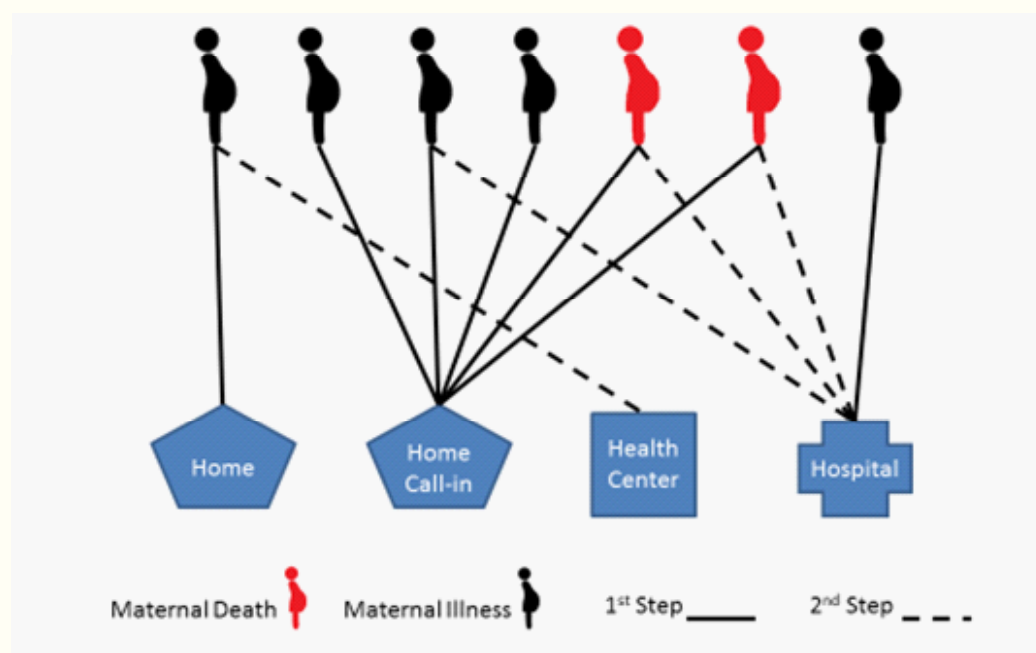
Several factors that could become barriers to care-seeking were usually present. One was the availability of health providers that could be reached at any time. The availability of transportation from remote locations and during the night also delayed treatment.

CARE IN THE HOME

In most cases of PPH and maternal mortality, nearly all events (symptoms) started from home, as giving birth there was the preference of most women in Jayawijaya. Because the symptoms were identified at home, birth attendants usually notified the husband immediately. From the information provided to him, the husband would then act quickly to inform the rest of the family and seek help. Given the weakened condition of the mother, the husband would usually seek first aid help that could be provided at home,

such as that of a mid-wife or CHW rather than take the mother to the hospital (Figure 4).

Figure 4: Pattern of Care-Seeking and Treatment for Maternal Complications



CARE OUTSIDE THE HOME

In the majority of cases included in the study, although the husband had the decision-making power to seek care outside of the home, in almost all cases, the recommendation originated with the midwife. When a mid-wife or CHW was unable to handle a case within the home, the decision was made to refer the case to the hospital for more comprehensive care and greater access to higher quality facilities and services. However, such care and/or immediate aid was not always reliable. For emergency services at the hospital, nurses/mid-wives/doctors and other support personnel and facilities were sometimes not available. When midwives or nurses were available, thorough treatment was delayed because of the need to wait for a doctor's approval. Other factors that affected the speed of obtaining aid related to issues associated with supporting facilities, such as blood banks' lack of blood stock at the hospital.

TRANSFERS, REFERRALS, AND COMPLIANCE WITH REFERRALS

For hospital referral cases, the midwife usually accompanied the mother and family to the hospital. The mid-wife's role in this accompaniment was very significant, as she would inform the health workers of the mother's situation and of what aid had been given so that the hospital could continue appropriate treatment.

This referral system is designed so that health services can work effectively at the village level. Initial treatment is performed by health workers in the home or at the PHC level. If the case cannot be handled or solved at the village/district level, it is then referred to the general hospital. This system ensures that accumulation of patients at the hospital is reduced and services can be accessed by those who need them most.

B. NEWBORN ILLNESS AND DEATH CASES

RECOGNITION OF NEWBORN DANGER SIGNS

Recognition of symptoms in newborns varied from case to case. Whereas the family quickly identified and recognized symptoms in one case, several others found symptoms of illness but did not recognize them as signs of danger. For example, one mother found red spots on her newborn's body and pus on the umbilical cord but only recognized these as physiological reactions of the baby's body to strengthening skin rather than as signs of danger. However, the symptoms that tended to be most easily recognizable as danger signs in newborns were asphyxia, purulent umbilical cord/swelling, patches/skin rash, mouth ulcers, vomiting, purulent eyes, and resistance to suckling. The severity of such symptoms was usually characterized by all-night crying and fever. Most symptoms were first recognized by the mother, whereas the father's involvement in newborn symptom recognition was usually low because he lived in a different honai where he could not keep consistent watch over the baby.

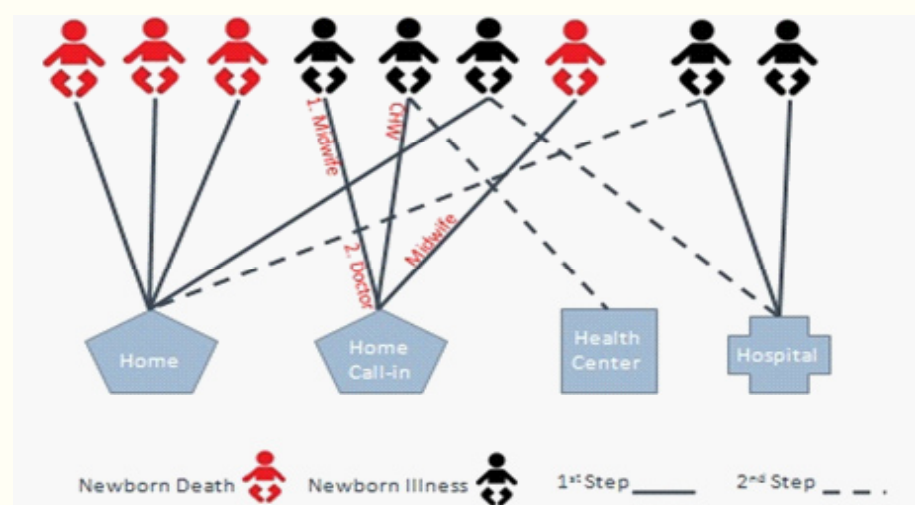
Factors that were often assumed to be a cause of newborn illness or death from the medical side were **prema-turity** and improper feeding. Nonmedical factors reported by respondents as a cause included parents' past mistakes (steal-ing, cheating, injuring another person, violating custom law, etc.), disturbances caused by demons, conditions of the house environment (e.g., effects of smoke furnaces), procedural errors during delivery (the umbilical cord being too strong or mucus present in the baby's mouth during delivery), bad habits of the family (e.g., smoking near the baby), and the feeding of foods other than breast milk before the age of six months (such as hipere/sweet potato).

CARE-SEEKING

This research found variations in those who were the key decision-makers for care of the newborn. In some cases, the mother acted as the main decision-maker; in other cases, the mother and father made decisions together. Mothers had a more dominant role in decision-making in cases of newborn mortality than in cases of newborn morbidity. For newborn morbidity, the husband's role in the decision to seek care was significant to the baby's health. Most decisions to seek or not seek care for newborns usually did not involve other family members.

The pattern of seeking care for cases of newborn illness and death usually began with home treatment, either performed solely by the family or by caregivers brought in from outside the house (CHW/midwife/doctor of the primary health center) which we define in figure 5 as home call-in. If the baby's condition did not improve, health workers would then recommend treatment from better health facilities, such as the hospital (Figure 5).

Figure 5: Pattern of Care-Seeking and Treatment for Newborn Complications



CARE IN THE HOME

In the Jayawijaya community, the care-seeking patterns for newborn cases generally have several stages. First, when parents begin to recognize danger signs, the family joins together to make a mutual confession of mistakes. This confession also can be accompanied by prayer performed by family, neighbors, pastors, or shepherds. Once confession has been made, the baby is believed to recover from his/her illness. However, in some instances in which the parents have made mistakes, such problems must be resolved by paying a penalty to the aggrieved person. For example, if the husband had an affair with another woman, the husband's family must pay a fine of pigs to the wife's family. The belief is that if these problems are solved, then the baby's condition will improve. If the baby's condition remains the same or worsens, treatment is then sought from health workers.

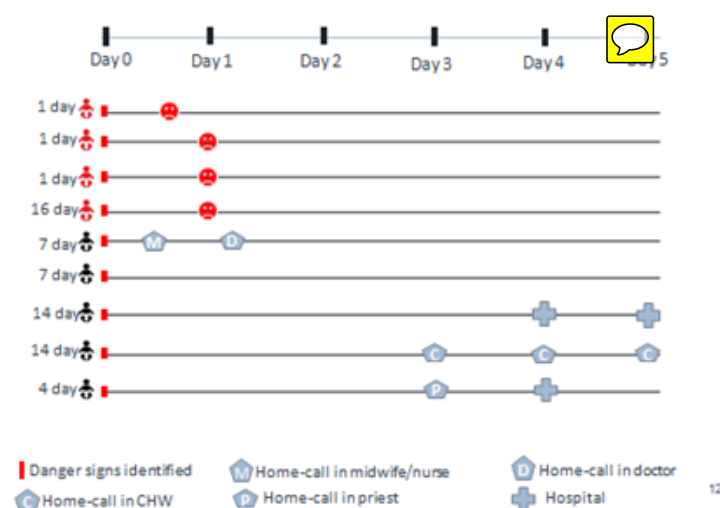
Though the above explicates a common pattern in this mountain community, the results of this study show a slightly different pattern. In some cases in which families chose to seek help from health professionals, the families first contacted cadres/health personnel who had a relationship with the baby's family. Home treatments for sick babies consisted of methods such as massaging the baby's back, praying, pairing objects that are considered to have curing abilities (bracelet of threads created by an uncle of the baby), and the sprinkling of salt around the house to eliminate interference by demons. Only after the cadres or health workers could not handle the case in the home was the baby brought to the hospital.

For more than half of the newborn cases in this study, families chose not to seek help from a healthcare provider. This could be the result of several factors, such as the mother's lack of knowledge of danger signs, the abandonment of the condition to God, financial constraints, and the location of health facilities. For instance, in one case of newborn illness, the parents did not seek treatment from a health facility because of a lack of finances for transportation to the clinic. Instead, the mother chose to surrender the condition of the baby to God.

CARE OUTSIDE OF THE HOME

When cadres or healthcare workers could not handle the case in the home, the parents were advised to bring the baby to the clinic or hospital. However, findings showed that care outside of the home was done only in some cases of newborn illness. On average, care outside of the home took place after four days following onset of the baby's illness (Figure 6). This treatment typically took place at the hospital.

Figure 6: Timeline for Newborn Cases



TRANSFERS, REFERRALS, AND COMPLIANCE WITH REFERRALS

The health referral system in Jayawijaya is generally arranged in several stages. In the first stage, the patient shows symptoms of illness and seeks care at a first-level health facility (i.e., the health center). If the health-care workers of the PHC cannot handle such patients, they are then referred to a more adequate health facility, such as the hospital. Each referred patient is to be accompanied by the healthcare worker who referred them and is to be provided with a referral letter from the health facility the issued the referral. However, public knowledge of this referral system seems to be lacking. To illustrate, in one newborn illness case, hospital treatment was delayed because the family did not obtain a referral letter from the clinic.

Factors that hindered the seeking of treatment included poor weather conditions, distance to health facilities, bad experiences with health care, regulation customs, maternal weakness after childbirth, and financial costs. As Jayawijaya District has implemented national health insurance that allows citizens to go to government health facilities free of charge, the largest financial factor that has become an obstacle is the cost of public transportation to get to such health facilities (Rp. 25,000-30,000 from villages to the city and Rp 5,000-10,000 within the city). Other transportation issues consist of the unavailability of public transportation during night hours. Cultural factors also impact delays in seeking treatment. Such factors include babies not being allowed to be brought out of the home before the age of two years, the umbilical cord not being released, and the need for a thanksgiving ceremony to be held before one seeks treatment.

CHALLENGES AND LESSONS LEARNED

The purpose of qualitative research is to explore the perspectives of participants. During operational research, implementation challenges were encountered in case identification and subsequent geographical location. Typically, patients who came from remote subdistricts or other districts used the address of relatives who lived near the nearest health facilities. These patients usually returned home immediately after treatment/medication was completed. In addition, the recording of addresses in the data register was not adequate to locate the patients' residence. This resulted in a longer time to find cases. To overcome this obstacle, the re-search team was assisted by CHWs, midwives, or facilitators of World Vision Indonesia (WVI) to help provide information to obtain cases.

Another limitation was that local cultural norms require the husband to be present during the interview, which caused delays in starting interviews. The permission of husbands was considered very important in the smooth conduct of the interview. However, the interview could not always be conducted in the presence of the wife's husband because of limited time and geographic factors. To gain the trust of the family, especially for the focal women, the research team was almost always accompanied by a cadre or WVI facilitator who was known to the interviewees. Other technical problems included the difficulty of communication in the local language and the difficulty of informants in describing the time of incidents reported. In Jayawijaya District, the community is divided into several local tribes that each has its own language. The solution to overcome this obstacle was to use a local translator (cadre or facilitator). However, during interviews, translators would often conclude the answers of the informant. This affected the research team's ability to probe with further exploratory questions. Finally, interpretation of reality and interviewees' choices about what to divulge contributed to the consequent risk of introducing personal bias into this interpretive act. Behavioral patterns were not always easy to identify; as a result, in some cases, the research team found it difficult to draw conclusions.

RECOMMENDATIONS FOR APPLICATION OF RESULTS

RECOMMENDATIONS FOR APPLICATION OF RESULTS

The research results suggest several actions that could be taken to improve maternal and child health issues in Jayawijaya District:

1. Increase equity in equipment, providers, and health facilities at PHC and village levels. Good health facilities/services are not uniformly available. The mountainous geographical conditions cause difficulties in accessing transportation. This factor makes it difficult for people, especially mothers and newborns, to reach adequate health services.
2. Strengthen the capacity of competent healthcare workers at the village level. Healthcare workers in Jayawijaya should improve service quality. This relates to ingrained habits held by people who are reluctant to check into healthcare facilities. Strengthening the capacity of healthcare workers who live in the village may expose more comprehensive mother and child health information. Moreover, increased quality of healthcare workers is expected to provide more rapid aid and adequate services in remote areas. These improvement also may provide health promotion on reproductive health, such as family planning, sex education, and sexually transmitted disease, including HIV/AIDS.
3. Increase capacity of CHWs to recognize symptoms as danger signs for the health of the mother and the newborn. CHWs in Jayawijaya have an important role and are close to the community. CHWs are seen as a force that is always ready to give help and advice about maternal and newborn health issues.
4. Increase the role of religious and community leaders in decision-making and the care-seeking process. Jayawijaya culture is still dominated by traditional and religious rules; the community still sees religious and community leaders as people whose advice should be obeyed. Close relationships with these leaders are important in improving knowledge, attitudes, and behavior relative to maternal and newborn health issues. The opinions of these highly respected figures affect how families make some decisions. If the religious and community leaders enhance their role in building a better health system, the approach is expected to be more appropriate to reach community levels. The influence of these leaders also is needed to change community habit relative to confession before seeking care.
5. Provide community-based transportation to access health care that can be used anytime, including during weekends and holidays.

REMAINING QUESTIONS

Limitations of this research suggest several questions for further exploration:

- a. Given that interviews were not conducted throughout the entire district, does this study represent the entire Jayawijaya District?
- b. Is there any difference in care-seeking patterns between rural and urban areas? What is the pattern in remote areas where it is very difficult to reach healthcare workers or healthcare facilities?
- c. Given that the results of the study show that care-seeking is faster for cases involving women than for newborns, is it true that women have a higher value in the society?
- d. Given the study's finding that cases of the mother's death are easier to locate, what is the status or condition of the health reporting system for illness and death of mothers/newborns?
- e. Given that the study did not find a pattern of care-seeking by the husband in cases of illness or newborn death, how does the husband's role in child care contribute to care-seeking?
- f. What is the effect of the husband's and wife's living in separate honai on recognition of symptoms?

NEXT STEPS

World Vision Indonesia, based on discussions taking place during local and national dissemination activities, will produce and implement an action plan to address some of the limitations in seeking appropriate care in the areas of maternal and newborn health found during this study.

World Vision US is committed to share results internally with the rest of the institutional staff across the World Vision partnership. These activities will include: panel discussion at World Vision Washington, DC, office about the final results of the study; World Vision International global webinar presentation on study final results; and publication of a research final report on the World Vision web page. Additionally, WVUS will prepare and submit abstracts for international conferences such as APHA 2016 annual conference, Women Deliver 2016 conference, and CORE Group 2016 spring conference.

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