



THE UNIVERSITY OF
SYDNEY

“We did not go because we had no money”

**Indirect Financial Barriers to Accessing Maternal, Neonatal and Child
Healthcare in Timor-Leste: A Qualitative Study**



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Abbreviations

AMTSL	Active Management of the Third Stage of Labor
BEmONC	Basic Emergency Obstetric and Neonatal Care
CCI	Composite Coverage Index
CHC	Community Health Centre
CHE	Current Health Expenditure
EmONC	Emergency Obstetric and Neonatal Care
EPI	Extended Program for Immunisation
GDP	Gross Domestic Product
GGHE-D	General Government Health Expenditure - Domestic
HMIS	Health Monitoring Information System
HNGV	Hospital Nacional Guido Valadares
MNCH	Maternal, Neonatal and Child Health
ORS	Oral Rehydration Solution
PSF	Promotor Saúde Família
SBA	Skilled Birth Attendance
SDG	Sustainable Development Goal
SISCa	Servisu Integrada du Saude Comunidade
UN	United Nations
UNTL	Universidade Nacional Timor Lorosae
UNICEF	United Nations Children's Fund
VNR	Voluntary National Review
WHO	World Health Organisation

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Executive Summary

Background

The 2030 Agenda includes 17 Sustainable Development Goals (SDGs) and 169 global targets across social, environmental and economic dimensions of development. These goals particularly focus on human rights, gender equality and the empowerment of women and girls. They aim to reduce inequality within and between countries (SDG10) recognizing that monitoring national-level outcomes in isolation can result in many women and children being left behind. This has led to a greater effort towards assessing equity of coverage with the aim of that coverage eventually being universal. Many low and middle income countries have low coverage amongst their poorest families driving substantial Maternal Neonatal and Child Health (MNCH) inequalities and leaving many of the poorest women and children behind. It is thought that indirect costs incurred whilst accessing these health facility-based services (e.g. paying for transport) are significant deterrents for these poorer households.

Timor-Leste is no exception to these findings. In 2019, Timor-Leste completed a Voluntary National Review (VNR) which highlighted the importance of ‘consolidating peace’ and ‘addressing municipal and rural-urban disparities’. The report stressed that resources and capacity building needed to be prioritized towards those who are furthest behind. It highlighted that 80% of those living below the poverty line are in rural areas and around 15% are from poor urban areas. For example, **antenatal coverage** nationally is moderate at 77%, but it ranges from 63% amongst the poorest to 91% amongst the rich (a **28% rich/poor coverage gap**). Similarly, **skilled birth attendance rates** nationally are 58% but underneath this lies one of the largest disparities on the MNCH continuum with only 26% coverage amongst the poorest yet 90% amongst the richest (a **64% rich/poor coverage gap**). **Postnatal care coverage for mothers** nationally is low at 35% but falls to 15% amongst the poorest but 63% for the richest (a **48% rich/poor coverage gap**). Care-seeking for symptoms of pneumonia and treatment of diarrhoea with oral rehydration solution (ORS) also have moderate coverage at 71% and 70% respectively. However, there is a **32% rich/poor coverage gap for pneumonia** and a 11% gap for diarrhoea management. Coverage of **postnatal care for babies** is the lowest at only 31% nationally and large disparities from 13% amongst the poor to 58% amongst the wealthy (a **rich/poor gap of 45%**).

Since healthcare is free in Timor-Leste, it is possible the indirect financial costs may play an important role in driving the rich/poor and rural/urban divide even further. Indirect financial costs include factors such as the time and lost income to the patient and those accompanying them to get healthcare. As poorer families are more likely to be agricultural workers or casual laborers, they don’t have the leave entitlements or social security benefits of salaried workers. Indirect costs also include transport, food, accommodation and repatriation of the deceased. They can amount to a high proportion of the poorer household’s income and may require families to borrow money or sell assets tipping them further into poverty and debt.

Thus, the Ministry of Health, in collaboration with UNICEF and WHO, commissioned this research to better understand and inform future planning to improve MNCH outcomes and to ‘leave no one behind’. The questions to be addressed are:

- What are the indirect financial barriers to healthcare in Timor-Leste?
- What are the costs to households of these indirect financial barriers to healthcare in Timor-Leste?
- What are the implications for services, programs and interventions in Timor-Leste?

Method

We conducted a qualitative study in four municipalities, completing 216 household, 40 stakeholder interviews and four case studies. The rural municipalities of Ainaro, Ermera and Lautem were selected due to poor MNCH outcomes and relatively remote communities were purposively sampled to gain more detailed insights into the experiences of poorer rural households with children under the age of five. In Dili we interviewed households from wealthier and poorer urban areas to explore rich/poor urban disparities. Experiences of MNCH were documented with a particular focus on indirect and unexpected out-of-pocket financial costs. We also interviewed community leaders (xefe suku sira), local doctors and nurses/midwives, NGO workers, health administrators, traditional healers, private clinic workers, paediatricians and policymakers.

Key results

Most households had attended a health centre for care of a sick child at least once during the previous month. If the nearest, staffed, health facility was too far from home, some families would just not go, especially if they had no transport or they needed to take time off work. Instead they might use traditional medicine or self-treat with medicines from a local kiosk.

In the wealthier Dili households, almost all babies were delivered by a skilled birth attendant at a health facility. In the poorer Dili households, some had homebirths. However, in the rural municipalities, having your baby at home was a common experience and cost far less than having a baby in a health facility. If problems are detected antenatally and the mother is referred to the municipality or national hospital the costs can be very significant for the family. For example, even if the mother is transferred by ambulance, the public or private transport costs and food for the family members is large cost for poorer households. The family may also lose up to one month in income if they are agricultural workers or kiosk and other laborers.

There were 46 households in our study who had experienced the death of a child. Babies died during complicated homebirths or with respiratory difficulties, a lack of breastmilk, fever, breathlessness or sudden death of unknown cause within the first days and weeks of life. The indirect costs resulting from referral of a very sick child or baby could be equivalent to one year's income for very poor households.

Transport costs and lost income were important indirect costs to poor families. It can take several hours to reach the facility and there may be long waiting times before the return journey. Many of the rural families and the urban poor in Dili, sell goods at the market or kiosks or work as farmers and laborers. If they are not at work, they lose money. Families estimated that **routine visits each month usually cost them at least one day of their household income** as the husband will often need to accompany the wife. We found that it was unusual for them to pay someone to look after their business. Rather, they would rely on extended family if possible, or close the kiosk for the duration required. Extended healthcare visits for health-facility based childbirth or serious illness may result in **up to one month in lost income**.

Food and accommodation costs were incurred with an inpatient stay or more than a day-only such as hospitalization for illness or childbirth. Accompanying family members may be able to stay with relatives but often sleep at the hospital. They need to source their own food and this can be quite a substantial costs for some. Some families reported their food costs to be over \$100 when the mother or child was hospitalized in Dili.

Medicines and equipment were a frequent cost incurred by families and was also thought to be important by stakeholders. **Families frequently paid from \$2-\$10 for medicines**, often at a local kiosk or pharmacy and frequently this was because the health facility did not have the stock

Of the 56 households living below the national poverty line of \$3.25 per day, we were able to estimate the recent expenditure on MNCH financial costs as a proportion of household income in 31 households.

There were 19.4% of poor households that spent more than half of their household income in the previous month on MNCH care alone. We also note that 12.9 % of these households spent their entire income or more on MNCH costs. These four households incurred a catastrophic level of expense in obtaining care. Three out of four of these households had sick children who needed hospital care

Only 20% of those families living below the national poverty line reported having their most recent birth at a health facility. The remainder had their baby at home, with 7 (12.7%) having either a doctor, midwife or traditional birth attendant with them at the house. The vast majority 37 (84.1%) of these homebirths in poor households were assisted by family members only. There was a significantly higher rate of facility-based births amongst those living above the poverty line compared with those below ($P=0.24$)

After triangulation of the data we identified the following key explanatory themes:

- (1) Mothers, babies and children in poor rural households are being 'left behind' and are experiencing indirect financial barriers to accessing healthcare
- (2) Indirect financial costs can be substantial for households considering a birth at a health facility attended by a skilled professional
- (3) A lack of affordable and effective postnatal care for mothers and babies makes them vulnerable to serious illness and death
- (4) Serious illnesses in mothers, babies and children incur substantial costs for rural families requiring referral to secondary and tertiary care & catastrophic indirect costs can tip households into further poverty and debt
- (5) Gaps in services and low-quality healthcare is creating indirect financial costs in both urban and rural settings and people are not willing to pay

Discussion and Recommendations

This study has identified that indirect and unexpected out-of-pocket costs are experienced by many households seeking MNCH healthcare and can account for a substantial proportion of their income. This is particularly the case for poorer households in rural areas. Local primary healthcare services are accessed frequently for routine maternal and childhood illnesses, vaccinations and antenatal care. However, the lost income, transport costs and the frequent requirement to purchase medicines due to stock outs can cause some families to turn to alternatives such as traditional healers close to their home or to self-treat by purchasing medicines from a local kiosk. Poor families in Dili face less indirect costs due to the availability of public transport, health facilities and vehicles. Stock-outs for medicines and equipment appear to be a system-wide problems with cost-shifting onto families causing additional financial stress.

There are seven recommendations from our findings:

Recommendation 1: Establish a multi-sectoral taskforce to address MNCH inequalities

Recommendation 2: Audit current obstetric service quality using a valid tool and consider redesign to shift from poor quality local care to high quality hospital & health centre care within two hours from homes

Recommendation 3: Co-design and implement a postnatal care program for mothers and babies that is consistent with international guidelines

Recommendation 4: Create staff incentives for quality improvement in obstetric and newborn care

Recommendation 5: Strengthen and support basic MNCH in the community

Recommendation 6: Consider a conditional cash transfer payment for poor rural families who give birth at a recognized health facility and complete postnatal care

Recommendation 7: Establish an emergency fund for costs incurred through serious illness for sick children in poor rural households

Conclusion

In conclusion, this study is consistent with other data highlighting disparities in MNCH care amongst poor rural families. Indirect and unexpected out-of-pocket costs account for a substantial proportion of the incomes of these households. Unless supply-side problems are addressed it is likely that these families will be unwilling to pay indirectly for MNCH care. Catastrophic costs incurred with referral pathways and serious illness need to also be addressed. We have suggested seven strategies for consideration by the Government of Timor-Leste in order that no Timorese women, babies or children will be 'left behind'.

Main Report

Introduction

Global Issues for Maternal, Neonatal & Child Health

In October 2015, the 193 member states of the UN, unanimously supported “*Transforming our world: the 2030 Agenda for Sustainable Development*”. (1) This 2030 Agenda includes 17 Sustainable Development Goals (SDGs) and 169 global targets across social, environmental and economic dimensions of development. These goals also focus on human rights, gender equality and the empowerment of women and girls. In particular, they build on the 2010 UN initiative “*Every Woman, Every Child*” which, in its second decade, has become the “*Global Strategy for Women’s, Children’s and Adolescents’ Health (2016-2030)*”. (2) The relevant goals and targets for maternal, neonatal and child health (MNCH) have been extracted and the global strategy of ‘*Survive, Thrive, Transform*’ is summarized below in Figure 1. (2-4)

Objectives and Targets Aligned with the Sustainable Development Goals	
SURVIVE	End preventable deaths
<ul style="list-style-type: none">• Reduce global maternal mortality to less than 70 per 100,000 live births• Reduce newborn mortality to at least as low as 12 per 1,000 live births in every country• Reduce under-five mortality to at least as low as 25 per 1,000 live births in every country• End epidemics of HIV, tuberculosis, malaria, neglected tropical diseases and other communicable diseases• Reduce by one-third premature mortality from non-communicable diseases and promote mental health and well-being	
THRIVE	Ensure health and well-being
<ul style="list-style-type: none">• End all forms of malnutrition and address the nutritional needs of children, adolescent girls and pregnant and lactating women• Ensure universal access to sexual and reproductive health care services (including family planning) and rights• Ensure that all girls and boys have access to good-quality childhood development• Substantially reduce pollution-related deaths and illnesses• Achieve universal health coverage, including financial risk protection and access to essential services, medicines and vaccines	
TRANSFORM	Expanding enabling environments
<ul style="list-style-type: none">• Eradicate extreme poverty• Ensure that all girls and boys complete free, equitable and good-quality primary and secondary education• Eliminate all harmful practices and all discrimination and violence against women and girls• Achieve universal and equitable access to safe and affordable drinking water and to adequate and equitable sanitation and hygiene• Enhance scientific research, upgrade technological capabilities and encourage innovation• Provide legal identity for all, including birth registration• Enhance the global partnership for sustainable development	

Figure 1: Adapted from the *Global Strategy for Women’s Children’s and Adolescents’ Health (2016-2030)*

As we approach the halfway mark for this agenda, efforts to track progress against the goals show a significant setback from the COVID-19 pandemic. (5, 6) Maternal, neonatal and child health and well-being has been disproportionately effected through increased poverty, job losses and overstretched health systems. (6)

Importantly for MNCH, the 2030 Agenda aims to eradicate extreme poverty (i.e. less than \$1.25 per day) and the number of people living below their national poverty lines (SDG1). It calls for safe, affordable and accessible transport systems, particularly for vulnerable groups such as women and children (SDG11.2). It states that pregnant women, newborns and children should be covered by social protection systems to achieve universal coverage (SDG1.3) and have access to basic services, improved nutrition, essential medicines and vaccines (SDG2,3,8). The integrated, multisectoral approach adopted by the SDGs recognizes that, in order to ‘*Survive, Thrive and Transform*’, women, babies and children need their environmental, social and economic needs addressed since they are such strong determinants of health, particularly for poorer families.

The 2030 Agenda aims to reduce inequality within and between countries (SDG10) recognizing that monitoring national-level outcomes in isolation can result in many women and children being left behind. (7, 8) This has led to a greater effort towards assessing equity of coverage with the aim of that coverage eventually being universal. (7) One such measure is the composite coverage index (CCI). It is a combined measure of eight key reproductive, maternal, newborn and child health interventions. (3, 7) A recent analysis of 83 low and middle income countries showed that many countries have low CCIs amongst their poorest families driving substantial MNCH inequalities and leaving many of the poorest women and children behind. (7) There has also been greater focus on the delivery channels for MNCH care and there is growing evidence that indicators that are delivered at the community-level generally have more equitable coverage than those requiring fixed health facilities. (9) It is thought that indirect costs incurred whilst accessing these health facility-based services (e.g. paying for transport) are significant deterrents for poorer households.

Indirect Financial Barriers and their Role in Health Inequality

Equitable access to healthcare for mothers, babies and children is crucial to achieving the 2030 Agenda. (2) The association between poverty and poor health has been well described. Poverty is associated with greater constraints upon and less opportunity to make choices over healthcare and it impacts significantly on people’s ability to access healthcare. (10) Healthcare access is often described as having both supply and demand factors across four domains – Geographic accessibility, Availability, Financial accessibility and Acceptability. (10) Of these four domains, it is the financial access barriers to healthcare that are considered to be the most important for poorer households and therefore driving further health inequalities. (10) In some countries there are significant *direct* costs for treatments and informal payments but there is also increasing focus on the *indirect* costs that deter poorer families from accessing healthcare and these can have serious economic consequences on these households.

Indirect financial costs include factors such as the time and lost income to the patient and those accompanying them to get healthcare. As poorer families are more likely to be agricultural workers or casual laborers, they don’t have the leave entitlements or social security benefits of salaried workers. Indirect costs also include transport, food, accommodation and repatriation of the deceased. They can amount to a high proportion of the poorer household’s income and may require families to borrow money or sell assets tipping them further into poverty and debt.

The Government of Timor-Leste’s Strategic Development Plan and the SDGs

In 2011, just one decade after gaining its independence, Timor-Leste set out a twenty-year plan for its future development. (11) Five years later, when the UN’s 2030 Agenda was agreed upon, they took the further opportunity to check the alignment of the 2011 Strategic Plan against the SDGs. (12) The Government of Timor-Leste has been a strong supporter of the 2030 Agenda from its inception, passing a

Resolution (No.54) through the Parliament on 23 September 2015 and the further ratification of the 2030 Agenda on 18 November 2015. Resolution No 19/2015 recommended that planning and budgets be aligned with the SDGs and Government Decree No 1, 1 February 2016 mandated that the SDGs be reflected in all annual plans and budgets. (12) The *National Health Sector Strategic Plan 2011-2030*, (13) has invested heavily in building health facilities across the country, in establishing a health workforce, and in developing a health monitoring information system (HMIS). From having almost no health workforce at the time of independence (2001) there are now approximately 7.2 doctors per 10,000 and 16.7 nurses per 10,000 population. (3)

Timor-Leste's free health service is centred on primary healthcare to deliver a basic service package. The original outreach program to villages – *Servisu Integrada du Saude Comunidade (SISCa)* and local health volunteers – *Promotor Saude Familia (PSFs)* - have now largely been replaced by health post facilities staffed by nurses, midwives and/or doctors plus the 'Saude na Familia' program which is a Cuban-style home-visitation program. These are the core to basic primary healthcare delivery at the community-level. Around 74% of the national population live in rural areas, with many of these households dependent on subsistence farming. Within each municipality there are also larger Community Health Centres (CHCs) including birthing facilities and usually a small number of in-patient beds. Several larger municipality hospitals and one tertiary national hospital, Hospital Nacional Guido Valadares (HNGV) in Dili are the referral pathways from the community should more advanced care be required.

Despite these achievements, there are still inequalities in health service utilization within Timor-Leste. (14) A national study of 1712 households undertaken in 2015, showed disparities in hospital utilization amongst the poor and in rural households, compared to their urban and wealthier counterparts. (15) Another study conducted around the same time used focus groups and interviews to identify what barriers might be driving these disparities in hospital utilization. (14) It found that on the supply-side, lack of patient transport, medicines, blood supplies, laboratory testing and health workers' attitudes to the poor needed to be addressed. On the demand-side, the indirect costs such as transport to and from facilities, accommodation and food for accompanying relatives and transport for the repatriation of the deceased were major deterrents to accessing healthcare. (14)

Current health expenditure (CHE) as a share of gross domestic product (GDP) has fluctuated since independence but remains low at around 4%. The Domestic General Government Health Expenditure (GGHE-D) is approximately USD45 per capita (2016) and there has been a heavy reliance on Overseas Donor Aid (ODA) for MNCH in particular, accounting for about \$14 per capita (2017) (3, 16)

In 2019, Timor-Leste completed a Voluntary National Review (VNR) which highlighted the importance of 'consolidating peace' and 'addressing municipal and rural-urban disparities'. The report stressed that resources and capacity building needed to be prioritized towards those who are furthest behind. (17) It highlighted that 80% of those living below the poverty line are in rural areas and around 15% are from poor urban areas. The report against SDG3 'Good Health and Wellbeing' notes the gains that have been made in health over the past two decades and important role of universal access to free healthcare being enshrined within the constitution. The VNR also noted the successful reduction/near-elimination of malaria nationwide but a continually high incidence of tuberculosis which is the highest cause of hospital deaths in the country. However, it was the disparities between the rich and poor that urged for greater focus to ensure that no one would be left behind.

Maternal, Neonatal and Child Health in Timor-Leste

Whilst the maternal mortality ratio in Timor-Leste has fallen to around 142 per 100,000 live births (2017), this is still short of the 2030 target of 70 per 100,000 live births. **Antenatal coverage** nationally is moderate at 77%, but it ranges from 63% amongst the poorest to 91% amongst the rich (a **28% rich/poor coverage gap**). Similarly, **skilled birth attendance rates** nationally are 58% but underneath this lies one of the largest disparities on the MNCH continuum with only 26% coverage amongst the poorest yet 90% amongst the richest (a **64% rich/poor coverage gap**). **Postnatal care coverage for mothers**

nationally is low at 35% but falls to 15% amongst the poorest but 63% for the richest (a **48% rich/poor coverage gap**).

Similarly, the under-five mortality rate in Timor-Leste has fallen to 44 per 1000 live births (2019) still a way above the 2030 goal of 25 per 1000 live births. Childhood immunization coverage remains consistently high at around 80% with an estimated 24% rich/poor coverage gap. Care-seeking for symptoms of pneumonia and treatment of diarrhoea with oral rehydration solution (ORS) also have moderate coverage at 71% and 70% respectively. However, there is a 32% rich/poor coverage gap for pneumonia and a 11% gap for diarrhoea management.

Of major concern is the **neonatal mortality rate which remains at 20 per 1,000 live births**, still above the 2030 target of 12 per 1,000 live births and representing 45% of all under five deaths. **Stillbirth rates** are also **high at 18 per 1000** births. Coverage of **postnatal care for babies** is the lowest at only 31% nationally and large disparities from 13% amongst the poor to 58% amongst the wealthy (a **rich/poor gap of 45%**). Whilst **early initiation of breastfeeding** is universally high at 75%, **exclusive breastfeeding** drops to 50% with a 20% rich/poor coverage gap.



Research Questions

As outlined above, Timor-Leste has a strong commitment to the 2030 Agenda of the Sustainable Development Goals and an early VNR pointed toward rural-urban and urban poor disparities in development. It recommended targeted prioritization of 'the furthest behind' i.e. poorer households, particularly in rural areas. Although Timor-Leste's constitutional commitment to free healthcare is significant, there remain significant disparities in health service utilization and in health outcomes for Timorese mothers, babies and children. Financial barriers to accessing healthcare appear to be important potential drivers of ongoing health disparities. Yet little is known about these experiences in families with children under the age of five. With only a decade to go in the 2030 Agenda, there's an urgent need to develop targeted strategies in MNCH to achieve the nation's goals.

Thus, the Ministry of Health, in collaboration with UNICEF and WHO, commissioned this research to better understand and inform future planning to improve MNCH outcomes and to 'leave no one behind'. The questions to be addressed are:

- What are the indirect financial barriers to healthcare in Timor-Leste?
- What are the costs to households of these indirect financial barriers to healthcare in Timor-Leste?
- What are the implications for services, programs and interventions in Timor-Leste?



Methods

Study design

To understand ‘what, where, how, when and why’ indirect financial costs are experienced by the households of mothers, babies and young children in Timor-Leste, we chose a qualitative study design. This method was able to capture the self-reported experiences of primary caregivers and key stakeholders through interviews with individuals. It enabled an in-depth description of these experiences in a deliberate and purposively selected sample of participants. As well as describing the healthcare experiences of mothers, babies and children in our sample, the study identified key themes for the impact of indirect costs on MNCH and used a health access framework (10) to propose evidence-informed strategies and interventions to address this problem.

Rationale for municipality selection

We know from the literature that there are rich/poor and urban/rural disparities in MNCH for Timorese families. There is also evidence that financial barriers to accessing MNCH care are particularly important for poor families and that, despite free healthcare in Timor-Leste the indirect costs incurred by families may be substantial. However, little is known about this.

It was therefore proposed that we undertake data collection in three of the municipalities with the highest poverty rates and worst MNCH indicators and also to collect data to assess disparities amongst the urban poor in Dili. It was not feasible to travel to Oecussi for data collection in this study due to resource limitations. Several national reports were used to inform this choice and it was agreed that Ainaro, Ermera and Lautem would be the selected municipalities (in addition to urban Dili). (18-20) Ainaro has particularly high child mortality rates, low vaccine coverage and low skilled birth attendance (SBA) rates. Dili had the lowest poverty rates and low access problems and generally some of the best MNCH indicators. However it is likely that these figures hide the underlying rich/poor disparities within this municipality. Ermera has high poverty rates, substantial access problems and low SBA rates, while Lautem has moderate access issues and MNCH indicators but was particularly chosen because of its geographic remoteness. In September 2020, the Countdown 2030 report showed that the CCI for these municipalities (except Dili) were amongst the lowest in the country, (3) thereby further confirming our selection rationale.

Table 1: MNCH Indicators by Municipality-Timor-Leste

Municipality	Poverty Rate International (%)	Access Problems: Pay for Treatment (%)	Access Problems: Transport (%)	Child Mortality per 1000 live births	Skilled Birth Attendance rates (%)	Basic vaccine coverage (%)
Aileu	23.7	35.7	43.1	36	71	59
Ainaro	28.9	40.9	53.7	56	23	18
Baucau	20.8	43.6	51.3	43	62	54
Bobonaro	36.2	39.2	58.3	36	49	45
Covalima	41.8	39.8	45.1	29	60	47
Dili	18.9	19.6	19.6	37	85	83
Ermera	46.8	77.6	86.3	34	20	15
Lautem	20.8	41.5	48.4	19	65	53
Liquica	32.9	42.2	47.7	33	45	55
Manatuto	34.8	55.9	60.1	43	66	47
Manufahi	31.1	34.3	50.0	40	47	30
Oecussi	54.0	34.3	34.2	76	34	23
Viqueque	24.3	24.7	35.8	49	59	43

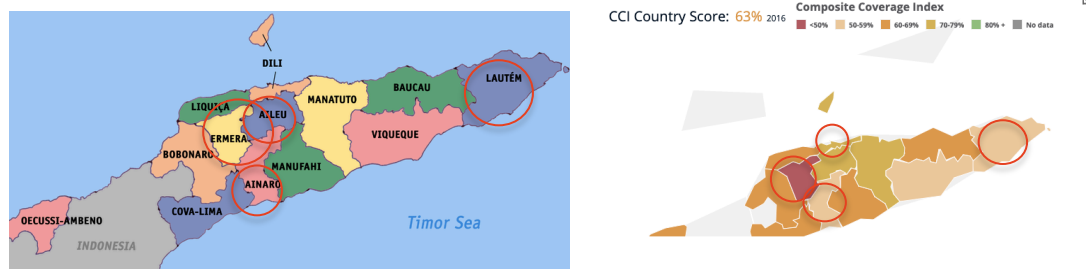


Figure 2: Map of Timor-Leste showing selected municipalities and 2020 CCI levels

Ethics and Governance

This study was approved by the Human Research Ethics Committee, Instituto Nacional da Saude, Timor-Leste (Approval Ref, No. 1990MS-INS/DEXII/2019). The research team was also supported by an advisory committee, consisting of senior experts from the Ministry of Health, INS, National Hospital, UNTL and the University of Sydney. The Committee was due to meet three times during the project. However, due to the COVID-19 pandemic, the number of meetings was curtailed to two. The first meeting was held in Dili on the 15 November 2019, chaired by the Ministry of Health. The final meeting was held on 28th July 2021 as a two hour workshop to present the results and discuss their interpretation and implications for MNCH programs, services and policies in Timor-Leste.

Data collection tools and topic guides

There were three types of data collected during this study.

- 1) Household interviews with primary caregivers of children under the age of five years.
- 2) In-depth interviews with key MNCH stakeholder in each municipality plus nationally
- 3) Case studies taking an ethnographic approach

The key topics covered across these tools were:

- A description of households demographically and socioeconomically
- An understanding of health and healthcare experiences for MNCH care within households, across communities and nationally
- A description of indirect costs incurred by households seeking MNCH care
- An understanding of additional out-of-pocket costs for MNCH care
- Insights into strengths and weaknesses of MNCH care in Timor-Leste
- Suggested strategies to address indirect financial barriers to MNCH care

Indirect financial costs included transport, accommodation, food, lost income, communication, gifts and repatriation. At the request of our advisory group we also sought information about unexpected out-of-pocket financial costs including medicines, fees (including traditional healers), tests/x-rays and blood transfusions.

Participant Recruitment, Sampling & Data Collection

Household Interviews

Households were eligible to participate if they had at least one child under the age of five living there and the primary caregiver of those children was willing to be interviewed. Subjects or respondents were only included after they have been informed about the interview procedures and have given their consent. The participation of the subjects in the interview was voluntary. They were advised that all data was anonymized and treated confidentially.

The researchers worked closely with local community leaders to ensure that their presence would be acceptable. Households were specifically sought out that might have young children under the age of five and we aimed to include some households where a child had died and/or the mother was deceased. Enumerators approached the primary caregivers directly and sought permission for the interview. Most of the questions were in an open-ended format to encourage the capture of richer and more detailed experiences. This was conducted in Tetum and the responses were noted verbatim onto a hard copy/paper version and later entered into an electronic form (via Survey Monkey ©) once internet access was available.

Within each rural municipality a range of households were approached but there was a deliberate effort to ensure that poorer households were well represented. The selection of villages (*suku sira*) was made in collaboration with local leaders with the aim of particularly capturing the experiences of households that were located further away from health facilities and therefore, more likely to have access issues. For confidentiality, we have not reported the names of these small communities.

In Dili, the data was collected in two stages. The first was a pilot completed in December 2019. After looking at the data, it was found that there were insufficient households from poorer neighbourhoods and further household interviews were undertaken to address this in February 2021. Given that within Dili, we wanted to explore the possible disparities between wealthier and poorer households, our sampling method was different to the rural areas.

Case Studies

During the household interviews, the enumerators and researchers in the field identified one household in each municipality that had some experience of indirect financial costs. They spent additional time with these families to construct a case study using ethnographic methods of observation and narratives. These more details stories were written into detailed notes and transcribed into electronic form once internet access was regained.

Stakeholder Interviews

The research team created a list of roles and types of stakeholders likely to have observed families experiencing financial costs and possible barriers to MNCH care. These included the community leader (*xefe suku*), local doctors and nurses/midwives, NGO workers, health administrators, traditional healers, private clinic workers, paediatricians and policymakers. Through our networks, we identified people who might fill these roles and approached them by email, by telephone or in-person, depending on the context. The interviews with individuals were conducted either in-person or by phone at a time convenient to the participant. Each was audio-recorded so that it could later be transcribed verbatim. These stakeholder interviews were mainly conducted by the research investigators due to the senior people involved. They were conducted either in Tetum or English, depending on the preferences of the interviewees.

Translation and Analysis

Household interview data was entered into the electronic Survey Monkey form verbatim from the enumerator's written notes by them. It was downloaded from this platform by LT who checked the data quality and set up categorical and continuous variables within an SPSS © database. Open-ended qualitative responses were analysed in Excel by LT in-language. Themes were identified and relevant quotes translated. Translations were cross-checked by native speaking members of the team. Data was monitored for saturation as it was entered and transcribed.

We used the International Standard Classification of Occupations to categorise types of employment. (21) The Timor-Leste National Poverty Line of \$3.25 per day was used to categorise 'poorer' household. (17)

Case studies and stakeholder interviews were transcribed verbatim and translated from Tetum into English (where required) by the UNTL research team due to the more complex language and data generated. Thus, these data were analysed thematically in English and triangulated with the household interviews. Excel and Word were used for the thematic analysis.

As the data was electronically available, LT assessed whether data saturation had been reached.

The research team discussed the themes to ensure consensus. In particular, the Timorese team members provided additional linguistic and cultural validation of the results. The range of monthly household income was reported due to the non-random sampling method used.

The Impact of the COVID-19

There were extensive delays to the project due to COVID-19. The University of Sydney team members were unable to travel to Timor-Leste for the main data collection phase so the enumerator training was completed via videolink and the UNTL investigators ensured the integrity of the data collection for the household interviews and case studies. Data collection was completed before the second wave lockdown of March 2021 and the disruption caused by Cyclone Seroja.



Results

We completed **216 household interviews with primary caregivers, 30 stakeholder interviews and four case studies**. Data saturation was reached within each municipality and across all three rural municipalities. The data from Dili emerged as having a different narrative and we treated these data separately with respect to data saturation. Hence there was a larger sample from Dili municipality to ensure both wealthy and poor urban experiences were captured. We also noted the closer proximity and greater range of health facilities available within Dili municipality and took this into consideration as well.

Characteristics of Participants

Our first data collection in Dili, resulted in a wealthier sample of households being interviewed. Using the National Poverty Line threshold of \$3.25 per day, this first sample only had one family below the national poverty line. However, with more targeted sampling, there were 25.5% households below the poverty line in the second round of data collection. This second sample was very similar to the rural municipalities with respect to poverty. We had 37.1% households in Ainaro below the national poverty line, 28.6% in Ermera, and 37.0% in Lautem.

Table 2 summarises the complete sample of household interview participants and shows that most of the primary caregivers were mothers, our sample included data on **280 children under the age of five** as part of a total number of 1137 household members. The three rural municipality samples were similar demographically and tended to have more households receiving pension support for grandparents living with them and a larger number of people living in each home.



Table 2: Characteristics of Households Completing Interviews (n=216)

Characteristic	Ainara (n=35)	Dili (n=93)	Ermera (n=42)	Lautem (n=46)	Total (n=216)
Primary caregiver					
Mother	35	82	39	43	168
Father	0	4	1	2	3
Grandmother	0	3	1	1	2
Aunt	0	2	1	0	1
Have had a child die from this household	4	15	19	8	46
No. of household occupants					
Neonates (0-6 weeks)	0	6	2	0	2
Infants (7 weeks-11 months)	9	20	9	15	42
Young Child (1-4 years)	45	111	52	61	236
Total children <5 years	54	137	63	76	280
Older Child (5-12 years)	56	115	68	62	256
Teenagers (13-17 years)	10	35	28	31	86
Adults (18 years and older)	117	207	120	112	515
Total no. of occupants	237	394	279	281	1137
No. of household occupants	Mean per house	Mean per house	Mean per house	Mean per house	Mean per house
Neonates (0-6 weeks)	0	<1	<1	0	<1
Infants (7 weeks-11 months)	<1	<1	<1	<1	<1
Young Child (1-4 years)	1.3	1.2	1.2	1.3	1.4
Older Child (5-12 years)	1.6	1.2	1.6	1.3	1.5
Teenagers (13-17 years)	<1	<1	<1	<1	<1
Adults (18 years and older)	3.3	2.2	2.9	2.4	3.0
Total no. of occupants	6.8	4.2	6.6	6.1	5.3
Occupation of adults (ISCO)*	n (% adults)	n (% adults)	n (% adults)	n (% adults)	n (% adults)
Legislators, senior officials, managers	0 (0)	12 (5.8)	0 (0)	0 (0)	12 (2.3)
Professionals	2 (1.7)	20 (9.7)	2 (1.7)	2 (1.8)	26 (5.0)
Technicians & associate professionals	0 (0)	3 (1.4)	0 (0)	0 (0)	3 (0.6)
Clerks	3 (2.6)	14 (6.8)	0 (0)	1 (0.9)	18 (3.5)
Service/shop/sales workers	2 (1.7)	16 (7.7)	3 (2.5)	1 (0.9)	22 (4.3)
Skilled agriculture/fisheries	2 (1.7)	0 (0)	1 (0.8)	0 (0)	3 (0.6)
Craft & trade workers	2 (1.7)	9 (4.3)	10 (8.3)	4 (3.6)	25 (4.9)
Plant/machine operators/assemblers	3 (2.6)	3 (1.4)	0 (0)	0 (0)	6 (1.2)
Elementary occupations	30 (25.7)	61 (29.4)	63 (52.5)	32 (28.6)	186 (36.1)
Not working or not stated	73 (62.4)	69 (33.3)	41 (34.2)	72 (64.3)	214 (41.6)
No. of households with pension support	n (% houses)	n (% houses)	n (% houses)	n (% houses)	n (% houses)
	17 (48.6)	23 (24.7)	15 (35.7)	17 (37.0)	72 (33.3)
Weekly household income (range)	\$0-\$250	\$0-\$1950	\$0-\$140	\$0-\$200	\$0-\$1950
Household Assets	n (% houses)	n (% houses)	n (% houses)	n (% houses)	n (% houses)
Car/Motorbike/bicycles	9 (25.7)	28 (30.1)	8 (19.0)	16 (34.8)	61 (28.2)
Livestock	35 (100)	44 (47.3)	39 (19.5)	42 (91.3)	160 (74.1)
Land	30 (85.7)	47 (50.5)	27 (64.3)	36 (78.3)	140 (64.8)
House	12 (34.3)	19 (20.4)	5 (2.4)	0 (0)	36 (16.7)
Radio	7 (20.0)	7 (7.5)	1 (2.4)	1 (2.2)	16 (7.4)
TV	1 (2.86)	26 (28.0)	7 (16.7)	10 (21.7)	44 (20.4)
Refrigerator	0 (0)	7 (7.5)	2 (4.8)	4 (9.5)	13 (6.0)

Table 3: Characteristics of Stakeholders Completing Interviews (n=30)

Role	Number interviewed
NGO workers	3
Clinical healthcare workers (doctors, midwives etc)	7
Health Administrators	14
Community Leaders	5
Traditional healers	1

Table 4: Key Features of Case Studies

Case 1- Dili Municipality:

A young child with a disability (wheelchair-bound) lived less than 1 km from a health centre in urban Dili. She became short of breath and the family had no money for transport. Her older brother ran to the clinic for help but the ambulance was 'broken' and he was told to return home. Almost one hour later the family returned because their daughter's breathlessness was much worse. A nurse was sent on her motorbike but by the time she got there the girl was very ill. A referral was registered for an ambulance but for some reason this never arrived and the girl died.

Case 2 – Ermera Municipality:

The mother helps her husband and son at the vegetable garden and coffee plantation each day. Sometimes she sells vegetables and she can earn around \$ 3.00 dollars a day. Her husband sells lottery coupons (SDSB) and earns \$2.50 per day. Sometimes he sells animals like dogs, chicken for more or less \$10.00. They own a piece of land where they plant their crops, and they also have 2 chickens and 6 dogs. Her first child had to be born in Dili, HNGV, because, according to the nurses, the child was too big, nearly 4 Kg. The same happened to the second child.

They had to stay in Dili for nearly a week and had to stop work. They spent about \$ 50.00 dollars on transportation, for food another \$ 50.00 dollars, telephone credit \$10.00, extra medicines for after the operation for \$20.00 to be taken at home/Ermera. They did not spend money for accommodation because they stayed with a relative in Dili.

Case 3 – Ainaro Municipality:

The family has 4 children aged 4, 3, 2 and 11 months old. The grandparents live with them. They are farmers, working their plot of land, where they can earn about \$ 6-10 dollars per week. They don't have any other source of income. Even though the grandparents are eligible for the pension they have not received any yet. Apart from the 4 hectares of land, they also have 1 pig, 2 goats, 4 dogs, 9 chickens. Last month their 2 year old daughter was sick with fever, cough and an ear infection. She needed to be treated twice but they only managed to get there once because at the second consultation the doctor said that there was no more medicines (a stock-out). When they took their daughter to the health facility they had to leave their work as a farmer and probably loss about \$ 1 per day for almost one week. Normally when a family member is sick they go to the health facility and the doctor gives them medicines for free. When the mother was pregnant with her last child, now aged 11 months, she had to go to HNGV due to complications with her pregnancy, and her husband and mother-in-law accompanied her to Dili. At that time they spent \$ 2 for a bucket for washing and cleaning and \$2.50 for toilet paper. They did not have money to pay for the transport from Dili to Ainaro. A relative gave them \$30.00 dollars to pay the transportation fee. The husband had to temporarily stop his work for a month while in Dili, and he lost about \$ 40.00 dollars. During the time in Dili her sister took care of the other children. They did not pay her; only bought some food for her.

Case 4 – Lautem Municipality:

The family has eight children. They work as farmers and their main income is from whatever they sell from there. The selling process is not on a daily basis and they only get around \$5.00 a day.

Their youngest son is 5 years old, and according to the doctors, he suffered from nephrotic syndrome. When he was really sick, his body was swollen and painful. They took him to the CHC, and after being assessed, the doctor told them that he needed to be transferred to Baucau Referral Hospital. Initially the father did not accept the idea of referral because they did not have money and judging from his son's appearance, he thought that he could not be saved. He said, "He will die on the trip to the hospital". But this idea was countered by the uncle who forced the family to bring the child for treatment. The family then agreed to take the child to get further treatment. They were transported from their house to the CHC by an ambulance, and also from the CHC to Baucau hospital. The accompanying family were: the parents and his sister. She had to come as well because the parents are not fluent in Tetum. The expenditure for the treatment was around \$100.00 dollars, and another \$100.00 dollars for food, accommodation and transport. Even though the trip to Baucau Referral Hospital took about two hours, the child was OK. The next day he was transferred to Hospital Nacional Guido Valadares (HNGV). In Dili, they were assisted by an uncle (the father's younger sibling) who gave them money to buy medicines. He continued to support them until the child recovered. Upon the child's recovery, they returned to their village by public transportation.

The trip duration from Dili to their village was about seven (7) hours. Despite the long trip, their condition was ok. The transportation fee was \$12.00 / person (\$36.00 for 3 people). Looking back at the experience, the father told us that he actually did not want to take his child to the hospital because they did not have money. But because his brother insisted, he had to borrow \$300.00 dollars from the neighbours, and he had to repay them with a cow. The sister also added that during the stay in Baucau they did not have a place to stay, so they could not cook. In that financial situation, it was hard for them, so sometimes they ate nothing.

The wealthier Dili sample had more professionals in salaried positions and some very high income-earners in senior national roles. The urban poor were mainly street-sellers of goods and kiosk workers. Rural occupations were most commonly agricultural or kiosk workers reliant on selling goods or produce. In Ermera, the coffee industry was an important source of income for some households.

The stakeholders that were interviewed are summarized in Table 3. The responses across all municipalities and nationally were found to be very consistent and, as such, data saturation was quickly reached. To ensure confidentiality for participants, we have not reported on this sample at the municipality-level as it would potentially identify some of the respondents. A brief outline of the key features from the four case studies is shown in Table 4.

Patterns of routine maternal, neonatal & child health & health service use

Routine MNCH Care:

The investment in primary health care at the local level by the Government of Timor-Leste has been generally successful in reaching households for the treatment of common MNCH problems and disease prevention. Antenatal care, immunization and the treatment of respiratory tract infections, fever and gastroenteritis were mentioned by almost all households as reasons for seeking care over the previous month. **Most households had attended a health centre for care of a sick child at least once during the previous month.** Some mothers with chronic health problems such as hypertension also attended their local health clinic regularly, although most mothers did not have a known chronic illnesses. The health of their children was an important priority for all families. Stakeholders agreed that this local-level provision of basic MNCH care was a strength of the health system. Being able to walk to services, even if they were outreach-based and less frequent, was highly valued. In some households they described the lay health worker (PSF) as their first point of contact for health advice.

*Lori ba konsulta iha postu ba moras isin manas no kabun moras. Ba postu tanba besik.
We go to consult at the health post for illnesses like fever and stomach problems because
it is close. (Household)*

*Programa SISCa fulan 1 dala 1 la'o di'ak ona maibe karik di'ak liu bele fulan ida dala 2
ka 3. Having the SISCa program once a month is going well, but perhaps it would be
better if it could be 2 or 3 times each month (Household)*

*Bá konsulta kabun laran moras, kotuk moras no ulun moras, tanba ai-moruk ho doutora
iha PSF la iha. [1] had a stomach ache, back ache and headache and consulted the doctor
for medicine because the PSF didn't have any (Household)*

*..in Dili during the lockdown time because of COVID 19, but the parents came like
normal, because for them it's very important they look after the health of their baby
during the pregnancy and immunize their babies, so they came, even in a bad situation.
(Nurse)*

*So some decentralization of governance – that would be a strength, and I think, that the
needs around maternal and child health are quite well understood by everybody. They
may not be so well financed, but they are well understood – that women and babies and
children and things to do with them are important. I think there's a lot of health promotion
and an awareness of those issues I think, as a provider anyway. (Paediatrician)*

*I think MNCH has been well-supported by the EPI, you know, the vaccine work that's been
done. I mean Timor still has a little way to go but I think that for such a new country with
such difficult road access, and the many problems of such a young health system they've
made good progress around vaccination. (NGO worker)*

Reasons that routine MNCH care was avoided

Whilst most households made a great effort to attend health facilities if their child was sick, some admitted that they did not go. If the nearest, staffed, health facility was too far from home, some families would just not go, especially if they had no transport or they needed to take time off work. Instead they might use traditional medicine or self-treat with medicines from a local kiosk.

Isin manas, ulun moras, seidak lori ba konsulta tanba dook husi hospital. [The child had] fever and headache but I haven't been to the hospital yet because it's too far.
(Householder)

Laiha tanba sira tenke fó aimoruk tradisionál tanba ne'e sira la para sira-nia servisu. We didn't go because we can't stop our work and we needed to use traditional medicine because of this. (Householder).

Dala barak liu kuradór tradisionál tanba distánsia husi uma ba CHC dook no transporte públiku laiha tanba dalan aat. Many times I use traditional medicine because the distance from my home to the CHC is far and we don't have any transport. (Householder).

Foti desizaun la bá, Tanba distánsia dook no ema hein alin ki'ik seluk la iha. Dala barak liu hola aimoruk iha kios. I decided not to go because the distance is far and I don't have anyone to look after the younger children. I mostly buy medicine from the kiosk.
(Householder).

Esperénsia balun ne'ebe mak la bá halo tratamentu saúde ho kestaun tanba katuas oan bá servisu e alin sira ba hotu eskola. Entaun deside la bá iha CHC no preferénsia liu sosa aimoruk iha kios sira. [My] experience is not to get healthcare because my husband is working and the children are at school so I prefer to buy medicine from the kiosks.
(Householder)

Birth-related patterns of care

We asked in detail about the most recent pregnancy within that household, assuming that this would be the easiest for people to recall and the most reflective of the current situation (past 5 years maximum). In the wealthier Dili households, almost all of these babies were delivered by a skilled birth attendant at a health facility. In the poorer Dili households, some had homebirths. However, **in the rural municipalities, having your baby at home was a common experience and cost far less than having a baby in a health facility.**

"Bebé moris iha uma. Avó feto ho aman mak akompañá. [The] baby was born at home with the help of the grandmother and [the baby's] father." (Householder)

If problems are detected antenatally and the mother is referred to the municipality or national hospital the costs can be very significant for the family. For example, even if the mother is transferred by ambulance, the public or private transport costs and food for the family members is large cost for poorer households. The family may also lose up to one month in income if they are agricultural workers or kiosk and other laborers.

For example, the father of this household (below) is a farmer who earns around \$12.50 per week (below the national poverty line). The indirect costs incurred by their referral to Dili was in excess of two months' income.

"Oan ikun partus iha HNGV. La'en, avó feto no alin feto ho mane sira mak akompañá. Iha momentu isin rua hasoru problema hanesan labarik halis hela ou toba la di'ak. Sa'e bus hodi fila mai hela fatin Ainaru \$ 55." \$15 pulsa La'en para servisu fulan 1 hodi halo

familia lakon rendimentu \$50. The youngest child was born at HNGV with my husband, mother and sister accompanying me. During my pregnancy I had some problems and they thought the child was not doing well. We paid \$55 to catch the bus back to Ainaro, \$15 on phone costs and my husband had to stop work for one month resulting in the family losing \$50 wages” (Householder)

The wife of a subsistence farmer had her pregnancy complicated by pre-eclampsia and had to be transferred to the municipality hospital. They had to spend \$80 on transport home, \$15 on medicines, \$10 on phone costs and \$200 on food because they had no family in Bacau. The child is now a healthy four-year-old.

“Ba CHC transferénsia ba ospital distritu hafoin transferénsia ba ospital referál Baucau tamba hipertensaun no pré-eclámpsia Partu iha ospital referál ajuda husi parteira Bob Doutor sira. [We] went to the CHC and were transferred to the district referral hospital in Baucau due to pre-eclampsia. The birth at the hospital was assisted by midwife/doctor Bob. (Householder)

Some families in rural areas described having a homebirth attended by a nurse or doctor. In these cases, the husband usually only took a few days or one week off work and they may have paid for the fuel costs of the healthcare worker to come to the house. Unfortunately, there were a number of descriptions of these homebirths (attended and unattended) that were complicated and resulted in the death of the baby. These included malpresentations (e.g. breech), cord asphyxia or prolapse and multiple pregnancies (twins).

“Oan mane ikun moris mai mate tiha, tanba ain mak sai uluk. Moris iha uma, doutora, la'en no família viziñu mak akompañá. Iha momentu partusulun moras no oin nakukun. [Our] son died at birth due to breech presentation. He was born at home attended by a doctor, my husband and other family members. At the time of the birth my head was painful and I felt faint.” (Householder)

Oan feto primeiru mate, ne'e akontese wainhira partus iha uma. Our first daughter died, this happened when I gave birth at home. (Householder)

Midwives described efforts to try and engage families in developing birth-plans but they were reluctant to be referred on from the CHC (if required) due to costs.

When they come, we always try to give counselling them about the issue of possible referral, or something like that. Because when in situations where they have to come to the hospital, the main issue for them is not having enough money. Sometimes they arrive here with severe condition. They usually stay home and when they see that their health condition is severe then decide to come to the hospital. In that situation, we can't do anything, we have to refer to another hospital that has more equipment to suit their condition. So some will complain about not having any money for that. Some will ask their extended family to support them with few money to solve the problem, and they will go. But when they did not get the support from family, unfortunately they prefer to stay. (Midwife)

Experiences of neonatal, infant and child death

There were **46 households in our study who had experienced the death of a child**. Whilst some of the issues associated with complex deliveries at home are outlined in the previous section, most of the additional deaths occurred in neonates or infants. Neonates were described as dying with respiratory difficulties, some due to a lack of breastmilk, fever and breathlessness, sudden death of unknown cause within the first days and weeks of life.

Oan mane primeiru mate ho idade semana 1, mate tanba isin manas no iis boot. Our first son died after one week due to fever and breathing difficulties. (Householder)

Iha oan mane ida mak mate no idade loron 3, la moras ida maibé kauza husi tanis la para to mate de'it. Our first son died after 3 days. He wasn't sick but he wouldn't stop crying and just died. (Householder)

Iha ida maka mate mane ida, moris loron 3 de'it lansun mate, mate tamba la susu. Our son died suddenly three days after birth because of no milk. (Householder)

Oan fetu primeiru wainhira halo fulan 1 mak mate derrepente deit. Oan mane terseiru halo fulan mak mate ne'e mós mate derrepente de'it. Our daughter died suddenly when she was one month old. Our third son died when he was one one month old, he also died suddenly. (Householder)

There were infants who died due to asthma and diarrhoeal illnesses but less frequent were experiences of death amongst children aged between 1 and 5 years. As with the obstetric experiences, the indirect costs resulting from referral of a very sick child or baby were very substantial. For example, a one-year-old child with a diarrhoeal illness was transferred from the CHC to the Municipality Hospital but unfortunately died. The family are farmers living just above the national poverty line. They spent close to one year's income on the costs. These included \$80 on transport, \$20 on communication, \$300 on food and \$30 on medicine. Their lost income was estimated to be around \$25 for the one-week duration of the child's illness. They were able to access a 'social ambulance' to repatriate their child's body which did not incur any costs for them. There were several accounts of large food costs such as these as families may sleep at the hospital but need to provide their own food. If a mother, baby or child is very ill, there may be quite a few accompanying family members supporting each other.



Experiences of Indirect and Unexpected Out-of-Pocket Health Costs in MNCH

Whilst our respondents mentioned various types of MNCH access issues during their interviews (e.g. cultural, geographic etc) these were not extensively explored as they were beyond the scope of this study. However, where these were relevant to Indirect Financial Costs they were included. For example, distance from the health-care facility might be relevant to indirect *transport* costs.

During the household interviews, we asked about indirect MNCH financial and unexpected out-of-pocket costs over the previous month and for the most recent pregnancy. Where enough information was provided, we also estimated the proportion of monthly household income spent on these costs for the **55 families living below the national poverty line**. These measures provided information on the impact of indirect and unexpected out-of-pocket costs on households as they seek MNCH care.

In addition to estimating the amount of money that households spent on these costs, we also analysed in more detail, those cases where care was not sought for a sick child and also the extent to which costs had caused households to avoid MNCH care over the previous 12 months.

Estimating indirect and unexpected out-of-pocket MNCH care costs

a. Indirect Financial Costs

Transport

Where public transport was available, or where mothers could walk to the healthcare facility, *transport* costs were often only a few dollars per healthcare visit. Similar amounts were spent on petrol costs if a motorbike or car was available. However, **if the nearest health facility was some distance from the home, or the mother, baby or child was serious ill and required referral to a secondary or tertiary facility, the transport costs could be substantial (\$30-\$80) per journey**, depending on the distance. Although the patient may be transferred by ambulance, their accompanying family members usually had to find the money and means to travel, sometimes borrowing from relatives or other members of their community. They would also have to pay for the return journeys of family members. Rural families may decide not to go.

Difikuldade ba sira atu asesu atendimentu saúde maka dalan ne'ebé aat no transporte publiku la bele movimentu iha ne'ebá hodi asesu ba CHC. It's difficult for people access healthcare at the CHC because the roads are bad and they can't move around on public transport. (Community leader)

La bá partus iha ospítal tanba distánsia dook no la iha transporte públiku. I didn't go to have my baby at the hospital because it was too far and there was no public transport. (Householder)

“Moras matan la lori ba ospítal tanba transporte laiha.” [The child] had an eye problem but I didn't take them to the hospital because I had no transport. (Householder)

No not for the money but not for the transportation because coming they are walking, they walk. (Nurse)

but the practice here in Timor, um, people tend to support or help each other, especially in the village, there is a need to transport someone to the health service, neighbours or other family would be willing to help and like hands-on providing the transportation (NGO worker)

Some of them, they choose, they decide when their member is sick, very, very sick, they choose not to come to Dili because when die this is problem. This is problem because we know we have Ministry of Social and they have to provide transportation but sometimes

it's very difficult. Although they have some transportation, they have to pay for their car but they don't have money. So some of them not come but some of them decide when their [family] member is very sick and they know they will die they decide to not come. Yes, this is in Maubisse. This is my experience in Maubisse. (Nurse)

But like to come from Atauro, for example, that's a pretty massive cost. I mean, I know sometimes they ask family for it. Other times I guess whatever have they've got or they sell. I'm not really sure. (Paediatrician)

Looking back at the experience, the father told us that he actually did not want to take his child to the hospital because they did not have money. But because his brother insisted, he has to lend \$ 300.00 dollars from the neighbours, and he has to repay them with a cow. (Case study reflection)

Lost income

Even routine visits to received MNCH care carry an opportunity cost for families due to lost income. It can take several hours to reach the facility and there may be long waiting times before the return journey. Many of the rural families and the urban poor in Dili, sell goods at the market or kiosks or work as farmers and laborers. If they are not at work, they lose money. Families estimated that **routine visits each month usually cost them at least one day of their household income** as the husband will often need to accompany the wife. We found that it was unusual for them to pay someone to look after their business. Rather, they would rely on extended family if possible, or close the kiosk for the duration required. Extended healthcare visits for health-facility based childbirth or serious illness may result in **up to one month in lost income**.

Family with the low income of course. They will face more difficulty compared to family that have a good income or have a steady job because more people in the village their work is, like if they are a farmer, so if they have to accompany their family to Dili for example, then they cannot, they might be, of course they will lose their income, it will give impact for them because they cannot work, they cannot sell their products, but compared to other people that have steady work or are working with institutions, they have a regular salary so their income is not really a problem for them. But for families that their work is relying on themselves, if they produce something, they can get an income. So it's a little bit difficult for them compared to other families that are working with an institution with a regular monthly salary. (NGO worker)

Accommodation & Food

These costs were mainly incurred through facility-based MNCH care that required an inpatient stay or more than a day-only such as hospitalization for illness or childbirth. Accompanying family members may be able to stay with relatives but often sleep at the hospital. They need to source their own food and this can be quite a substantial costs for some. Some families reported their food costs to be over \$100 when the mother or child was hospitalized in Dili.

The problem is when they arrive in Dili for how they have accommodation, for family they stay in hospital but food everyday is a problem (Nurse)

during the stay in Baucau they did not have a place to stay, so they could not cook. In that financial situation, it was hard for them, so sometimes they did eat nothing. (Case study reflection)

Gifts and communication

People did not report gifts as a cost and the mobile phone top-ups were usually less than a few dollars.

Repatriation of the deceased

One of the families interviewed, had a child who died recently from a diarrhoeal illness after transfer to the National Hospital in Dili. They were able to use a 'social ambulance' to return the deceased. Since most of the children who had died, did so at home, we had little opportunity to discuss this with the householders. However, some of the stakeholders felt that repatriation costs might be a deterrent to seeking care if family members thought there was a strong possibility the patient would die.

Many devastating examples. There was this thing where public transport wouldn't take a patient if they were dead. So a child, if a child or a baby died, they weren't allowed to go on the public transport, so patients would have to wrap the baby up or something so that nobody knew they had a dead patient in there. So, you could come all the way from Ermera, or whatever, Suai, in a taxi and the child dies and somehow you have to get back and there was this occasional kind of system where they came on a retrieval. So if an ambulance was going back then they would take them but then they would have to wait, wait, wait for an ambulance to come from that district to take them back. So it almost never happened. And so somehow the family would be left with this body that they would somehow have to get home. They would have to pay a private car or something. You know it was like, and then yeah, so that would always a financial stress, distress. And it was to the point where patients knew about it and wouldn't want to go into the referral centre because they didn't think their child would survive and how were they going to get home. It was very in the front of their minds. (Paediatrician)



b. Unexpected out-of-pocket costs

Medicines and medical equipment

This was a frequent cost incurred by families and was also thought to be important by stakeholders. **Families frequently paid from \$2-\$10 for medicines**, often at a local kiosk or pharmacy and frequently this was because the health facility did not have the stock. They may have already incurred costs due to transport and lost income, only to find that the health facility doesn't have the necessary medication. As mentioned earlier, some people self-treat from kiosks because of the unreliable access to medicines. One of the doctors in a CHC in Dili reported that patients may need to purchase their own intravenous (IV) or intramuscular (IM) medication and families also described having to buy medication for complications during labour at their CHC. Families also reported paying \$10 for vitamins during pregnancy and may spend variable amounts \$2-\$80 on traditional remedies. As mentioned earlier, whilst some of these choices in using traditional medicines have cultural drivers (e.g. bone healers), there were also families who found the close proximity and care of these individuals preferable. It is difficult to know to what extent indirect financial costs associated with facility-based care plays a role in these decisions.

yes because there is not available we have to buy because there can use IV and intermuscular in intravenous, so they have to buy in a boutique. This is the cost a little bit higher. (Doctor, GP)

but medicines, I think is, because sometimes we don't really have the medicine in stock and family are required to buy the medicines outside in the private pharmacy. the government needs to have a good plan of providing the medicines that are needed, have a good, the central pharmacy has to have a good, regular communication with the health providers, especially the specialist doctors that are working in the hospitals. Like people to give their essential medicines list so whenever the government will procure, it will address the needs, because if there is no collaboration between the central pharmacy and the doctors who are going to prescribe the medicines – the doctors will prescribe the medicine and the medicine is not available (NGO worker)

“Iha CHC distritu. Akompaña husi la'en, maun, avó mane, tia no parteira. Momentu partus ran fakar no ain bubu. Sosa aimoruk aumenta ran nian \$30.” At the district CHC. Accompanied by my husband, extended family and the midwife. At the time of birth I had swollen legs and had to pay \$30 for medicine and a blood test.

“Hola ai-moruk iha menjadi \$ 45”. [We] paid \$45 for medicine

“Iha esperénsia seluk momentu ain ho liman to'os no hela iha uma de'it durante fulan 2 no kuraderu tradisionál = \$ 20.00 ho asu ida, sei baku ba osan Karik nia folin = \$40.00 Sosa tua = \$ 5 Sosa kafé no masin midar = \$2.00” [We] paid a traditional healer \$20 plus a dog worth perhaps \$40 for 2 month's homecare and we paid for wine and coffee \$5 and \$2

The families of children with serious conditions reported paying large sums for treatment. For example, the family of a child with nephrotic syndrome reported paying \$100 for his treatment.

Fees to health-workers, tests, X-rays and Blood transfusions

Apart from fees to traditional healers, these costs were mainly reported by wealthier families in Dili who chose to access private clinics and pay for tests.

“Inan ba leno (USG) bainhira grávida no teste raan iha klínika privadu +/- \$55” [We] paid \$55 for a blood test at a private clinic

The proportion of household income spent on MNCH financial costs by families living below the national poverty line & catastrophic spending

Of the 56 households living below the national poverty line of \$3.25 per day, we were able to estimate the recent expenditure on MNCH financial costs as a proportion of household income in **31 households**. **There were 19.4% of poor households that spent more than half of their household income in the previous month on MNCH care alone.**

We also note that 12.9 % of these households spent their entire income or more on MNCH costs. These four households incurred a catastrophic level of expense in obtaining care. Three out of four of these households had sick children who needed hospital care as follows:

- A two-year old boy with fever, cough and difficulty breathing required transfer to the CHC and then on to the municipality hospital for two weeks. He is the youngest of six children and his father is a farmer earning \$20 per week. The family lost \$40 in income, paid \$5 for motorbike transport and \$35 on food. **100% of monthly income spent.** (Ainaro Municipality)
- Two-year old, youngest of four children in poor urban household. Father sells vegetables for a living and they exist on less than a dollar per day. Child unwell with fever and rash and seen at clinic twice. Loss of income, food and traditional medicine costs were incurred. **100% of monthly income spent.** (Dili Municipality)
- Two-year old sustained a burn to his hand and needed treatment of the Municipality Hospital. Father works looking after cattle on a very low income. Incurred costs of \$80 transport to return home, \$250 in food for the family and lost income for two weeks. **1794% of monthly income spent.** (Lautem District)
- Youngest boy of three children (aged 1 year and three months) unwell with diarrhoeal illness and transferred to the municipality hospital then on to the National Hospital where he died. The family spent \$80 on transport and \$20 on comms. They were able to use a community ambulance to repatriate the body. They spent \$30 on medicine and \$300 on food. **1000% of monthly household income spent.** (Lautem Municipality)

Table 5: Household Income Spent on MNCH Financial Costs in the Past Month amongst Households Living below the National Poverty Line (n=31)

Percent of Monthly Household Income Spent	N (%) Households Living in Poverty
<10	7 (22.6)
10-24	8 (25.8)
25-49	9 (29.0)
50-74	2 (6.5)
75-99	0
100 or more	4 (12.9)

Facility-based birthing amongst those living below the National Poverty Line

Only 20% of those families living below the national poverty line reported having their most recent birth at a health facility. The remainder had their baby at home, with 7 (12.7%) having either a doctor, midwife or traditional birth attendant with them at the house. The vast majority 37 (84.1%) of these homebirths in poor households were assisted by family members only. There was a significantly higher rate of facility-based births amongst those living above the poverty line compared with those below ($P=0.024$)

Table 6: Facility-based Childbirths among those living below the National Poverty Line

	Living below Poverty Line N (%)	Living above Poverty Line N (%)	Not known N (%)
Facility-based birth	11 (20.0)	39 (41.9)	8 (32.0)
Homebirth	44 (80.0)	54 (58.1)	17 (68.0)

The financial costs of having a facility-based birth in Dili municipality were low, even for those households living in poverty. There were minimal food costs, a few dollars spent on petrol and perhaps one or two days of lost income for poor households having a baby at the CHC or the National Hospital. By contrast, poor households having a baby at health facilities in rural areas had considerable transport costs depending on the distance. For example, families in Ainaro reported spending \$20-\$30 on transport but this was \$180 for a family in Lautem to rent a car to get to the Municipality Hospital in Baucau. Families in rural areas also lose more income and have to purchase food when they travel to a health facility for the birth.



The Impact of Indirect Financial Barriers in MNCH: Explanatory Themes

Across the three datasets (household interviews, stakeholder interviews and case studies) we found five key themes.

- **Mothers, babies and children in poor rural households are being ‘left behind’ and are experiencing indirect financial barriers to accessing healthcare**

Most households needed to access healthcare at least once per month for a sick child. Additional healthcare visits may also be required if the mother is unwell, needs antenatal care or the children require immunisations. Lost income, transport and medicine costs were usually incurred with each visit and could account for a substantial proportion of their income particularly for rural families living below the national poverty line. These costs were much less for families in urban Dili where facilities are close to home and affordable transport is readily available. Where available in rural areas, community health workers (PSFs) fill some gaps in service provision, particularly for less serious health problems.

“Bá konsulta moras, tanba kada fulan doutora mai iha ami-nia PSF”. The doctor only come once a month so we consult the PSF when sick.

“Ulun moras dala 1 no bá konsulta iha PSF hodi simu ai-moruk”. [I] had a headache and went to the PSF for medicine

“Konsulta de’it iha PSF, tanba motór la iha atu bá CHC Ainaro ne’ebé dook.” [We] just go to the PSF because the CHC in Ainaro is too far.

“Konsulta de’it iha PSF lokál, tanba moras la grave.” [We] just see the PSF because our sickness is not serious.

However, rural households and stakeholders reported that they had avoided seeking MNCH care in the past year on at least one occasion because of overall costs, transport, lost income and/or out-of-pocket medicine expenses. Most of the rural households rely on selling goods or farm laboring and they lose income each time they have to travel to a health facility which may take the entire day. Proximity to services and the availability of public transport and private vehicles in Dili provides a stark contrast and reduces almost all of these indirect financial costs for the households.

In Timor, because we work mostly in the districts and not only in Dili, I have noticed 4 problems: transportation, food, clothes, money and also the thought of being transferred from CHC to Municipal Hospital and then further to Dili. These are always what makes them reluctant to come to the health facilities for treatment.

- **Indirect financial costs can be substantial for households considering a birth at a health facility attended by a skilled professional**

People living above the poverty line were more likely to have their babies at a health facility than living below it. About one in five households that we interviewed had at least one child who had died. Most commonly these accounts were of a child dying at birth, particularly from complication at the time of delivery such as cord asphyxia, twin pregnancies and malpresentations such as breech or transverse lie. Although efforts have been made through programs such as ‘Liga Inan’ to put birth plans in place and to facilitate skilled birth attendance once labour commences, many families do not enact their plan and only call the midwife after the birth or if there are complications. The costs of having a baby at home attended by family members are minimal. Whereas transport, lost income, medication and food expenses for the family going to the CHC or municipality hospital can be substantial.

When they come, we always try to give counselling to them about the issue of possible referral, or something like that. Because when they are in a situation where they have to come to the hospital, the main issue for them is not having enough money. Sometimes they arrive here with a severe condition. They usually stay home and when they see that their health condition is severe then they decide to come to the hospital. In that situation, we can't do anything, we have to refer them to another hospital that has more equipment to suit their condition. So some will complain about not having any money for that. Some will ask their extended family to support them with some money to solve the problem, and they will go. But when they don't get the support from family, unfortunately they prefer to stay.

- **A lack of affordable and effective postnatal care for mothers and babies makes them vulnerable to serious illness and death**

We identified that many neonatal deaths were attributable to respiratory problems or failure to establish breastfeeding. Very young babies also died from febrile and other illnesses that were not diagnosed or treated.

Oan mane primeiru mate ho idade semana 1, mate tanba isin manas no iis boot. Our first son died aged 1 week, because of fever and difficulty breathing. (Household)

Iha oan mane ida mak mate no idade loron 3, la moras ida maibé kauza husi tanis la para to'o mate de'it. Our first son died aged 3 days. He wasn't sick but wouldn't stop crying and just died. (Household)

Uh, I think there's not really any structured postnatal visits or follow up. That's really ad hoc. That's a major problem. You know it would be a big thing to move to a strategy whereby midwives went to do home visits and we know from our own experience from trying to launch a service like that, that actually the patients felt quite edgy about having home visits. They thought they were being investigated by child welfare or something and they didn't really want people coming into their homes or to investigate their parenting. So that wasn't necessarily welcomed by the consumer but some sort of structured postnatal care would be of value given the number of children who die in that first six months through breastfeeding failure or diarrhoea or people mixing formula wrong and all of these sort of things.

- **Serious illnesses in mothers, babies and children incur substantial costs for rural families requiring referral to secondary and tertiary care & catastrophic indirect costs can tip households into further poverty and debt**

As outlined earlier, when a pregnancy becomes high risk or a child is very unwell, some families have to pay extraordinary amounts of money as a proportion of their income in order to obtain that specialized care. For some this is catastrophic and may involve going into significant debt to family or community members. Some delay or decline treatment, particularly if they feel there is a high chance that their wife or child may die.

They even said that "Going to the CHC is ok but, from there they will send us to Dili, and they only allow one or two family member to accompany us. Other family members also want to come, but they are not allowed." Another barrier they encounter is if other family members are not allowed to come together with the patient in the ambulance, they have to travel by public transportation and they don't have money for that. On the other hand they also think that if someone is referred to Dili that means that most probably she will die.

Mostly mothers. Because sometimes to visit the hospital they wait on each other's decision, the family members' decision; for example, when the new-born baby has asphyxia, and the baby needs to be transferred immediately but parents delay it because they need to wait for their uncle, grandfather or grandmother's decision whereas the parent's decision is supposed to be the most important. And then it's too late.

- **Gaps in services and low-quality healthcare is creating indirect financial costs in both urban and rural settings and people are not willing to pay**

Basic service packages of MNCH care are not reliably available, particularly in rural areas. Infrastructure and lack of equipment such as electricity, water, oxygen, instruments and so on, mean that families are unnecessarily referred to Dili, thereby incurring costs or perhaps declining treatment.

So I suppose that's another barrier isn't it? The lack of the basics at their district level. So for example, a neonate with severe jaundice, I mean there's no phototherapy and there's no biochemistry testing in Viqueque um, you know, the things that are in that basic service package that they said they're all going to provide at the district level, most of those things aren't there. So people would need to come all the way to Dili, for services that could be provided at a more local hospital or inpatient sector. That's a big cost. (Paediatrician)

We know they have shortages in basic medical equipment. I mean a pregnant woman coming in should be able to access a fetal doppler and urinalysis but they can't and you know, these are really bedrock level markers of quality care, or at least pre-requisites for quality care. Those are broadly now available. I mean in a lot of places they don't even have a functional blood pressure cuff so there are major drawbacks in the supply chain and in the resourcing of centres. (NGO worker)

They often don't have the right sort of scales to be able to weigh small children, they're not all that good at using growth charts, they claim stock outs very often don't have enough therapeutics food – plumpynut, timor-lita and all that – they're stocked out. So basically patients are coming in, to have their child weighed and be told that their child is underweight and to be given pretty low quality counselling and then sent away (NGO worker)

Medicine stock-outs continue to be a major cause of unexpected out-of-pocket expenses and families may 'waste' indirect costs by attending a clinic which does not have the recommended medicines, is not staffed or perhaps not even open.

there are costs – that people have to walk for an hour and a half, wait for a whole morning to see someone then walk an hour and a half back. That's consuming peoples' time and it's affecting their employability and it's taking a physical cost as well. And we do know instances where patients are told by a doctor that they need this medication, we don't have it, they can try and buy it at a pharmacy, good luck. So sometimes that cost is being passed onto the patient because it's not available in the government system at that particular time. Stock outs are very common.

Discussion

This study has identified that indirect and unexpected out-of-pocket costs are experienced by many households seeking MNCH healthcare and can account for a substantial proportion of their income. This is particularly the case for poorer households in rural areas. Local primary healthcare services are accessed frequently for routine maternal and childhood illnesses, vaccinations and antenatal care. However, the lost income, transport costs and the frequent requirement to purchase medicines due to stock outs can cause some families to turn to alternatives such as traditional healers close to their home or to self-treat by purchasing medicines from a local kiosk. Poor families in Dili face less indirect costs due to the availability of public transport, health facilities and vehicles. Stock-outs for medicines and equipment appear to be a system-wide problems with cost-shifting onto families causing additional financial stress.

Poor families are much more likely to have a homebirth with associated risks of complications with facility-based deliveries incurring greater costs due to lost income, food and transport for the mother and accompanying relatives. Even at health facilities, mothers returned home within hours of delivery and did not receive postnatal care. A number of families described the death of babies within days of birth due to fever, respiratory problems, feeding difficulties and unknown causes.

Similarly, seriously ill children in poor rural household who require inpatient care, (particularly if referred to a secondary or tertiary facility), can incur catastrophic costs that can plunge them into further poverty and debt.

By contrast, wealthier families are more likely to have a salary, particularly in Dili and do not lose income in the same way that farm laborers and stall owners do. They almost always have their child born in a health facility and may even choose to pay for private care if they feel dissatisfied with the free government healthcare received. They pay discretionary amounts for tests such as ultrasound in pregnancy and for vitamin supplements and other medication that may be recommended.

Without addressing these disparities, it will be difficult to meet the SDG MNCH targets and the poorest rural women, babies and children will be left behind. There are a number of possible strategies that could be implemented to address this. These have been shown to be effective in other country settings and some of them were also proposed by our stakeholders during their interviews. Using the framework that shaped the design of our collection tools, we know that financial barriers have both demand-side and supply-side barriers and our recommendations therefore, adopt this approach. An investment in this issue needs to be prioritized.



Recommendations

Recommendation 1: Establish a multi-sectoral taskforce to address MNCH inequalities

It is clear from the results of this study and from discussion with the stakeholders, the advisory group and attendees at the virtual workshop, that these issues will not be addressed through a purely health-focussed approach. Solutions are most likely to require involvement of other Ministries (e.g. social security, finance, employment, roads etc) and partnership with key community organisations in rural areas. This needs to be a post-pandemic priority to avoid poor rural mothers, babies and children being left further behind.

Supply-side strategies

Whilst it's important to have the physical buildings of health facilities, the effectiveness of these can be undermined if they don't have appropriate staffing, basic equipment, medicines, accessible working hours and so on. The disparities in skilled birth attendance rates for rural poor households, the coverage of postnatal maternal and newborn care and the reduction of child mortality at the community-level will not improve unless supply-side issues are addressed. These would mitigate many of the indirect and unexpected out-of-pocket costs incurred by families and we propose four strategies on this side.

Recommendation 2: Audit current obstetric service quality using a valid tool and consider redesign to shift from poor quality local care to high quality hospital & health centre care within two hours from homes

Whilst there has been considerable effort in training health staff through Basic Emergency Obstetric and Neonatal Care (BEmONC) training and Emergency Obstetric and Neonatal Care (EmONC) training, our respondents described facilities that do not have equipment, electricity or essential medicines. Given the substantial indirect costs incurred by families when they attend a health facility for birthing, they need to be sure that the care is 'worth the cost' incurred. In other words, our data suggests that many rural households are not willing to pay (indirectly) for the locally available obstetric care.

One recent study has suggested a new approach focusing on the assessment of quality alongside volume of delivery as a way to improve obstetric and neonatal outcomes. (22) The premise behind this approach is that low-volume facilities have worse maternal and neonatal outcomes. They developed a 'Quality of Basic Maternal Care Functions Index' which is based on 14 items.

Structural indicators include: 1) skilled provider availability, 2) referral capacity (functional ambulance or plan and capacity to call one), 3) electricity, 4) safe water and 5) resources for infection control in the delivery room (soap and water, gloves, sharps box and surface disinfectant). Process indicators include 1) use of partographs and 2) routine practice of active management of third stage of labor (AMTSL) – giving oxytocin in third stage of labour, cord traction and uterine massage. There are also five signal functions for basic care 1) capacity to remove retained products 2) parenteral oxytocin for haemorrhage given in past 3 months 3) parenteral magnesium sulfate for [pre]eclampsia given in past 3 months 4) antibiotics for maternal infection given in past 3 months and 5) manual removal of placenta in past 3 months. In addition there are two WHO indicators of assisted vaginal delivery and neonatal resuscitation for facility emergency care capacity. Internationally, a threshold of 500 births per year has been deemed as adequate to ensure good maternal and neonatal outcomes.

This study proposes that rather than spreading resources and skills thinly at the local level, governments should consider ensuring higher quality, higher volume health facilities within 2 hours of home. (22) Our study reports that many services would be unlikely to meet these quality indicators and there will be no incentive or willingness to pay indirect costs by households if these minimum standards are not met.

There are problems related to pregnant mothers when it's time for them to give birth; when there is any emergency issue and they cannot be attended to in the village, they need to be taken to Ainaro because we need light (electricity), we need proper conditions.

So it's obviously helpful if a child with malnutrition can actually be receiving food supplements rather than being told go and buy more meat and vegetables for a family that's obviously in real financial pain.

One of the good things in this village is that the government have build a health post in the village. However there are problems that we face, the first on is there is no doctor and midwife working at this health post. This is due to the non-availability of electricity in this area, so they can not stay in our village. Second, is when we talk about transportation, especially in emergency cases when a pregnant woman is due to give birth; because we have healthcare centre but we do not have doctor and midwife, so when we failed transported her (to CHC Ainaro), we only wait for her death. In this opportunity we want to ask to the government, in the future when make strategic plan, need to consider it and allocate a doctor and midwife in the rural areas such as ours. That's the problem that we currently facing.

You can't ask people to do their jobs well if you don't give them to tools to be able to do that. You can't treat infection and have high levels of hygiene if you have no running water and no alcohol gel and no gloves or whatever. So those at least are solvable problems that Timor-Leste with a concerted effort over the next few years to solve those, that would remove one big input to the poor quality but only one.

the investment from the government through the government's state budget is still very, very low to the program under maternal and child health department to address the MNCH issue. So based on my previous experience in the MCH department when we try hard to advocate the state budget for the MCH department there is always a saying that because MCH department has a lot of partners still interested to support in this area, so the government state budget is allocated more to the programs that have less support from partners – for example, to the non-communicable diseases program or other programs that doesn't really have support from partners. Then the second one, is not only the budget that normally provided by the government state budget is only covering small activity like supported supervision and the annual budget is always I think less than \$10,000 for the MCH programs and I think that it is really important for government to start to put more on the MCH department, and not always sticking to rely on partners, um... for trainings or even for procurement of medical equipment and supplies because we know that if they do the monitoring of supported supervision to the lower levels there is an issue about the equipment or even though we try hard to train our health workers, but if there is no sufficient equipment to support their daily work, it is still a big challenge to provide the quality MNCH services to the community.

Recommendation 3: Co-design and implement a postnatal care program for mothers and babies that is consistent with international guidelines

The coverage of postnatal care is universally low in Timor-Leste, but particularly lacking in rural areas. Our study documented accounts of newborn deaths, particularly during homebirths or in the first few days and weeks of life. The WHO guidelines on postnatal care of the mother and newborn have 12 recommendations and these should be urgently prioritised. (See Figure 4) Other countries have successfully implemented postnatal care through utilizing local community health volunteers or care workers (23-25)

and we recommend exploring the possibility of expanding the role of the PSFs in Timor-Leste to assist with this. To ensure acceptability among families, a co-designed approach should be taken.

<p>WHO Guidelines for postnatal care</p> <ol style="list-style-type: none"> 1. All mothers and babies should receive care in a facility for at least 24 hours after birth. 2. A minimum of three postnatal checks are recommended – one at 48-72 hours, one at 7-14 days and one at six weeks after birth. 3. Home visits are recommended 4. The baby should be checked for feeding difficulties, fever, respiratory problems, jaundice and neurological development. 5. Exclusive breastfeeding is recommended for the first six months 6. Daily chlorhexidine cord care should be attended as this is a high neonatal mortality setting 7. Other postnatal care for the baby should be completed (e.g. delay bathing for 24 hours, promote immunization, appropriate clothing, preterm and underweight babies identified and referred etc 8. Postnatal care of the mother should include monitoring pv blood and lochia loss, micturition, breast feeding and breastcare, perineal care, monitor for depression 9. Education and counselling on healthy postnatal activities 10. Iron and folic acid supplementation for three months 11. Prophylactic antibiotics considered if third or fourth degree tear 12. Provide psychosocial support
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Figure 4: Summary of WHO recommendations for postnatal care

Recommendation 4: Create staff incentives for quality improvement in obstetric and newborn care

Several respondents suggested the use of staff incentives to improve the supply of high-quality care. These included such initiatives as 1) mortality and morbidity reviews locally as quality improvement and professional development activities 2) patient reported measures and feedback mechanisms 3) career pathways for midwives and doctors who proved high volume-high quality care.

Most of the solutions are long game development strategies in terms of the district setting, the whole framework that goes around healthcare providers from their training, their competency assessment their credentialling, the tracking of their performance to direct career pathways which would try to motivate people to develop professionally, to build some hierarchy in the system, maintenance of standards etc.

I do wonder if further support around patient complaints and feedback processes – if the feedback was able to be positive or just to highlight failures like ‘we went to the health post and the midwife wasn’t there’ or ‘or we went there and they had no amoxycillin’ and then all of those things then get logged and they get forwarded to the quality managers in the different municipalities who are in charge of resolving those problems and that’s not going to fix everything but it’s going to highlight a lot of problems but in time if it gives people a voice about what they need and want and if they’re being slapped when they are delivering a baby then it would be good for that feedback to be coming back as a complaint. So again that won’t fix all the problems but it might be a good step in the right direction to increase the empowerment of communities to feel like they have a voice in their own healthcare and if there are things that can be done then that obviously needs to be matched with some follow through. If the health managers have no budget or ability to discipline their staff or whatever it is, to do so at least it has some teeth with it, but I think investing heavily in that consumer side to give the patient some advocacy and some opportunity to challenge what’s going on and to try and drive improvement and basically demand from their own health services that this is not good enough..because that

leadership is not coming from within the health profession [the next comment has not been included at the request of the respondent]...because that leadership is coming from within the health profession itself, there's a sort of inertia there, then perhaps it needs to come from the people and it needs to be taken up within the parliament and be basically a people's revolution. Demanding better quality health services. At the moment the people of East Timor are not either empowered or not able to advocate for their own health powerfully enough to be able to bring about the winds of change. So whether it's something like a complaints process at least we could start to move towards that and I wonder if that could be something that might be considered.

the human resource I think, is one of the challenges as well, because in national level itself, there is a limited human resource dedicated to program and MNCH so only one officer is managing the whole maternal health programs. So I think this is one of the main challenges as well. I can give you an example from maternal health program or in the safe motherhood program under the MCH department, there are several programs such as maternal perinatal death surveillance and response, there is the EMOC program, there is the PMTCT, and only one officer to handle those various programs. I think it's a bit difficult for her, yeah. Yes, and for the newborn care, I think before we have like one staff for IMCI program and newborn care together. But now, I think there are two officers but I think it's still, um, because many other competing priorities sometimes make them difficult to focus to give their more support to the down-level. For example, to the municipalities down to the health post. It's supposed to be like you are supporting supervision or monitoring at the national level down to the lower level but because of the limited human resource, sometimes these regular activities could not be implemented.

Recommendation 5: Strengthen and support basic MNCH in the community

Our study showed strong demand for routine child healthcare, despite some indirect costs. However, the quality of care and lack of reliable access to essential medicines was a widespread problem. As with the case of obstetric services, we suggest a focus on strengthening the quality of child health services at the community level. This could be done through health posts and PSFs. For example, in South Africa, one study showed that scaling up five simple interventions (hand washing with soap, therapeutic feeding for wasting, ORS, oral antibiotics for pneumonia and appropriate complementary feeding) would reduce child mortality by 82%.

Whilst national coverage indicators for key child health measures look favourable, there are significant disparities in the care-seeking and management of pneumonia, exclusive and continued breast feeding and ORS treatment for diarrhoea. The poorest households fall significantly short of international thresholds on all measures. (3) Our study confirms that indirect costs play a part in these disparities for poor rural families.

Demand-side strategies

These are strategies that assist and incentivise mothers, babies and children to seek healthcare. We found this to be a particular issue in two aspects of MNCH care 1) mitigating the costs of have a birth at a health facility and 2) mitigating the costs for families to obtain care for seriously ill children, particularly where rurally-based children are transferred to secondary and/or tertiary care. However, unless the quality of maternity and paediatric care meets appropriate standards it would be unethical to incentivize in this way.

The mechanism for these payments would need to be worked through but may be achieved in collaboration with the Ministry for Social Solidarity or perhaps through community-managed disaster funds.

Recommendation 6: Consider a conditional cash transfer payment for poor rural families who give birth at a recognized health facility and complete postnatal care

Other countries have had some success in increasing SBA rates and reducing MNCH mortality through conditional cash transfers. (26) Under such programs, poor rural households would receive a cash payment if their birth occurs at an appropriate health facility. The payment should compensate for the indirect costs identified in this study (e.g. lost income, food, transport etc).

Recommendation 7: Establish an emergency fund for costs incurred through serious illness for sick children in poor rural households

Rural families who incur catastrophic costs as a result of referral to secondary or tertiary care should be able to claim an emergency payment to compensate them for lost incomes, food, transport etc.

Conclusion

In conclusion, this study is consistent with other data highlighting disparities in MNCH care amongst poor rural families. Indirect and unexpected out-of-pocket costs account for a substantial proportion of the incomes of these households. Unless supply-side problems are addressed it is likely that these families will be unwilling to pay indirectly for MNCH care. Catastrophic costs incurred with referral pathways and serious illness need to also be addressed. We have suggested seven strategies for consideration by the Government of Timor-Leste in order that no Timorese women, babies or children will be 'left behind'.



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Appendices

Appendix 1: Terms of Reference for Advisory Group

“Study to identify indirect financial barriers to accessing Maternal, Neonatal and Child Health at Healthcare Facilities in Timor-Leste”

November 2019

Name:

Advisory Group to ‘Identify Indirect Financial Barriers to Accessing Maternal, Neonatal and Child Health at Healthcare Facilities in Timor-Leste’

Responsibilities:

1. The Advisory Group (AG) is responsible for providing feedback to the University of Sydney (USyd) research team on the design and conduct of the above project.
2. The AG will meet at least three times throughout the period of the research project to:
 - a) Provide feedback and comment on the initial research plan prior to ethics submission
 - b) Provide feedback and comment on matters arising during the conduct of the research project and
 - c) Provide feedback and comment on the results of the research.

Governance:

The USyd research team, who are independently conducting the study, will have to present and update the progress to the AG which in turns will provide feedback on the progress of the research project. The Maternal and Child Health Department at MoH will act as the secretariat for the AG. The USyd researchers are responsible to a number of groups including the National Ethics Committee of Timor-Leste and will disseminate the results on completion to the Consultative Council/Council of Directors from the MoH.

Composition:

Core Members	Non-core members
<p>MoH:</p> <p>National Director of Public Health (Sr Pedro Canisio)</p> <p>National Director for Financial Management (Sr. Marcelo Amaral, SE)</p> <p>Director for Cabinet for Policy, Planning and Cooperation (Sr. Narciso Fernandes, MPH)</p> <p>Head of Maternal and Child Health (Sra. Isabel Gomes)</p> <p>EPI Officer (Sr Manuel Mausiry)</p> <p>IMCI Officer (Dr Jose Felix)</p> <p>UNTL:</p> <p>Dr Joao Martins</p> <p>INS:</p> <p>Head of Research Department INS (Sr. Joaquim Soares, SKM)</p> <p>Sr. Raimundo Neves (IMNCI trainer)</p> <p>HNGV:</p> <p>Dra Milena dos Santos – Paediatricians (Head of Paediatric Department)</p> <p>Dr Augusto (O&G)</p> <p>The USyd team comprises:</p> <p>Dr Nicholas Goodwin</p> <p>Prof Lyndal Trevena</p>	<p>UNICEF</p> <p>WHO</p> <p>UNFPA</p> <p>Child Fund</p> <p>National Commission for Child Rights (KNDL)</p> <p>Health Alliance International (HAI)</p>

Appendix 2: Household Interview Data Collection Tool

Household interviews

Hello, I'm {insert name} and I'm a researcher from UNTL. We are collecting information for a research

study about healthcare-related costs for mothers, caregivers and children under the age of 5 years in

Timor-Leste. It is a partnership between the Ministry of Health, UNTL, UNICEF, WHO and the University

of Sydney. The research has been approved by the INS ethics committee and your answers will be

confidential.

1. Are you willing to assist us?

Yes

No

2. Can I begin by checking whether there is at least one child under the age of 5 years living in this home?

Yes

No

3. For this study we need to interview the main caregiver for the children under 5 in this household. Is that you, or is that person able to speak with me now?

Yes

No

4. What is your relationship to the children under 5? (This question should only be asked of the primary caregiver).

5. If answered 'other' to previous question, please note their relationship to the children

Child 1

Child 2

Child 3

Child 4

Child 5

Child 6

Child 7

Child 8

Child 9

Child 10

Adult 1

Adult 2

Adult 3

Adult 4

Adult 5

Adult 6

Adult 7

6. Who lives here? What is their gender and age? Please provide a brief description of all people living in this

house from youngest to oldest. (For example, Child 1 = Boy aged 2, Child 2 = Girl aged 10,

Adult 1 = Mother

aged 28, Adult 2 = Father aged 30, Adult 3 = Grandmother aged 52)

Adult 1

Adult 2

Adult 3

Adult 4

Adult 5

Adult 6

Adult 7

7. Now I'd like to ask you some questions about the adults living in this house who are working and earning

money. Can you tell me who works, what type of job they do and how much they earn each week? (If possible,

refer to the household number in the previous question. For example, Adult 2 = Father, policeman, \$100 pw)

8. Are there any other regular sources of income? If so, who earns those, how and what amount is that per

week? (For example: Adult 3 = Grandmother, government pension, \$50 pw)

9. Does your household own other property such as another house, land, refrigerator, TV, car, motorbike,

tractors, livestock? If so, what are they? (For example, 2 motorbikes, two cows, 10 chickens)

Child 1

Child 2

Child 3

Child 4

Child 5

10. Thank you. Now I'd like to ask you some questions about the health of your children who are under 5

years old. I am interested ONLY in the past month. Have any of your children been unwell over the past

month? What problem(s) did they have? How many times did they need professional healthcare over the past

month? Who provided that? (e.g. Child 1 = runny nose once only, not seen by HCP; Child 3 = cough once and

diarrhoea once, seen by nurse at health post)

11. Do you have any children who have died? If so, what age and gender were they and what did they die

from? (e.g. Boy aged 2, died TB)

Transport

Accommodation

Gifts

Communication (e.g. phone calls)

Repatriation of the deceased

Medicines or other treatments

Blood transfusions

Fees or payments to a healthcare worker

(including traditional healers, private clinics etc)

Tests and investigations
(e.g. X-rays, ultrasound, blood tests)

Food

Other

12. Now I'd like to ask you about money you may have spent on getting healthcare for your children under 5 over the past month. Consider the total costs for all of these child health visits for your household over the past month. How much did you have to spend and what for? (For example, Transport - buses to the health post = \$2)

13. Over the past month when your children under 5 years were sick, did anyone have to take time off work to care for them or to attend healthcare visits? Who did that and how much time off did they take? If the family lost any income because of this please tell us roughly how much that was? (e.g. father did not work at the market one day so that he could take child to the health post. This cost the family \$10 in income.)

14. Did you have to pay for someone else to do your work or look after your household while you took your child under 5 for healthcare over the past month? If so how much? (e.g. paid friend \$5 to maintain the crops while took child to the health post)

Your local PSF

Traditional healers

Your local CHC

Your municipality hospital

The National Hospital

A Private doctor or clinic

Other

15. Now I'd like to ask you about where you generally would seek healthcare for your children under 5. (In other words, not just over the past month). For each of these types of healthcare service, would you take your child under 5 to this place and if so, what for and why? (e.g. Local PSF for advice about a cough because they live nearby)

16. Now I'd like to ask some similar questions about your health as the children's primary caregiver. Do you have any ongoing problems with your health? If so, what are they? (e.g. high blood pressure, asthma, headaches, heavy periods, stomach pains)

17. For this question I am interested ONLY in the past month. Have you been unwell or needed to seek healthcare over the past month? What problem(s) did you have? How many times did you need professional healthcare over the past month? Who provided that? (e.g. headache once only and went to health post, also

went to health post to get blood pressure medicine)

Transport

Accommodation

Gifts

Communication (e.g.

phone calls)

Repatriation of the

deceased

Medicines or other

treatments

Blood transfusions

Fees or payments to a

healthcare worker

(including traditional

healers, private clinics etc)

Tests and investigations

(e.g. X-rays, ultrasound,

blood tests)

Food

Other

18. Now I'd like to ask you about money you may have spent on getting healthcare for yourself over the past

month. Consider the total costs for all of your health visits over the past month. How much did you have to

spend and what for? (For example, Transport - buses to the health post = \$2)

19. Over the past month when you were sick, did anyone have to take time off work to care for you or to take

you to a healthcare visit? Who did that and how much time off did they take? If the family lost any income

because of this please tell us roughly how much that was? (e.g. husband did not work at the market one day

so that he could take child to the health post. This cost the family \$10 in income.)

20. Did you have to pay for someone else to do your work or look after your household while you

got healthcare over the past month? If so how much? (e.g. paid friend \$5 to look after the shop while stayed

home to rest)

Your local PSF

Traditional healers

Your local CHC

Your municipality hospital

The National Hospital

A Private doctor or clinic

Other

21. Now I'd like to ask you about where you generally would seek healthcare for yourself. (In other words, not

just over the past month). For each of these types of healthcare service, if you were unwell would you go to

this place and if so, what for and why? (e.g. Local health post for stomach pains because I trust the nurse there)

22. Is the primary caregiver that is being interviewed the children's mother?

Yes

No

23. Now I'd like to ask some questions about the children's mother. Does she have any ongoing problems

with your health? If so, what are they? (e.g. is currently pregnant, otherwise well)

24. For this question I am interested ONLY in the past month. Has the children's mother been unwell or

needed to seek healthcare over the past month? What problem(s) did she have? How many times did she

need professional healthcare over the past month? Who provided that? (e.g. needed a pregnancy checkup

and went to health post to see the midwife once)

Transport

Accommodation

Gifts

Communication (e.g. phone calls)

Repatriation of the deceased

Medicines or other treatments

Blood transfusions

Fees or payments to a healthcare worker

(including traditional healers, private clinics etc)

Tests and investigations (e.g. X-rays, ultrasound, blood tests)

Food

Other

25. Now I'd like to ask you about money the household may have spent on getting healthcare for the mother

over the past month. Consider the total costs for all of the mother's health visits over the past month. How

much did you have to spend and what for? (For example, Transport - buses to the health post = \$2)

26. Over the past month when the mother was sick, did she or anyone else have to take time off work to care

for her or to take her to a healthcare visit? Who did that and how much time off did they take? If the family lost any income because of this please tell us roughly how much that was? (e.g. mother did not work one day so she could go for ANC visit. This cost the family \$10 in income.

27. Did you have to pay for someone else to do the mother's work or look after the household while she

got healthcare over the past month? If so how much? (e.g. paid friend \$5 to look after other children while

went to health post for ANC)

Your local PSF

Traditional healers

Your local CHC

Your municipality hospital

The National Hospital

A Private doctor or clinic

Other

28. Now I'd like to ask you about where the mother would generally seek healthcare for herself.

(In other

words, not just over the past month). For each of these types of healthcare service, if she was unwell would

she go to this place and if so, what for and why? (e.g. CHC for delivery of baby because that is where they

have the facilities)

29. Now I'd like to ask some specific questions about the most recent pregnancy that the children's mother/you had. Which of these best describes that pregnancy.

The pregnancy with the youngest child that lives in this house

The pregnancy with a child who has died

The pregnancy in which the mother died

30. Where was your (or the mother's) most recent baby born? Who was at the birth? Were there any health

problems with the pregnancy and birth? If so what were they? (For example: born at CHC, midwife present, no

health problems)

Transport

Accommodation

Gifts

Communication (e.g.

phone calls)

Repatriation of the

deceased

Medicines or other

treatments

Blood transfusions

Fees or payments to a

healthcare worker

(including traditional healers, private clinics etc)

Tests and investigations

(e.g. X-rays, ultrasound, blood tests)

Food

Other

31. Now I'd like to ask you about money the household may have spent on getting healthcare for the most

recent pregnancy. Consider the total costs for all of the mother's health visits during the pregnancy and delivery. How much did you have to spend and what for? (For example, Transport - buses to the CHC at least

five times = \$10, Accommodation for relatives when waiting for birth = \$20, Special vitamins = \$10)

32. During this last pregnancy did you or anyone else have to take time off work to get healthcare? Who did

that and how much time off did they take? If the family lost any income because of this please tell us roughly

how much that was? (e.g. Mother took six months off work and did not have any maternity allowances at her

workplace, so she lost around \$240 income overall)

33. Did you have to pay for someone else to do the mother's work or look after the household while she

got healthcare during the pregnancy and birth of the child? If so how much?

34. Thank you. You have been very helpful, I only have a few final questions. We'd like you to tell us any

examples or stories where you had to pay money to get healthcare for you (the mother) or children under 5

years? (Please prompt for indirect costs)

35. Can you tell us any examples or stories where you did NOT have to pay money to get healthcare for you

(the mother) or children under 5 years? (Please prompt for indirect costs)

36. Can you tell me any examples or stories where you decided NOT to get healthcare for the children, the

children's mother, or yourself because of costs?

Never Rarely Sometimes Often Always

Overall costs

Transport costs

Accommodation costs

Food costs

Lost income

Medicine costs

Cost of blood tests, Xrays

etc

Blood transfusion costs

37. Please indicate, during the past year, whether and how often your household avoided getting healthcare

for the mother or children based on the following:

38. Thank you so much for your time and help. Before I go, I just want to check whether there are any other

things you'd like to mention? Thanks!

Appendix 3: Stakeholder Interview Guide

Study to identify indirect financial barriers to accessing maternal, neonatal and child health at healthcare facilities in Timor-Leste

STAKEHOLDER INTERVIEW GUIDELINES

8 October 2020

Introductory script

Hello, my name is I am working on a research study about maternal and child health which is supported by the Ministry of Health. It is being conducted in collaboration with the University of Sydney in Australia. (Show support letter/official documentation for verification of identity). You might recall that we contacted you about this earlier and you agreed to speak with us. Is that still OK?

Consent

As we mentioned earlier, we are conducting these interviews independently and your answers will be confidential. We will record this interview so that we have an accurate record of your answers, but we will not link your name with any of the answers or published results so that your privacy will be protected. The interview may take up to one hour depending on how it goes.

Record consent on audio device. Begin the interview.

Please state your name, position and organization. Thank you, we will now move onto the questions.

1. What are the “best things” about your community?
2. What are the major health challenges facing your community?
3. Do you think the community as a whole is aware of locally available health services?
4. What do you think are the greatest barriers to accessing health services in your community?
5. Costs, both direct and indirect can act as barriers to accessing health services. What do you think are the financial barriers to health services affecting people in your community?
6. I have handed you a list of indirect financial barriers (Attachment A), please rank them from 1 (most important) to 10 (least important).
7. Which of these costs present the biggest barriers? Why?
8. What other financial barriers to health service access are not listed?

9. Are you aware of particular populations or groups in your area that are more affected by these financial barriers?
 - a. If yes, are there any particular health issues affecting those groups?
10. Are you aware of ways in which women and children are affected differently by these financial barriers? Can you give some examples?
11. Are you aware of ways in which disabled people are affected differently by these financial barriers? Can you tell me a little more about that? Any examples?
12. How do you think people currently overcome these financial barriers to health services?
13. What suggestions do you have for ways to overcome these barriers?
14. Do you know of any organizations already working on these issues? If yes, what are they doing?
15. Does your organization have policies, programs, services or other activities to reduce financial barriers to healthcare?
16. Can you think of a recent case of a person or family experiencing these barriers in a health facility? What happened? Was the problem resolved? Why or why not?
17. How would you or your facility deal with financial issues if they were raised by a patient or their family in your facility?
18. What are some of the resources or assets that exist in your area that might be able to help address these financial barriers?
19. If you were to give one piece of advice to overcome these financial barriers to healthcare, what would it be? Is there other advice you would offer?

Thank you for your time, close interview.

Attachment A. List of financial barriers to health

Transport
 Accommodation
 Food
 Medicines
 Gifts
 Communication
 Lost income
 Blood
 Specialist services (tests, experts)
 Repatriation of the deceased

Appendix 4: Household Case Study Guide

Study to identify indirect financial barriers to accessing maternal, neonatal and child health at healthcare facilities in Timor-Leste

CASE STUDY GUIDELINES

This study includes four (4) case studies – one each from the four municipalities of Dili, Ermera, Ainaro and Lautem. The purpose is to develop a deeper understanding of the household experiences of indirect financial barriers to healthcare.

The case studies should be conducted with households who participate in the household survey. Having earlier confirmed consent, at the end of the survey data collectors should tell the respondent they have more detailed questions about their experiences.

The case study data collection should include standard information (demographic) and be based on the questions below. The interviewer should also follow the individual journey of the household, using “how-why-what” questions to better understand their perspectives, thoughts and opinions. Take photos and record sounds as much as possible.

What to observe and write?

- The focus of the case study is the household experience of financial barriers to health services.
- Your task is to observe and write about the journey of the mother, father (if available) and their child(ren) plus their extended families, and their interactions with health services, facilities and programs.
- Health services could include hospitals, community health centers, health posts, private midwives, PSFs (Family Health Promoters), home visits, traditional healers and others.

What to ask?

1. Thinking of your most recent experience of a health service when you had to spend money, tell me in as much detail as you feel comfortable the way it happened.
2. When did you first realize that you needed to access a health service? How did you feel and what were the considerations in your mind in choosing the place to go for help?
3. How did you make a decision to access that health service? Who did you speak to and what did you talk about with them?
4. Did you try to treat yourself, or did a family member help? What did they say and do for you? How much did it cost you? What happened and what were the results? Were you satisfied?
5. Did you visit a traditional healer? What did they say and do for you? How much did it cost you? What happened and what were the results? Were you satisfied?
6. Before you left, what tasks or work did you need to complete or give to someone else? How did that make you feel?
7. If you were working, did you need to ask permission to go? Did you lose any wages or payments for work? If yes, how much in total?
8. How did you travel to the health service? Did anyone come with you? Who and why?
9. How long did it take you to get there? What type of transport did you use? Where did you stop? What happened along the way?

10. What happened when you arrived at the health facility? What information did you give them and what did they ask from you? Did they ask for any money? Or documents?
11. How long did you wait until you were seen by a health professional?
12. How was the treatment process? What happened? How long were you there? Who was with you? Did you have to pay for anything?
13. After treatment, how did the facility help you to recover and go home? Did anyone help you with transport?
14. How long did it take you to get home? What type of transport did you use? Where did you stop? What happened along the way?
15. Were there any other costs you had to pay after you arrived home?
16. Is there anything else you would like to share about your experience with the health service?

Thank you for your time, close interview.

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