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REPRODUCTIVE, MATERNAL, NEWBORN, CHILD, AND ADOLESCENT HEALTH AND NUTRITION

A MULTILEVEL STUDY OF CHALLENGES, RESPONSES, AND OPPORTUNITIES FOR SOCIAL AND BEHAVIOR CHANGE IN TIMOR-LESTE 2022

Local Health System Sustainability Project

Task Order 1, USAID Integrated Health Systems IDIQ

September 2022

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Local Health System Sustainability Project

The Local Health System Sustainability Project (LHSS) under the USAID Integrated Health Systems IDIQ helps low- and middle-income countries transition to sustainable, self-financed health systems as a means to support access to universal health coverage. The project works with partner countries and local stakeholders to reduce financial barriers to care and treatment, ensure equitable access to essential health services for all people, and improve the quality of health services. Led by Abt Associates, the five-year, $209 million project will build local capacity to sustain strong health system performance, supporting countries on their journey to self-reliance and prosperity.

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ACRONYMS

CHC	Community Health Center
FGD	Focus Group Discussion
GBV	Gender-based violence
GoTL	Government of Timor-Leste
HP	Health Post
KII	Key informant interviews
LGBT	Lesbian, gay, bisexual, transgender people
LHSS	Local Health System Sustainability Project
MNCHN	Maternal, newborn, child health and nutrition
MSG	Mother support groups
NGO	Non-governmental organization
PAR	Participatory action research
PWD	People with disabilities
RMNCAHN	Reproductive, maternal, newborn, child, and adolescent health and nutrition
SBC	Social and behavior change
SDG	Sustainable Development Goals
SISCa	*Servisu Integrado da Saúde Comunitaria* (Integrated Community Health Services)
SnF	*Saúde na Familia* (Health in the Family)
STI	sexually transmitted infections
USAID	United States Agency for International Development

1. EXECUTIVE SUMMARY

The reproductive, maternal, newborn, child, and adolescent health and nutrition (RMNCAHN) context in Timor-Leste is fraught with longstanding challenges. Timor-Leste has yet to make significant progress towards achieving the RMNCAHN Sustainable Development Goals (SDGs). Health services in Timor-Leste have improved over the past years however maternal and child undernutrition remain a country challenge, access and quality of services remain uneven, and nutrition response is suboptimal.

This qualitative study supports the Government of Timor-Leste Ministry of Health deepen its understanding of RMNCAHN determinants and identify solutions that can be leveraged to accelerate related Social and Behavior Change (SBC) interventions. The study objectives are to: 1) identify the key health, social and cultural determinants that need to be addressed to support SBC at the household level for inclusive RMNCAHN; and 2) determine what culturally and contextually relevant solutions can be leveraged to accelerate RMNCAHN social and behavior change.

The Activity used three qualitative methods—participatory action research (PAR), key informant interviews (KIIs), and focus group discussions (FGDs) in six municipalities (Baucau, Covalima, Dili, Ermera, Manufahi, and RAEOA) that are representatives of the Timor-Leste population and that deliver health services primarily through community health centers and health posts. Following consultation with local entities and stakeholders, the activity identified 224 participants across the six municipalities. The 110 PAR participants included representation of people with disabilities (PWD; vision, hearing, limb, and mental impairments), pregnant and lactating women, parents, and traditional birth attendants; while 81 KII and 33 FGD participants included representatives from Local Authorities, Municipal Health Service, Community Health Service, and Health Post personnel. The Activity collected the data during the months of April and May 2022.

Building on previous research this study deepens understanding of many RMNCAHN aspects and provides insights into priority health interventions and social and cultural determinants of population behaviors. We present below specific recommendations for strengthening inclusive RMNCAHN interventions across several population groups:

Table 1: RMNCAHN Recommendations

Maternal and infant health	Address maternal and infant emergency cases, including ensuring that adequate plans are made to ensure facility-based delivery of neonates —especially in high-risk cases—to avoid additional health risks and to reduce maternal and neonatal mortality. Ensure availability of equipment, resources, personnel, and maternity beds at health facilities. Engage with traditional healers (matan do'ok), traditional leaders, religious leaders, community leaders, community-based midwives, and traditional birth attendants to support complementary health care. Engage with families to ensure certain cultural beliefs, practices, and authority structures do not negatively affect the health of women, neonates, or infants and promote practices with positive impact.
Child and adolescent health	Increase formal and informal, including family and community support networks for provision of care for infants and children to reduce malnutrition and under-5 mortality. Engage with adolescents and share youth tailored information on RMNCAHN concerns in schools and other community settings. Conduct values clarification exercises with health workers to support the provision of information, improve care and support and ensure health facilities are adolescent friendly. Assess and improve sexual and reproductive health care provision for adolescents including providing universal access to contraception, including condoms to reduce unplanned pregnancies and sexually transmitted infection transmission.
Health of people with disabilities	Conduct values clarification exercises with health workers to support the provision of respectful, dignified, and inclusive care for PWD. Encourage health workers to provide advice and issue requests for improvements to health facility infrastructure that will overcome challenges faced by PWD with mobility impairments. Provide training in tailored health care provision for PWD, including all aspects of reproductive health. Improve and expand the range of health communication materials, including materials tailored to addressing PWD-specific RMNCAHN concerns. Establish links with social services to support needs that go beyond what can be provided at health facilities.
Male involvement	Prioritize male engagement, including to improve men's knowledge of RMNCAHN. Encourage and support men to attend antenatal visits with their wives and to have a delivery plan This includes ensuring arrangements are made to deal with pregnancy-related and obstetric emergencies, being present during delivery,

	supporting their wives in caring for infants and children, supporting exclusive breastfeeding, supporting postnatal care visits and infant and child vaccination, and supporting child nutrition. Deepen men's understanding of nutritional foods available locally and family needs for balanced meals and vitamin supplementation.
Nutrition	Expand community engagement on nutritional concerns, including through local leadership structures and groups. Improve understanding of cost and other efficiencies for nutrition derived from local subsistence and agricultural production, including by engaging with traditional and other leaders in communities. Engage with PWD and their families on nutritional needs and support for PWD, including children with disability, and strengthen links to support systems. Improve understanding of the vital importance of exclusive breastfeeding during the infant's first six months.

The study concluded with findings applicable to the broader RMNCAHN population including the need to:

1) address poor health facilities infrastructure;
2) ensure RMNCAHN outcomes gains are even across communities;
3) identify and address risks associated with traditional health practices;
4) strengthen integration of gender equality in professional and leadership roles to further empower women;
5) ensure all SBC efforts are inclusive at multiple levels of society;
6) advocate for and further strengthen community engagement in building social networks to strengthen health outcomes of communities;
7) leverage community leaders in community mobilization; and
8) learn from the COVID-19 response lessons to prepare for future pandemics.

Overall, there is a need to intensify efforts to achieve key targets for the SDGs for 2030 and align with overarching national goals and policies. This includes building resilience and sustainability by ensuring integration of inclusive RMNCAHN interventions at multiple levels; incorporating SBC approaches across RMNCAHN programs; strengthening health and community systems; supporting health providers, including traditional providers; engaging in partnerships, including with community leaders and groups; and emphasizing responsibility and accountability throughout health and community systems.

2. BACKGROUND

Timor-Leste comprises 12 municipalities and one Special Administrative Region—RAEOA, or *Regiao Administrativa Especial RAEOA Ambeno*, which is an exclave located in neighboring Indonesian West Timor. The country's official languages are Portuguese and Tetum. English is also spoken, as are several indigenous languages.

Over the past two decades since independence, Timor-Leste has made impressive strides in rebuilding its infrastructure, institutional frameworks, democratic processes, and core human resources. However, health system challenges have held back progress on key health indicators. Increased use of social and behavior change (SBC) activities that target healthy behaviors and improved advocacy and participatory governance are likely to contribute to strengthening the health system and transforming health in the country.

Strategic direction is provided through the National Health Sector Strategic Plan 2011-2030 and is supported through primary health care provision, health promotion programming, and the *Saúde na Familia* (Health in the Family) program.

The USAID Health System Sustainability Activity aims to create a more resilient, self-reliant, efficient, responsive, and adaptable health system through strengthening health sector governance, strengthening health sector workforce management, improving healthy behaviors, and improving civic engagement and advocacy for health systems strengthening.

The Activity supports the use of SBC approaches and tools to increase community adoption of healthy behaviors by influencing social norms that underpin those behaviors, and by building the capacity of civil society organizations, the health system, and communities to effectively implement SBC activities. SBC aims to not only improve the demand for accountable, affordable, accessible, and reliable care but also address support for the behaviors of all people, communities, and organizations within the health system for the equitable provision of quality care.

USAID Vision for Health System Strengthening

In conducting this research the Activity was guided by USAID's Vision for Health System Strengthening 2030 emphasizes the importance of flexibility of resources, policies, and responses to address constantly emerging challenges for resilient health systems.[i] This includes: (1) integrating activities that are strongly grounded in locally derived solutions led by local organizations and empowering leaders and personnel within health and community systems to resolve health problems as they occur; (2) explicitly integrating social and behavior change (SBC) approaches into integrated activities; and (3) engaging in inclusive, country-led partnerships.

HEALTH DATA

2.1.1 KEY RMNCAHN DATA

Reproductive, Maternal, Newborn, Child, and Adolescent Health and Nutrition (RMNCAHN) refers to the health and wellbeing of women during pregnancy, childbirth, and the post-partum period and the health of newborn, children, and adolescents, with nutrition as a cross-cutting factor. Gender, disability, and equitable access are related considerations. RMNCAHN links directly to meeting health needs, reducing mortality, ensuring adequate nutrition, and providing access to effective, appropriate, acceptable, equitable, and safe health care and services.

Table 1 shows key mortality and fertility data in Timor-Leste and South Asia against the Sustainable Development Goal (SDG) targets for 2030. Maternal mortality and neonatal mortality are slightly lower in Timor-Leste in comparison to South Asia, whereas under-5 mortality is somewhat higher. The total fertility rate in Timor-Leste in 2016 was nearly twice as high as in South Asia, at 4.2 versus 2.3. Wanted fertility was lower in 2016 than the actual fertility rate—3.5 versus 4.2. Fewer than half of women aged 15-49 in Timor-Leste (47%) had their family planning needs met with modern methods in 2016. Considerable progress is needed to achieve the SDGs by 2030.

Table 1: Mortality and fertility data: Timor-Leste and South Asia versus SDG targets for 2030

Indicator	Timor-Leste	South Asia	SDG targets for 2030
Maternal mortality (deaths per 100,000 live births)	142 (2020)	163 (2017)	70
Neonatal mortality (deaths per 1,000 live births)	20.4 (2020)	24 (2020)	12
Under-5 mortality (deaths per 1,000 live births)	45.8 (2020)	39 (2020)	25
Adolescent mortality (deaths per 100,000 population)	73.3 (2020)	-	-
Total fertility rate	4.2 (2016)	2.3 (2020)	2
Fertility rate wanted	3.5 (2016)	-	-
Family planning needs met with modern methods among women aged 15-49	47% (2016)	-	Universal access

In 2016, antenatal coverage of at least four health care visits by pregnant women to a health facility was 77%. Nearly one in five children (19%) had not received any vaccinations by the age of 12-23 months, whereas 49% had received all their basic vaccinations.

The median age at first birth among women aged 25-49 is 23 years; 29% of women have their second or higher-order birth within 24 months of the previous birth; and 7% of women aged 15-

19 have begun childbearing.[ii] Most women aged 15-49 who have had a live birth in the five years preceding being surveyed received antenatal care from a skilled health worker for their most recent birth. Around half (49%) of births take place at a health facility, and 57% are assisted by skilled providers.

The adolescent birth rate in Timor-Leste is 42 per 1,000 young women aged 15-19.[iii] Among women aged 20-24, 3% were married or in a union by age 15 and 15% by age 18. Around a third (36%) of women aged 15-49 make their own reproductive health choices (including sexual relations, contraceptive use, reproductive health care). Regarding exposure to violence by an intimate partner in the past 12 months, 33% of women aged 15 and older experienced physical violence, 5% experienced sexual violence, and 9% experienced psychological violence.

2.1.2 HEALTH SERVICES

Health care provision in Timor-Leste involves a network of outreach services, Health Posts (HPs), and Community Health Centers (CHCs) at both municipal and sub-municipal levels, including referral, regional, and national hospitals.[iv] Although access to health care has improved in the country, access to health facilities remains uneven. For example, in 2018, 46% of women had challenges with distance reaching a health facility, 44% required transport, 41% did not want to access health care alone, 38% lacked money for treatment, and 35% had trouble getting permission from others to go to the facility.[v] The majority of women (60%) were concerned about the quality of health care provided at health facilities; 56% had concerns about being treated respectfully. Consequently, women delay seeking care, which leads to negative health outcomes.[vi] Economic status is also a limiting factor, and health services are underused by people who are poor versus those well-off.[vii]

NUTRITION

SDG 2 aims to end hunger, achieve food security and improved nutrition, and promote sustainable agriculture. According (preliminarily) to the Food and Nutrition Survey 2020[viii] in Timor-Leste:

- Exclusive breastfeeding rates of infants (under 6 months) is 62% (at least 50% is targeted by the World Health Organization).
- Stunting among children under age 5 is 47% (considered very high by the World Health Organization).
- Wasting is 9% (considered "serious").
- Underweight among children under age 5 is 32%.

These indicators have improved modestly since 2013.

According to the 2016 Timor-Leste Demographic and Health Survey, 40% of children aged 6-59 months are anemic, and 27% of women and 25% of men aged 15-49 are underweight. Around half of children aged 5 years or younger sleep under an insecticide-treated bed net.[ix]

Poorer and less-educated families are more affected by these negative nutrition-related health conditions. For example, a review of rural livelihoods found that agriculture remains predominantly subsistence-based, with some cash available through government pensions and salaries.[x] Around a third of women (32%) and nearly half of men (45%) aged 15-49 work in agriculture. Some 28% of women and 10% of men are engaged in services, 5% of women and 23% of men are involved in skilled manual labor, and 18% of women and 3% of men are involved in domestic service.[xi] Households that can accumulate wealth through non-farm income sources have better outcomes for child health, although outcomes have been found to be inconsistent across households.

There are general nutritional challenges in Timor-Leste. For example, between 2013 and 2015, 27% of the population experienced hunger, 82% of infants and young children were not consuming a minimum acceptable diet, and 72% did not meet the minimum requirements for dietary diversity.[xii] In 2016, 46% of all children under age 5 years were stunted, 24% were wasted, and 40% were anemic. Rural children are at higher risk of these factors than urban children. Poor nutrition of mothers is a contributory factor, and the prevalence of anemia is around 23% among women of reproductive age. Adequate breastfeeding practices occur at a higher rate among women in poorer communities than in wealthy communities. Vaccination coverage is low.[xiii]

The causes of maternal and child undernutrition in Timor-Leste include intersecting immediate factors (nutrient intake and disease burden), underlying factors (childcare and feeding practices, reproductive health, gender disempowerment, household hygiene, dietary diversity, food security, health services), and basic factors (poverty and other economic, social, and political factors).[xiv]

Most people in urban areas in Timor-Leste (92%) have access to safely managed drinking water, as do 75% of people living in rural areas. A sanitation facility including soap and water for handwashing is available for 76% of people in urban areas and 45% of people in rural areas.

SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

A 2017 report on sexual and reproductive health and rights in Timor-Leste[xv] highlights the need for attention to social and cultural norms, community-based programming, and improved services (including youth-friendly) to support change in relation to the following RMNCAHN focal areas:

- Compared to urban settings, rural women and girls have less access to sexual and reproductive health services including skilled care during childbirth, antenatal and postnatal care, and emergency care when needed. While modern contraceptive prevalence has risen from 7% in the early 2000s to 24% in 2016, around 25% of married women are estimated to have unmet needs for family planning. Adolescents and unmarried young adults face the risks of unplanned pregnancies, early marriage, or unsafe abortions. Understanding of sexual and reproductive health issues and concerns, including risks of HIV and other sexually transmitted infections (STIs), is insufficient among young people. Appropriate youth outreach, youth-friendly health services, and access to sexual reproductive health information are lacking.

- While HIV prevalence was low, at 0.2% among people aged 15-49 in 2020,[xvi] it remains necessary to address the prevention, treatment, and care needs of higher-risk populations including sex workers, gay men and other men who have sex with men, transgender people, uniformed personnel, and sexual partners of people within these groups.
- Timor-Leste ranks low on the United Nations Gender equality index (128 out of 187),[xvii] and gender inequality and gender-based violence (GBV) are pervasive. A study on the links between violence against women and reproductive health and child mortality found higher likelihood that ever-married women who experienced violence would defer to traditional birth control methods, will have experienced a pregnancy termination, will have had a child who has died, will have a low birthweight infant, and will have partially vaccinated children.[xviii] While intimate partner violence predominantly affects women in relationships, lesbian, gay, bisexual, and transgender (LGBT) people and people with disabilities (PWD) are also negatively affected. Although Timor-Leste's laws are rights-focused, reporting and prosecution rates are low.

MEN AND WOMEN

While policies support the rights of women, various obstacles stand in the way of achieving gender equality. Gender roles remain patriarchal; other obstacles include lack of access to reproductive health, rights, and education; lack of financial stability; and limited political representation.[xix] Certain cultural beliefs, logics, and practices perpetuate poor maternal health care outcomes. This situation is made worse by a lack of culturally appropriate approaches and communication, distrust in the health system, and geographic limitations. [xx] Importantly, understanding health in biomedical terms is not the dominant frame of reference for many people in Timor-Leste; instead, various traditional and cultural taboos and restrictions shape how pregnancy, childbirth, and the postnatal period play out.

Violence against women negatively affects the mental and physical health of affected women. It increases exposure to negative health circumstances, while also negatively affecting their infants and children. A study in 2015 in Timor-Leste highlights that more than a third of ever-married women have experienced sexual or domestic violence by their most recent partner.[xxi] Such experiences, in turn, negatively affect access to family planning, maternal health care, and birth outcomes. It is recommended that interventions target and support affected women, and that prevention programs should focus on men. A study engaging midwives identified opportunities for them to support women who were victimized, but this requires adequate training and linkages to support systems.[xxii]

The Catholic Church plays an important role in reproductive health decision-making in Timor-Leste. The Church is positioned historically as a supporter of the struggle for independence and has been involved in providing health services, including reproductive health in the context of "official" Catholic doctrine. Interviews with Church representatives found a broad spectrum of attitudes and opinions among nuns and priests. These included recognition of the challenges faced by women adhering to natural contraceptive methods, with some openness towards condoms

and other modern methods.[xxiii] While Timorese women recognize Catholic doctrine, they are widely supportive of the right to reproductive self-determination; they support modern contraceptive methods and are concerned about maternal mortality. Men also support the need to make choices about the size of one's family.

A peer education project with men on reproductive health found that while health-related knowledge and attitudes are an important foundation for change, vital health infrastructure and supportive health personnel need to be in place to facilitate that change. It also found that engaging men and women together is necessary to challenging entrenched gender inequalities.[xxiv]

A study in 2017 found that men were seldom present during antenatal health care visits and were usually unable to be present at birth or attend postnatal consultations.[xxv] However, men had positive attitudes towards supporting their partners—for example, needing to be present for pregnancy complications, comprehending that their support would be favorable for their partner's outcomes, and caring for their partner's wellbeing. Role models and influencers for men include close family members, elders, community leaders, and health professionals.

An analysis of sexual decision-making in 2015 found that sex is framed in terms of wishes and rights, with perceived entitlements largely being framed by men. Consequently, violence and coercion are directed towards women, and unwanted pregnancies are part of this mix.[xxvi] Women's access to contraception is impeded by various external factors, most often by family, cultural, traditional, and educational influences.[xxvii]

Delays in accessing antenatal care and care during labor and birth in Timor-Leste are influenced by minimal birth preparedness of fathers. Regarding fathers, culturally framed beliefs about reproductive biology are a challenge. Other challenges include accessing services (distance, lack of transport, poor roads), planning, and lack of cultural sensitivity of health care personnel.[xxviii,xxix] Using local birth attendants and home births are therefore considered to be preferable. Recommended strategies include more inclusive support for local midwives, improved cultural sensitivity by health providers, support to service access, and gender-sensitive engagement—particularly in relation to addressing maternal mortality risks.

An exploration of sexual and reproductive health decision-making was conducted among men and women in four Timor-Leste municipalities. While sexual and reproductive health rights were recognized, there were contrasting perceptions and gender imbalances regarding decisions to have sex, including for pleasure, reproduction, and following birth of children. Socio-cultural factors, including religion, contribute to imbalances and stand in contrast to support for reproductive health and rights in government policies.[xxx]

PEOPLE WITH DISABILITIES

The Constitution of Democratic Republic of Timor-Leste secures the rights of people with disability through Articles 16 and 21, clarifying that they should be free from any form of discrimination and should be treated equally as other citizens. Emphasis is placed on inclusivity within the health system:[xxxi]

> *The creation of a universal and general national health service has the fundamental objective of enabling access to health care for all citizens on an equal basis, whatever their color, race, marital status, sex,...or physical or mental condition, as well as guaranteeing equity in the distribution of resources and in the use of services.*

Timor-Leste promulgated a "Resolution to Promote and Protect Rights of People with Disabilities" in 2019[xxxii] that focuses on inclusion in all aspects of public life. It addresses the needs of PWD through a National Action Plan for People with Disabilities 2014-2018.[xxxiii] The Action Plan follows the United Nations definition of disability as those "who have long term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others."

Gender disparities in relation to disability are recognized—for example, the greater marginalization of girls and women with disability in public life and participation in development of other programs, their greater vulnerability to sexual and gender-based violence, and inadequacies in relation to accessing health care and receiving communication. The Timor-Leste Association of People with Disability works on the front line to advocate for the right of PWD to access public services such as health, education, employment, and more.

There were about 38,000 PWD in Timor-Leste in 2015[xxxiv]; most (86%) were living in rural areas. People who are visually impaired comprise around 38% of all PWD, followed by people with hearing impairments (20%) and people with psychosocial impairments (9%). Around 68% of people with disability have never been to school.

The majority of people with disability have no access to employment. Only 86% of PWD receive social subsidies from the government.[xxxv]

PWD face barriers to reproductive health information and services compared to those who are not disabled. Services may be poorly configured or inappropriate to support PWD, and attitudes and actions in communities and among health care providers also may be stigmatizing or discriminatory. "Demand-side" factors include not knowing their rights, additional costs of health care, limited mobility, internalized stigma; and lack of information; "supply-side" factors include attitudes of health care personnel and limited ability to serve people with disabilities, communication barriers, and inaccessible facilities.[xxxvi]

Barriers for PWD in Timor-Leste include negative traditional views of disability, experiences of exclusion in early life, physical challenges related to accessing education (and interrupted schooling contributing to low literacy), and difficulty gaining paid employment. Personal resilience helped to overcome barriers—for example, by establishing relationships with peers or others in their community who face similar circumstances and are living a fulfilling, productive life, by creatively solving problems, and by building on one's pride based on achievements. Diffusion of any endorsed changes is slow.[xxxvii]

A study conducted in 2015 noted lack of recognition of needs, sexuality, and reproductive health rights of women with disability by health care providers at health facilities in Timor-Leste.[xxxviii] The majority of health care providers have a limited understanding of disability impairments, lack a human rights–based approach to disability, and primarily view disability as involving physical

impairment and to a lesser extent, vision impairment. Some health service providers and community members do not acknowledge the sexuality of women with disabilities—for example, expressing disbelief when women with disabilities are pregnant.

An evaluation of the Disability Inclusive Health program in Timor-Leste in 2020[xxxix] found that:

- Training has improved the knowledge and attitudes of health staff, in turn improving health service provision for PWD—a process that supports the expansion of the training program through the Ministry of Health.
- Booklets and posters support knowledge dissemination, but they are not widely used by health workers.
- Examples of sexual abuse and assault of women with disability by health workers, and poor responses to pregnant women with disabilities who have been raped, were identified.

Recommendations include expanding training, improving monitoring, fostering facility-level action plans and change-agents, and improving accountability.

ADOLESCENTS

Adolescents make up one quarter of the Timor-Leste population. Unemployment rates among young people aged 15-24 are high in South-East Asia (ranging from 42% in Maldives to 29% in Bhutan) but are relatively low in Timor-Leste at 14%.[xl] The median age of marriage is 18. Analysis of family and school connectedness shows low scores for Timor-Leste relative to others in the region; 40% of adolescents do not have access to electronic media (a factor that affects access to information and connectedness). Around 12% of adolescent births are unwanted, and demand for contraception is 40%. While national strategies and plans address the needs of adolescents, there are regulatory limits imposed for services such as contraception, including emergency contraception—for example, age limits, marital status, or spousal consent.[xli]

An analysis of the Global School-Based Student Health Survey in Indonesia, Laos, Thailand, and Timor-Leste in 2015 found that 26% of adolescents had ever had sex, 56% had not used a condom at last sex, and 62% did not use birth control at last sex.[xlii]

A 2015 study found that while parents agree that it is important to discuss reproductive health, sex, and sexuality with adolescents, this step is not necessarily taken. There is therefore a need to intensify communication on impacts of teenage pregnancy and HIV, including in rural areas.[xliii]

2.1.3 SBC & COMMUNICATION

SOCIAL AND BEHAVIOR CHANGE

SBC takes place in the context of policy, institutional, organizational, social, community, family, and individual-level factors. Bringing about change in health through SBC involves interactive, theory-based, and research-driven processes that take norms and practices into account at all of these levels to support change.

SBC activities at various levels include:

- **Health providers:** Interpersonal communication, health provider training, disability-inclusive health training, and GBV training. Note: in order to change behavior at the household and individual levels, structural and resources changes are generally required at the facility level to allow for better experiences and thus behavior change related to service uptake.
- **Community level:** Community-based monitoring for health, development of community action plans, community transport, community scorecards, and community advocacy—although conducted at a small scale.
- **Communication materials:** These are linked to program activities, with centralized control for consistency, and incorporating a behavior change communication strategy for sexual and reproductive health.

Regarding social, community, family, and individual-level factors, several studies in Timor-Leste inform SBC approaches:

- A study of peer education for GBV and reproductive health for men found that peer education was effective.[xliv]
- A study of midwife responses to GBV indicated that identifying experiences of GBV and emphasizing linkages to community-based support structures should be emphasized.[xlv]
- A study of immunization coverage identified the need for convenient, reliable, friendly, and informative health services.[xlvi] The importance of ensuring appropriate standards of care also was identified in a study on public health care access.[xlvii]
- A study of health approaches for connecting mothers to health providers through text messaging (the Mobile Health program) found that these facilitated supportive communication with health care providers.[xlviii]
- A study of the experiences of people living with HIV in Dili highlighted stigma and discrimination experiences including gossip, social exclusion, and threats of violence in their communities, and a lack of confidentiality and inappropriate treatment by health facility staff.[xlix]

Socioeconomic inequalities influence RMNCAHN. For example, a study of fertility rates of adolescents in Timor-Leste found that adolescent girls who are poor, uneducated, and from rural areas are far more likely to have more births than those who are rich, educated, or urban residents.[l]

A "three delays model" analysis of Timor-Leste explored: (1) recognizing a health problem and deciding to seek care; (2) reaching an appropriate source of care; and (3) receiving adequate and appropriate care.[li] Factors contributing to the first delay include low educational levels, lack of knowledge and poor recognition of danger signs, limited birth preparedness, and insufficient decision-making processes. The second delay is influenced by distance to health facilities, lack of transport, financial costs, and other time and opportunity barriers. The third delay is underpinned by lack of equipment and supplies, insufficient staff, lack of trained staff, and poor staff attitudes.

Apart from various recommendations for structural support, SBC communication needs identified include:

- Developing culturally appropriate verbal or visual communication, including relevant language and literacy levels.
- Supporting ways to engage with information to assist learning and internalizing of information.
- Using preferred information sources.
- Focusing information on key concerns (e.g., danger signs).
- Intensifying efforts to promote birth preparedness and complication readiness.

Programmatic support to national strategies is provided through community health systems including *Servisu Integrado da Saúde Comunitaria* (SISCa), Mother Support Groups (MSG), the *Saúde na Familia* (Health in the Family) program, Community-Based Monitoring for Health, and the school health program. There is also a SBC strategy for nutrition; a communication strategy for maternal, newborn, and child health and nutrition (MNHCN); an open defecation-free program; Mobile Health program; health promotion corners; a school health program; and night events for health promotion.

A brief review of SBC related to RMNCAHN by the Timor-Leste Ministry of Health[lii] (Health Promotion Technical Working Group) identified the following considerations:

- Health facilities are not seen by the community as the first point of contact for health seeking; access to health facilities is constrained by distance, lack of transport, and lack of resources.
- RMNCAHN outcomes are influenced by social, cultural, and religious contexts.
- Women's agency is diminished in relation to reproductive health and childcare decision-making, in the context of poor spousal interactions.
- Home births are common; postnatal care services are underused.
- Parents do not have sufficient capacity to ensure that children receive adequate nutrition; the risks of undernutrition are not well understood.
- Adolescent health programs have been delivered inconsistently and are not systematically implemented through the existing community health system.
- Male engagement is lacking; this perpetuates the disempowerment of women to access reproductive health care.
- GBV is perpetuated by cultural factors and inadequate engagement with informal and formal justice systems.
- Teenage pregnancies are a pressing challenge and largely are due to inadequate access to health resources and services and unsafe sex.

- PWD and LGBT people lack access to inclusive health services; they are subject to stigma and discrimination, including refusal of health service access.
- Current approaches to incentivizing and supporting health behavior change do not address sustainability.

Although there are diverse community programs, community engagement and feedback mechanisms are lacking. While the Ministry of Health has a strong existing community health program, additional resources and capacity-building are needed.

While SBC interventions (including advocacy, training, and mobilization) are conducted regularly, and information and communication materials are disseminated, monitoring and evaluation of reach and use of SBC are not routinely implemented. There are insufficient resources for PWD, and insights into specific and general audience SBC needs are lacking. SBC needs to be seen as a holistic approach including advocacy, community engagement and participatory planning, community mobilization, community capacity-strengthening, evidence-based SBC and communication, and hard and soft infrastructure to support behavior change at all levels (policy, institutional, organizational, community, household, and individual) and addressed the issues within the facilities/health care system and among users in order to be sustainable.

COMMUNICATION REACH

Around one in five women (22%) and men (19%) aged 15-49 in Timor-Leste have no education; 11% and 12%, respectively, have attended schooling beyond secondary school.[liii] Three quarters of women (75%) and slightly more men (82%) aged 15-49 are literate.

In 2016, 84% of households owned a mobile phone; 40%, a television; and 25%, a radio.[liv] More than half (55%) of men and women aged 15-49 do not access a newspaper, radio, or television on a weekly basis. Reach is lower in rural areas; in some areas—for example, among women in Ermera and men in Viqueuqe—there is minimal regular exposure. Internet access in the past 12 months averages 53% for men and women in urban areas versus 14% for men and women in rural areas. Television is the most common source of messages about family planning.

METHODS

Previous research establishes that the RMNCAHN context in Timor-Leste includes sustained challenges. Against the SDGs related to reproductive health and nutrition, achievements to date are around 50% of target, and intensive efforts will be needed towards 2030. While health services in Timor-Leste have improved, access and quality of services remain uneven. Maternal and child undernutrition are insufficiently addressed, and there is a need to address diverse aspects of nutrition response.

There is an interplay between traditional and modern medicine when it comes to accessing health care and a need to improve community engagement for health. This is true especially with regard to critical health concerns such as maternal and infant mortality, but also more broadly regarding gender and sexual and reproductive health and decision-making.

Men and adolescents continue to face challenges regarding RMNCAHN including health care access, and PWD are considerably underserved. There is a need to strengthen and improve SBC to support RMNCAHN across audiences, including strengthening community capacities and empowerment through processes of engagement and mobilization at all levels.

Against this background, this qualitative study sets out to support the Government of Timor-Leste (GoTL) Ministry of Health to deepen understanding of RMNCAHN determinants across districts and to identify solutions that can be leveraged to accelerate SBC in support of strategic goals. The study objectives are to:

- Identify the combination of key determinants, including social and gender norms and other socioeconomic and cultural considerations, that need to be addressed to support SBC at the household level for inclusive RMNCAHN.
- Determine what culturally and contextually relevant solutions exist that can be leveraged to accelerate processes of social and behavior change in support of GoTL's strategic goals.

Three qualitative methods were used—Participatory Action Research (PAR), Key Informant Interviews (KIIs), and Focus Group Discussions (FGDs).

1. PAR involves researchers and participants working together to explore local issues or concerns towards identifying solutions.[lv] Through PAR, community representatives are engaged in critical-thinking activities that deepen understanding of their culture and context, including how challenges can be addressed in ways that are relevant, practical, and sustainable.
2. KIIs are structured or semi-structured interviews with one or more participants at a time undertaken to understand their individual insights into an issue or concern. Participants are knowledgeable about their community and typically include leaders, stakeholders, professionals, or others with expertise who can provide first-hand information.
3. FGDs are brief interactive discussions with groups of participants. They are conducted with people who have common characteristics and a capacity to inform research themes based on their knowledge of the identified issues within their context.

For the purposes of this study, the PAR component followed the format of a one-day workshop; the KIIs and FGDs were allocated one to two hours each.

The study team comprised a lead investigator based in the United States of America and a local team lead investigator. The research leads provided overall guidance to the study, including training of the fieldwork team; supervision of data collection, quality control, support to translation, and transcription; and data coding, analysis, and report writing. The study was overseen through Save the Children headquarters in Washington, DC and technical lead personnel in Timor-Leste.

ETHICAL CONSIDERATIONS AND STUDY APPROVAL

The study design followed ethical research principles, and training in research ethics was provided to the fieldwork team. Participants were provided with consent forms that described the ethical considerations, and written consent was required. Written consent also was required for photographs taken during the study sessions. Protective measures to prevent the transmission of SARS-CoV-2/COVID-19 were incorporated to ensure safety of the participants and research team. These included open-air venues, wearing of facemasks, and hand hygiene.

The study protocol was reviewed and approved by the Save the Children Ethics Review Committee in the United States and by the *Instituto Nasional De Saúde* of the Ministry of Health in Timor-Leste.

STUDY SITES

The study was conducted in six municipalities, all of which deliver formal health services through CHCs and HPs, with hospitals located in some municipalities. The municipalities were selected for variety and representativeness of the Timor-Leste context:

- **Baucau**, which is the second-largest economic hub and has the third-largest population, taking high levels of mobility into account.
- **Covalima**, which is a remote municipality that lies along the border with Indonesia and includes cross-border economic activity.
- **Dili** (central region), which is the capital and the smallest municipality, which also has the highest population density. It is the economic hub and center for higher education.
- **Ermera**, which has the second-highest population in the country. It has rugged terrain, and access to basic social services is challenging—especially health, education, clean water, and sanitation facilities.
- **Manufahi**, which is mainly dependent on agricultural production. The geography is challenging, and access to basic social services is limited.
- **RAEOA**, which is an exclave surrounded by Indonesia and is governed by an autonomous administrative policy and economic regime.

Study communities were selected in each municipality following consultation with local health structures and stakeholders.

STUDY PARTICIPANTS

There were 224 participants across the six municipalities—110 PAR participants, 81 KII participants, and 33 FGD participants. PAR participants included representation of PWD (vision, hearing, limb, and mental impairments), pregnant and lactating women, parents, and traditional birth attendants. KII and FGD participants included Local Authority representatives and Municipal Health Service (MHS), CHC, and HP personnel.

Recruitment was conducted through contact with MHS directors in each study area via a formal letter from the GoTL Ministry of Health. A follow-up call was made to discuss criteria for participant recruitment.

For the PAR recruitment, the MHS directors coordinated with administrators, who in turn coordinated with the chiefs of villages, CHCs, and HPs. As soon as the team arrived in the municipalities, two members of the team engaged with chiefs of village and heads of CHCs and HPs to recruit the PAR participants, following the criteria established in the protocol. Potential participants received phone calls to establish that they met criteria for participation and to make them aware of research processes planned. All participants were easy to reach, except some PWD. Recruitment of PWD was done through community leaders or through focal points of disability organizations at the municipalities.

For the FGD recruitment, relevant staff for inclusive RMNCAHN were contacted at the selected CHCs in the six municipalities. FGD participants were recruited by the head of the CHC based on the research criteria. For the KII recruitment, community leaders were recruited by the chiefs of villages, MHS participants were recruited by MHS directors, and HP participants were recruited by heads of CHCs.

The six thematically organized PAR workshops addressed the following themes: (1) maternal health; (2) nutrition; (3) adolescent health; (4) newborn and child health; (5) PWD; and (6) reproductive health. Table 2 provides an overview of the PAR participants.

Table 2: PAR study sites, themes, and participants

Study Site	RMNCAHN and a focus on…	Age range	Men	Women	Total
RAEOA – Ahani Passabe	Maternal health	**18-63**	**7**	**13**	**20**
Ermera – Letefoho Hauou	Nutrition	**18-55**	**6**	**20**	**26**
Baucau – Triloka	Adolescent health	**19-32**	**8**	**8**	**16**
Covalima – Maudemo	Newborn and child health	**18-51**	**5**	**13**	**18**
Dili – Gricenfor	Disability	**18-60**	**9**	**6**	**15**
Manufahi – Uma Berloic	Reproductive health	**25-64**	**5**	**10**	**15**
Total			**40**	**70**	**110**

KIIs followed the format of small group interviews. Participants comprised (1) local authority members, including village and hamlet chiefs, gender representatives (men, women), youth representatives, administrators, and other delegates; (2) municipal and district health authorities, including coordinators of family health, maternal and infant health, inclusive health, HIV and STIs, nutrition, and health promotion, among others; (3) HP personnel, including doctors, nurses, midwives, and pharmacists, among others. Table 3 provides an overview of the KII participants.

Table 3: KII study sites, themes, and participants

Study Site	Participants representing…	Men	Women	TOTAL
RAEOA	Local authority, Pasabe	4	0	4
	Regional health	3	2	5
	HP, Haemnano	1	2	3
Ermera	Local authority, Haupu	5	2	7
	Municipal/district health, Gleno	2	4	6
	HP	0	2	2
Baucau	Local authority, Triloka	2	1	3
	Municipa/district health, Ria Mare	2	3	5
	HP, Triloka Osoala	1	4	5
Covalima	Local authority, Beco	4	1	5
	Municipal/district health, Debos, Suai Villa	4	2	6
	HP, Beco	1	3	4
Dili	Local authority, Bidau Santa Ana	3	1	4
	Municipal/district health, Formosa	1	4	5
	HP, Hera	0	4	4
Manufahi	Local authority, Tai-tudac	4	2	6
	Municipal/district health	2	2	4
	HP, Feric-Sare, Alas	1	2	3
Total		40	41	81

FGD participants comprised CHC personnel including doctors, nurses, nutritionists, midwives, and health promoters, among others. Table 4 provides an overview of the FGD participants.

Table 4: FGD study communities and participants

Study Site	Participants representing	Male	Female	Total
RAEOA	CHC, Passabe Abani	6	2	8
Ermera	CHC, Railaco	3	2	5
Baucau	CHC, Laga	2	3	5
Covalima	CHC, Fatumea	4	1	5
Dili	CHC, Bidau Santa Ana	3	1	4
Manufahi	CHC Alas	3	3	6
Total		21	12	33

DISCUSSION GUIDES

Thematic question guides were developed for the PAR components, and separate question guides were developed for the KIIs and FGDs.

Referencing the demographic and RMNCAHN–related characteristics of participants, PAR sessions explored: (1) perspectives on change, including factors contributing to change over the past five to ten years; (2) understanding of health, reproductive health, and nutrition; (3) perspectives on changes specific to RMNCAHN over time and factors contributing to these changes; (4) desired changes related to RMNCAHN; and (5) perspectives on sources of information. In addition, participants in respective sites focused on an additional theme—either maternal health, nutrition, adolescent health, newborn and child health, disability, or reproductive health. Discussions were open-ended and allowed for critical dialogue and co-learning between participants and researchers.

Referencing the role of participants, KIIs and FGDs explored similar themes to those explored in the PAR.

DATA COLLECTION AND ANALYSIS

To prepare the team for fieldwork, a pilot PAR study was conducted in Dili during April 2022. The pilot study process allowed for adjustments to be made in approaches to community entry, time keeping, participant recruitment, dress code of the research team, research techniques, and minor revisions to the workshop guide.

Data collection for the study was conducted over a three-week period during April and May 2022 by two teams comprising researchers, facilitators, translators, and note-takers. The teams worked in two municipalities in parallel. All sessions were conducted in Tetum.

PAR sessions were conducted at central venues in villages, mostly in open-air roofed structures. Participants were seated in a large circle for discussions led by facilitators. Moveable seating was redistributed to allow for small group discussions led by participants themselves. Findings from the latter discussions were then shared with all participants in a large group setting. Activities were interspersed with ice breakers, energizers, and refreshment breaks.

KIIs were led by an interviewer with three to seven participants in a venue convenient to participants. Opportunities were provided for people to speak according to their roles as health service providers, community leaders, or stakeholders.

FGDs were led by a facilitator at the CHCs and included four to eight participants. Opportunities were provided for people to speak according to their roles as health service providers, community leaders, or stakeholders.

The research teams were supported by the research leads. Regular debriefing sessions were held to reflect on findings and to strengthen the data collection process.

All data was recorded using digital recorders. Recordings were transferred at a central point and were translated from Tetum to English by members of the research team in Timor-Leste and transcribed by members of the research team in Timor-Leste and in the United States.

Transcriptions were reviewed to identify themes for coding, which was then implemented using HyperResearch qualitative software. This enabled analysis across themes and geographies.

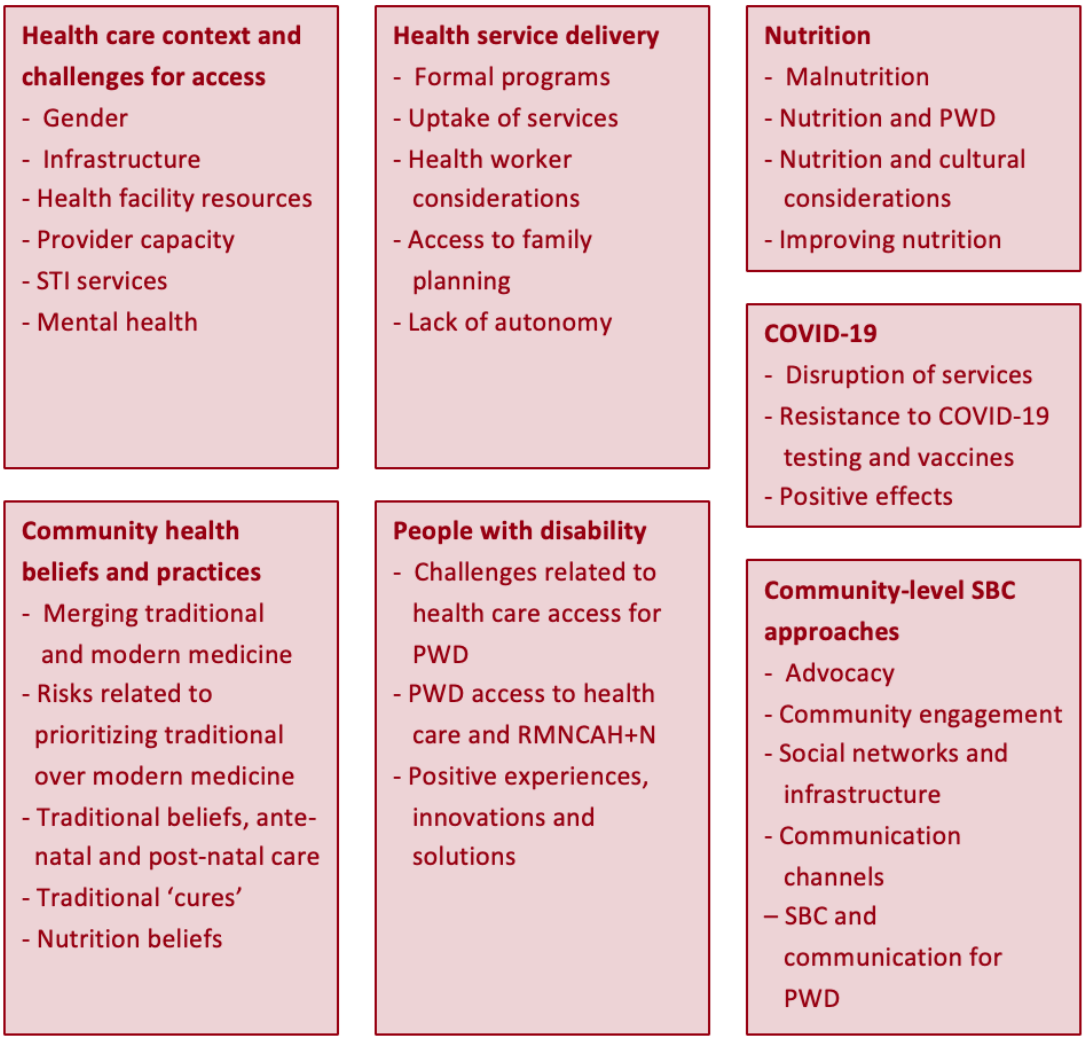
LIMITATIONS

While the concerns of several vulnerable groups were explored, it was not possible to explore all exhaustively. As a result some groups were not included in this study, such as people who are LGBT.

3. FINDINGS

The findings of this study are presented across eight main themes: (1) health care context and challenges for access; (2) community health beliefs and practices; (3) health service delivery; (4) people with disability; (5) nutrition; (6) COVID-19; and (7) community-level SBC approaches. Figure 1 illustrates the subthemes addressed under each thematic heading.

Figure 1: Study themes and sub-themes



THE HEALTH CARE CONTEXT AND CHALLENGES FOR ACCESS

The living and economic circumstances of people in Timor-Leste have improved over time. Infrastructure such as roads, schools, and health facilities have been built; electrification has expanded; public transport has improved; there is better access to water and sanitation (including household tap water and latrines); more people have transitioned to living in semi-permanent and modern houses; and veterans and others are receiving pensions and subsidies.

Health care continues to improve. In relation to RMNCAHN, mothers, infants, and children are benefitting from improved access to health facilities due to new facilities being built. Women are accessing family planning, and birth spacing has improved.

Maternal and infant mortality remain a pressing challenge and recent cases were mentioned across all study sites.

Infants are routinely breastfed, including with colostrum[1] immediately after birth. Child mortality and malnutrition has declined among children. Malnourished children can access treatment and food supplements. Immunization of children has improved, and infants and children are being routinely vaccinated and weighed at health facilities. Women and men are better nourished.

Community members (including children) are accessing treatment for diseases such as dengue, sanitation has reduced the occurrence of diarrhea, and concerns such as early marriage are on the decline. Positive changes in communities are said to be well-evident, including in relation to environmental health.

Wider availability of mobile phones has simplified access to resources, and this is a particular benefit for young people. Smoking is on the decline for some groups, although it a remains common among youth and men, despite awareness raising regarding harmful effects.

There is a sense of pride in the commitment to progress by the government including, for example, pride in the government having signed the convention to protect children.

GENDER

Changes in gender relations are appreciated—notably that there is equal access to schooling and that women are taking leadership roles including as public servants and in politics. However, women's roles in the family continue to be focused on household chores, cooking, washing, and childcare, with little involvement by men. This contributes to stress and conflict.

Intimate and gender-based violence continue to occur, mostly linked to household tensions and inequalities or alcohol use. Pursuing criminal prosecution in response to GBV is challenging, given that if men are jailed, families lose a breadwinner. Instead, resolution is sought through the intervention of family members.

Women's organizations are providing support and protection for women who are pregnant outside of marriage or are divorced.

Men are included as a focus for health promotion activities and health care access and are more inclined to seek treatment when they are ill.

INFRASTRUCTURE

[1] Colostrum is the first milk following birth that is very important for protecting newborns from infections. It is rich in immunoglobin G, which has an important role in disease resistance.

Improvements in infrastructure such as roads, electricity, water, sanitation, and expansion of health facilities have increased opportunities for health care access in Timor-Leste. However, infrastructural challenges continue to limit access to health care in the country. Road conditions are not good in many areas, and there were numerous reports of situations where ambulances could not reach women who were close to giving birth or experiencing complications. Sometimes pregnant women need to be transported to health facilities by motorbike to deliver their babies.

When the weather is bad, or distance to health facilities is considerable, women have no option but to deliver their babies at home. In Manufahi, Local Authority participants reported that a need remained for the construction of additional HPs. Across municipalities, participants recalled numerous mother and infant deaths due to challenges related to inadequate planning for delivery and transport.

HEALTH FACILITY RESOURCES

Distance from health facilities remains a challenge for people living in remote rural communities. When community members lack funds for public transport, or public transport is not available, or roads are impassable for vehicles during the rainy season, they may end up walking two to three hours to reach the nearest health facility. Health workers also are unable to conduct outreach visits and also are unable to reach communities to deliver emergency care due to bad roads and lack of transportation.

Although more ambulances are available for attending to emergency cases, there are still insufficient numbers of ambulances (and drivers). *In Baucau, chiefs and local leaders are assisting in providing support in emergency situations, calling for health assistants and assisting with transportation of patients by offering their personal motorcycles.*

Health workers sometimes resort to attending emergency cases by travelling on motorcycles themselves, although this is described as "scary." It is also difficult to attend to emergency cases when they occur "in the middle of the night."

There were numerous reports of broken or damaged equipment at health facilities or inadequate equipment. There are also challenges related to staff not knowing how to use certain equipment due to lack of training. Some facilities don't have an adequate supply of clean water.

Lack of space or maternity beds for deliveries was a concern, even though midwives are available. Deliveries are more challenging due to a lack of delivery kits; in some settings, women were referred from HPs to the MHS to ensure that they receive care.

Stock-outs of medicines, contraceptives, and nutritional supplements are an ongoing problem, and this contributes to people reverting to traditional medicines:

> *When we have the sexually transmitted disease, we go the health post, but the medicine is stock out, so we just come back home to use traditional medicine.* (PAR participant, Baucau)

When there are stock-outs of supplements such as iron or folic acid, pregnant women are advised to eat vegetables to obtain at least some supplements.

In RAEOA, it was reported there were shortages of medicines to support maternal emergencies, and there have not been responses to requests made to the sub-regional pharmacy. Patients are referred to the regional hospital, then query why the referral was made. A WhatsApp group has been established to discuss stock-outs, but concerns remain unresolved.

PROVIDER CAPACITY

Although availability of skilled human resources have improved quality of health service provision to certain extent, allocations are insufficient in some areas—for example, in Covalima there was one doctor covering six hamlets. In some communities, health workers are not consistently available at health facilities, and emergency cases can't be attended to.

Challenges related to access cause frustrations for health care workers and communities alike. For example, according to Local Authority participants in RAEOA, when pregnant women do not attend antenatal care appointments on time or on the correct day, it is said that they are reprimanded by health workers.

In Manufahi, it was mentioned that health workers were not available at a HP for a number of days, and this posed challenges for addressing health concerns. While there have been improvements over time, persistent underlying factors include staff living some distance from the facilities.

> *When we go to see the doctors at the hospital, sometimes they are not there. Probably they went to other places to treat other patients or do other programs, and we could not meet with them. But if we compare it to the past, the situation now is a bit better because we have our own hospital in the suku.* (PAR participant, Ermera)

> *They have the residence here. The government has built a residence for them. But sometimes they do not live here. They do not stay with us here, and it is difficult when we need them in an emergency situation and they are not there.* (PAR participant, RAEOA)

Although accommodation is provided for health facility staff, there appears to be dissatisfaction with available facilities, as well as a preference for living in nearby towns rather than in rural communities. Participants from local authorities were concerned that it remained challenging to motivate health workers to reside in the communities that they serve. Where this is not occurring, communities end up being underserved on weekends and also face more severe health risks in emergency situations that occur after hours.

Health workers in Manufahi noted that they were not receiving adequate training. Consequently, they lack the capacity to make some diagnoses. In Covalima, a health worker said she was trained only to administer contraceptive injections and therefore has to refer women who would like a contraceptive implant to a trained midwife or doctor.

STI SERVICES

Testing for STIs is conducted when pregnant women attend antenatal care visits. If STIs are found, health workers "convince the husband to come with his wife." Some health workers report that

they have not been adequately trained to diagnose STIs [diagnosis can also be syndromic, not requiring physical exam]. There are also challenges with confidentiality when STIs are diagnosed. Patients are said to be uncomfortable with the counselling they are given and do not always accept the advice given. When STI referrals are made, there is some resistance from patients; there is also a lack of feedback following referral visits:

> *We transfer them to the National Hospital, but some of them really disagree because they don't have money. And even with transfer to the National Hospital, they never give any feedback regarding treatment they got at National Hospital.* (FGD participant, CHC, Dili)

In Baucau, MHS participants were keen to advocate for condom use for STI prevention, including gaining acceptance through government programs and the Church. However, there are tensions regarding reproductive health education, and condoms are not sufficiently accepted in some settings.

> *The government established programs to prevent the transmission of sexual infections. We need to use the condom. We need to do the promotion in education, starting in junior high school and senior high school. But community use of condoms has not been authorized. The best solution is a condom to prevent STIs. We need to work together and try to convince the leaders of the Church to accept all the programs as the way to guarantee that people are free from HIV or sexual transmitted infections. Authorization to use the condom is the only way.* (KII participant, MHS, Baucau)

There were numerous references to young people being shy to attend health facilities to discuss reproductive health concerns or seek treatment for STIs. Consequently, they reach out to traditional healers:

> *There is no medicine to cure those diseases, that's why the traditional medicine is still the important medicine to cure those diseases.* (PAR participant, Baucau)

Traditional and modern medicine is also followed:

> *Sometimes the youth come to the health facility to do a consultation, then they recover from their illness. But sometimes they go to the traditional doctor first if they feel like they got sick because of witchcraft. So they check up first at the traditional doctor before going to do a checkup in the health facility.* (PAR participant, Manufahi)

MENTAL HEALTH

There appear to be some signs of psychological stress in communities, and there were reports of suicides across a number of settings:

> *What mostly happens here is people committing suicide by hanging themselves on trees. Sometimes it happens to young men and women, and sometimes it happens to older couples/people. The reason behind this, actually we do not really know. Maybe because they were stressed, because of family problems or parents. It has been happening since 2012 until now.* (PAR participant, Ermera)

COMMUNITY HEALTH BELIEFS AND PRACTICES

Although traditional practices remain common, considerations related to pregnancy and the treatment of certain illnesses are now more aligned with modern medicine. Improvements include:

- Feeding newborns with colostrum milk, whereas previously this was extracted by the mother and not given to the babies.
- Keeping post-partum mothers close to a burning fire after labor is less common, but still continues.
- Girls and women are now washing their hair during menstruation and using sanitary pads.
- Babies are being taken to health facilities when they are ill, whereas previously traditional medicines were given.
- STIs are now more likely to be treated with modern medicines, and this has contributed to reducing STI-related infertility.

Previously, marriages were arranged, but this practice is changing to some extent, with young people being free to decide whom they wish to marry without intervention from family members. This change is attributed to "now being in the globalization era." Early marriages that do occur generally involve young people aged 17 or 18, with marriages at younger ages being less common.

The negative impacts of early marriage were noted by a CHC participant in RAEOA, and some parents still seek out early marriages:

> *A girl that may be 13 or 14 and gives birth to a child…a child is giving birth to another child. This will bring economic burdens or mental health burdens to the marriage. The parents and the community know that this practice is wrong, and yet they still want to practice this.*

Young people tend to adopt modern values and ways of thinking due to their exposure to the internet and social media. Completing one's education serves as a motivator for girls to avoid teenage pregnancy and focus on a successful future.

MERGING TRADITIONAL AND MODERN MEDICINE

People across all study communities are integrating traditional and modern medicine. For example:

> *We have trust in God, culture, and health facilities. (Female PAR participant, Manufahi)*
>
> *Sometimes, before they bring the sick people to the center, they do a ritual. We advise them in emergency cases, to bring the patient here first and then to do the ritual at home.* (FGD participant, CHC, Covalima)
>
> *When we go to the field, we always remind them that we are not challenging them to ignore or eliminate the culture of their community. But when they have problems with their health, they should go to the facility to get attended to and receive treatment…. The culture can continue by those who are*

not affected, and those who are suffering from illness can go to get treatment at the facility. (FGD participant, CHC, Baucau)

*After vaccination of an infant, traditional medicine is also used. They put leaves from a tree on the leg of a child. (*FGD participant, CHC, Dili)

For those mothers who still do the cultural practice, of staying inside the house for four days and four nights, when I visit them, I ask permission to go inside the house and vaccinate the babies. They give me permission. (FGD participant, CHC, RAEOA)

For those who do not have children, get treatment at hospital, and do cultural practices. For example, they honor the ancestors so that they can have children again. (PAR participant, RAEOA)

In Manufahi, the *Liga Inan* (Connecting Mothers) program included teaching traditional healers to "respect medical protocols" to allow them to attend cases together with health professionals. In some communities, it was mentioned that young people who were now better educated through schooling were encouraging elders to seek care through modern medicine:

The youth start to convince the elderly that when they get sick, they should visit the health center or post. (KII participant, Local Authority, Covalima)

RISKS RELATED TO PRIORITIZING TRADITIONAL OVER MODERN MEDICINE

Prioritization of traditional practices may contribute to considerable harm. This includes emergency cases that unfold among pregnant women who are close to delivery. For example, family members or husbands may prevent women from attending health facilities and also may insist on risky home deliveries despite previous counselling by health workers. Such circumstances may lead to severe negative health outcomes.

Sometimes the pregnant women come along here. We do a lot of advice and counselling for her. But when she goes back to the family, she also listens to her family. Sometimes, the family-in-law impedes the woman's access to the health center. They say: 'If you want to go, you must go alone. I will not accompany you.' And the woman will feel afraid and has no choice. She has to comply, and therefore she decides to deliver the baby at home…. There are numerous reports of women who have heavy bleeding or hemorrhage during birth, and this quickly becomes a life-threatening emergency. It is only then that the health facility is contacted. (FGD participants, CHC, Manufahi)

Traditional rituals during delivery may also result in delays, and even death:

The in-law family insisted that she wait for the husband and should follow some traditional rituals, and in the end, then she died on the way to the hospital. (KII participant, MHS, Ermera)

While traditional midwives play an important role in home deliveries, there are reports of situations where their skills and support are inadequate. These include situations where life-threatening complications occur. For example, in Manufahi, a CHC participant observed: *"Traditional birth attendants may attend a birth, but when complications arise, they run away."* Also, in Manufahi, it was mentioned that a traditional birth attendant protected her financial interests by discouraging pregnant women from going to health facilities for delivery.

Traditional birth attendants are said to not give post-delivery care, but rather to focus only on the delivery process and the infant; "cut the umbilical cord and then leave." As a result, health workers have to attend to post-delivery assessments, counselling, and care.

> *When there is a complication during birth, they do not know what to do. They always call us in that situation to come and help. But what I saw with my own eyes is that in the process of giving birth, the traditional midwives do not help the mother to give birth. They just care about the baby but not about the mother.* (FGD participant, CHC, RAEOA)

There were many reports of bleeding occurring during births attended by traditional birth attendants, who are described as "not doing anything to help" or "not knowing what to do," and deaths occurring as a result. Also, sometimes the placenta does not come out completely, or the umbilical cord is not tied off; bleeding and infection occurs and also vaginal swelling.

Women who are close to giving birth may defer to the advice of their relatives when it comes to deciding whether to deliver at a health facility. Such situations pose risks for the mother and baby:

> *The difficulty is lateness in making the decision. We are observing the fears before they are going to make a decision. They need to wait for their aunt, their father, grandmother, or father-in-law, mother-in-law, to be present and from that occasion they can decide. Sometimes it will create risk for themselves, a problem or difficulty. This always happens in the community.* (KII participant, MHS, Baucau)

This concern is described as the most difficult task *"that we all must face together. It is not only the responsibility of the health workers here"* (FGD participant, CHC, RAEOA).

Traditional medicines are sought in the case of diseases that cannot be cured by modern medicine or when treatments are not effective:

> *It doesn't mean that I do not trust or believe in the health workers. But after going to the health center, my baby's condition was still the same. I had to find an alternative, which was going to the traditional healer to find traditional medicine…. When she applied the traditional medicine to the baby's skin, the baby got healthy again.* (KII participant, Local Authority, Manufahi)

Some people are said to be cynical about the potential for effective treatment through modern medicine, and in combination with distance from health facilities, may be reluctant to seek treatment.

> *For those communities in the rural areas, some people do not come to a health facility for consultation because they feel that they have serious illnesses that cannot be cured. Another reason is the distance between the health facility and their houses, so when they get attacked by diseases, they surrender to the situation and condition.* (FGD participant, CHC, Manufahi)

TRADITIONAL BELIEFS, ANTENATAL AND POSTNATAL CARE

There are some traditional practices that may cause harm during the antenatal period. For example, massaging of the belly during pregnancy.

> *They do a lot of massage around the tummy. And sometimes we have to give some advice to the mother. 'Please don't do a lot of massage. Don't do the positioning of the baby. During the pregnancy it can affect the baby.' We can see that around 50% of the mothers believe in traditional healing and do a lot of massage around the tummy.* (KII participant, HP, Covalima)

The smoke, or *sei,* tradition is practiced in some settings. This involves mother and baby being required by family members to sit or lie above smoking embers for a period of four to eight days, but extending up to 40 days in some communities.[lvi] This practice is viewed as an important traditional practice, but also can incorporate modern medicine.

> *Before modern medication came here, our ancestors do this so that the babies and the mothers can get the warmth from the red-hot coals. Nowadays, we do not put the red hot coals too much because it can damage them, so we only put little pieces of the red hot coals to keep the body warm. Because we are living in a modern society, after some rituals, they send the mother and the child to get the treatment in the hospital, including after getting pregnant and after delivery.* (KII participant, Local Authority, RAEOA)

From the point of view of health workers, the smoke tradition contributes to respiratory problems for mothers and infants and is discouraged by health workers.

> *As health workers, we tell them that they don't need to do this practice again…. But they do not listen to us. It sometimes causes the baby to have fever, or rash on the skin, or other diseases.… Also, the mother sometimes feels dizzy.* (FGD participant, CHC, RAEOA)

A few beliefs related to attire or washing practices for women were mentioned by participants. For example, jewelry should not be worn by pregnant women, because it is believed that it may cause the umbilical cord to strangle the baby. Hair should not be washed by women for a month after birth as it may cause vaginal discharge. The mother also is not allowed to touch cold water.

There are also beliefs related to the placenta—for example, burying it in the ground. Previously, the umbilical cord was hung in a tree, but this was said to cause a child to be distracted and unhappy.

TRADITIONAL "CURES"

There are perceptions that some diseases are curable only through traditional medicine—for example, "uliras disease," which is an allergic reaction to food. Some rules that are dictated by one's ancestors cannot be changed:

> *One of the challenges to achieve good nutrition is that we cannot change the practices that have been inherited by the family.* (PAR participant, RAEOA)

People are also shy to seek treatment for STIs, and therefore defer to traditional medicine such as *"cooking tree bark to drink, covering the vagina with ground leaves and washing with warm water"* (female PAR participant, Manufahi). Syphilis in men is associated with drinking *tua mutin* (traditional white wine), infrequent urination, eating chili, and also non-monogamous ("free") sex. Vaginal discharge is attributed to eating pumpkins.

There is also the belief that HIV can be cured through traditional medicine:

> *I saw here in this community that the person who knows traditional medicine has cured some HIV patients. They get well and are cured after been treated using traditional medicine."* (PAR participant, Baucau)

NUTRITION BELIEFS

Traditional beliefs include prohibiting certain foods following birth. For example, new mothers are not allowed to eat rice until their babies are able to walk and may not hold anything *"based on their culture."* It is said that if this requirement, which is set by the ancestors, is not adhered to, the mother and baby will get sick. In Dili, it was mentioned that eating mung beans leads to difficulties during delivery.

Nutrition beliefs are deeply rooted and may contradict recommendations by health workers; for example, consumption of foods such as cassava, papaya leaves, eggs, or fish that are culturally prohibited.

> *We cannot eat, we are not allowed to eat, those things. If we break the law, the rules, and we eat those foods, some terrible things might happen to our family members or to ourselves. For example, some bad things could happen to our husbands who work far away and also pregnant mothers. When we deliver the baby, the baby might be blind or the baby might live with a disability, if we do not follow the rules.* (PAR participant, RAEOA)

HEALTH SERVICE DELIVERY

FORMAL PROGRAMS

There is much appreciation for a number of changes in health service delivery, including the increasing number of HPs, which overcome challenges of distance. The SISCa program, which was widely implemented prior to COVID-19, is much appreciated. As female participants in Baucau observe:

> *We always go to the Health Post which is closer to us to get a treatment. We have also participated in SISCa program. Before the health facility was not closer to us, but now it is within the community, and it is easy for us to get access.*
>
> *Before it was difficult for us to get a treatment and also consult about our health in the facility because it was at a distance. On the other hand, some pregnant women are delivering their baby in their own house and never attending the antenatal care until they deliver. Now everything is easier because the health facility is closer.*

The creation of the *Saúde na Família* (SnF) program is valued for bringing health services closer to the community, as well as increasing awareness and improving service uptake. The SnF includes household visits and improved information on the number of households lacking latrines, clean water, and other hygiene-related facilities, as is observed in RAEOA.

The Mobile Health program—*Liga Inan* (Connecting Mothers)—has allowed women to obtain information, support, and links to care through mobile phones, including during COVID-19. This involves sending and receiving text messages with health workers who can provide advice on the timing of attending a health facility for delivery. In Dili, an non-governmental organization (NGO) called *Hamutuk Nasaun Saudavel* (Together a Healthy Country), which was previously the Health

Alliance International and Catalpa International, provides mobile phones and airtime vouchers for health workers to keep in contact with pregnant women.

UPTAKE OF SERVICES

Vaccination uptake for infants and children has improved. Early infant vaccination is routinized when births occur at health facilities; it also is prioritized when deliveries occur at home:

> *Some families in rural and remote areas deliver the baby at home. If they deliver the baby in the morning, in the afternoon they bring the baby for immunizations. We give them advice to return after four weeks, and six months.…They really are committed to the dates we advise.* (FGD participant, CHC, Covalima)

Sometimes vaccinations are overlooked due to irregular attendance at health facilities, and vaccine stock-outs also occur from time to time. It is noted that measles cases have decreased, and there is an increase in attention given to record keeping, ensuring completion of all recommended vaccinations.

There is improved use of family planning methods—especially long-acting reversible contraceptives:

> *Access to family planning has helped women. They no longer have skinny bodies due to malnutrition.* (PAR participant, Manufahi)

Women are aware of the need for antenatal visits when they are pregnant and appreciate antenatal care when they receive it. When pregnant women are more consistently accessing antenatal care, their babies are more likely to be delivered at health facilities. This improves health outcomes for both mother and child. While health workers encourage delivery at health facilities, they also attend home deliveries.

Late initiation of antenatal care occurs among less-literate women, who are said to wait until the movement of the baby is felt or there are obvious external signs such as an enlarged belly. In some cases, antenatal care is delayed until the last trimester. Antenatal care includes planning for the delivery, although this does not always obviate unplanned deliveries:

> *They suddenly appear at the health facility when they are expecting to deliver the babies. So, it is a bit difficult for us.* (FGD participant, CHC, Comoro-Dili)

Fathers are encouraged to accompany their wives when accessing health care, and this is occurring in some settings:

> *Most of the fathers take their wives and their children to get the medication or treatment in the Health Post here. For example, in the neighboring area and their sub village, they take their wives and babies to come to the Health Post to get treatment.* (KII participant, Local Authority, Manufahi)

> *As we know, when delivering a new baby, they need to go to the Health Center. At the Health Center they can prevent mortality of the women and babies. Most of the pregnant women delivering a baby have good access to the Health Center. I think this is a good change.* (PAR participant, Dili)

Births are safer due to the increased availability of trained health providers (doctors, midwives, and nurses in some cases), safe and clean delivery and essential newborn care, and availability of

medical equipment. When there are worries about cutting the umbilical cord or when the placenta does not come out, women are seeking advice and care at health facilities.

Infants are more likely to be exclusively breastfed during the first six months, and nutrition for children has improved. Treatment for children, pregnant women, and adults who are underweight is also more advanced. *Bolsa de Mae*—a social protection program that provides for food subsidy for poor families—is much appreciated. Nutrition and other assistance are also provided through NGOs.

HEALTH WORKER CONSIDERATIONS

Health workers are committed to giving good service, despite challenges related to health facility functionality.

> *We need to give a good attendance because we are serving our communities.… All of the health workers who are working here are originally from this place. So we need to do our best for the community.* (FGD participant, CHC, Baucau)

> *Even though we have ambulances, there is a high coverage area; for example, when one ambulance covers 15 villages… If one case is happening in one village and suddenly there is another call, it will not be covered because of the distances between villages.* (KII participant, MHS, Baucau)

Nurses, midwives, and doctors are community-based in some settings, and the number of nurses and midwives has increased. Consequently, the capacity to attend to emergency cases is improved.

> *Here in this suku, if there are any emergency cases, they can phone the health workers to come, and they always come, even if it is in the middle of the night.* (PAR Participant, Ermera)

In Manufahi, an audit and process of registering households reached 100% and has helped to understand the number of people living in each household, their living conditions, and health status. Participatory diagnosis has also allowed for feedback to local authorities on the status of health in communities, and specific themes such as tuberculosis can be covered.

Also in Manufahi, MHS participants mentioned learning classes that are provided for pregnant women by midwives and health workers to help women understand when to access urgent care.

> *I do the consultation with the maternal patients. I can say that every year we can see changes. With good health promotion, we can see the knowledge of health…. We have learning classes from the midwives and professional health staff so they can learn from each other. The mothers learn to identify symptoms and danger signs, so they can come to the consultation early.* (KII participant, MHS, Manufahi)

Specific training also has been provided to health workers on STIs and HIV, antenatal testing was instituted, and linkages were established with national HIV structures.

These changes in health service delivery have contributed to reduced illness and mortality, including maternal mortality, and improvements in the health of infants and children.

ACCESS TO FAMILY PLANNING

Women are routinely accessing modern family planning methods at health facilities, although there is still a need to provide women options of all methods, including options for men, so they can make an informed choice. A full range of contraceptive methods are available, and more recently over the past few years there has been an increased use of implants across the country.

Information on family planning is received from health centers and NGOs such as Marie Stopes. For those who are aware of family planning, benefits include birth spacing and being in a position to prepare for one's future. Some couples seek contraception to avoid disruption of their plans to study or to seek work, or to ensure that a child is not born when the parents are jobless.

There were concerns that some contraceptive methods caused hemorrhoids, bloating, bleeding, or constipation. There were also some myths related to contraception including notions that using contraception led to infertility and that intrauterine devices (IUDs) could travel inside the body.

The importance of birth spacing is appreciated, and couples are more aware of the economic and other benefits of family planning, including reducing the number of children that they have.

> *Through the family planning program, couples reduce the number of children they want to have. For couples in modern days, they have babies at long intervals. But in the past, there was no such space for deciding to have babies because they did not know information regarding reproductive health.* (KII participant, Local Authority, Manufahi)

Adolescents still do not have unrestricted access to family planning services at many health facilities. It is perceived that health workers are concerned that providing contraceptives to adolescents will encourage non-monogamous "free" sex. Lack of access to contraception for adolescents leads to unplanned pregnancies:

> *There is an impact on parents. They work hard to send their children to school but then their children get pregnant earlier, leave their school, and all of their hard work is for nothing.* (Male participant, Manufahi)

Some health workers are reluctant to engage single girls or women requesting contraception, and defer to religious and other arguments:

> *Our policy does not allow that. If the girl comes and is not accompanied with a husband, then we cannot attend to her.… Our religion and our culture will not allow this. Free sex will be practiced if we allow adolescents access to family planning.* (KII participant, MHS, Dili)

Most health workers require that adolescents have permission to access contraception, and there are fears of retribution if they do not have adequate permission:

> *If she asks us to authorize her to participate in family planning, the best solution is that I will call her parents to come to sit together and take a final decision. Because, even if it is her right, we need to confirm first with the family because we don't want it to put us at risk in the future.* (FGD participant, CHC, Baucau)

However, some health workers are concerned that teenage pregnancies are on the increase, and there are also new cases of HIV. And young people are reluctant to visit health facilities for sexual matters:

> Some adolescents are shy to come to health centers. They are afraid people may disclose their disease, and they will not come. Some are very young already pregnant. (KII participant, MHS, Dili).

Young women participating in the PAR discussions who had previously been pregnant noted that they had not received much information on infant care. They did, however, know that exclusive breastfeeding should be practiced for six months. There were reports of adolescent girls seeking abortions. Family support is lacking. For example, as observed by PAR participants in Dili:

> *Some families, when their daughter gets pregnant and their daughter wants to go to the health center, they have to go by themselves. Sometimes they get bad treatment from their family.*

Condoms are appreciated for providing dual protection benefits:

> *Using condoms not only prevents women from pregnancy, but also prevents women or men from diseases such as HIV or some STIs. We have to love ourselves and take care of ourselves.* (PAR participant, Dili)

In Covalima, HP participants mentioned that a few adolescents came to ask for condoms, but such requests are infrequent.

LACK OF AUTONOMY

While some women are free to make contraceptive decisions on their own, many require permission from their husbands.

Requiring permission to access family planning is detrimental for women who do not want children, and they experience anxiety as a result of their disempowerment.

> *There was one woman, she wanted to do family planning, but the husband didn't want to, and she got pregnant almost every year. Some mothers come here. They are very sad, they cry in front of us. They want to do family planning, but they cannot decide. Some women just do it in hiding. They don't want their husband to know, so they do the injections. But slowly the husband notices that the wife doesn't have menstruation.* (KII participant, MHS, Manufahi)

Such tensions contribute to domestic violence. There is a need for advocacy and support through local and higher authorities.

Another reason for family interference is having paid dowry and having expectations for grandchildren. Some families also seek to have a balance of sons and daughters, and some families believe *"the more children they have, the better. Having many children is a blessing to the family."* However, in RAEOA, Local Authority participants emphasized that people should know that having paid a dowry does not mean that a woman has been "bought" and is therefore owned.

> *Some couples want to access contraception, but their in-laws do not allow them. They are told to have many children, so that the children can be divided to the women's and men's side.* (PAR participant, Manufahi)

There were reports of husbands or family members insisting that health workers remove implants of women who had previously had these inserted. To avoid conflicts, health workers accede. As a CHC participant in Baucau highlights:

We decided as a team that if someone wants to participate in the family planning program, we advise them to be accompanied by their husbands. If the husband is not with them, such problems can happen again.

In some communities, religious pressures hold sway, and contraception is discouraged. Health workers note that as a result, people have many children, but also face challenges of joblessness and low income.

Their religion doesn't allow them to participate in family planning. And the problem is that people then always complain to us about how many children they have in their family. Especially because they are jobless and the income for the family is low. (FGD participant, CHC, Dili)

PEOPLE WITH DISABILITY

Disability was explored in the PAR discussions in Dili, and disability was also referenced across all sites, including through FGDs and KIIs.

While disability is a general category for people with various physical and intellectual impairments, each impairment or disability has different implications for PWD. Consequently, health services need to follow a varied and nuanced approach to providing assistance to PWD.

PWD are increasingly able to access government support and subsidies. It is well appreciated that the numbers of health facilities have increased, and this has reduced the distance necessary to reach facilities. It is recognized that the political efforts supporting inclusive health access for PWD are being taken into account, but it is felt that these have not fully reached the facility level.

CHALLENGES RELATED TO HEALTH CARE ACCESS FOR PWD

Stigma and discrimination towards PWD persist in communities, more often in rural communities, and this contributes to mental stress and isolation. There are reports of children with disability being kept at home, out of public view, and discriminatory terms being used that undermine the dignity of PWD.

Health services at most of the municipalities lack a common intervention framework to help people with special needs including PWD. For example, in Covalima, they do not have documentation systems or records that highlight PWD in the health system. Health resources for PWD are also not uniformly available. For example, a PWD in Manufahi with a hearing disability said he routinely consulted the health facility regarding his hearing but has not yet recovered. He also mentioned a friend who had similar hearing challenges, who had not received a hearing aid as promised.

Pregnant PWD face discrimination, including negative reactions from family members:

The community always think negatively about pregnant women with disabilities. Discrimination comes from their parents, their family; they discriminate. They don't agree that their disabled daughter could be pregnant, and the family wants to kill or destroy the baby." (Male PAR participant, Dili)

Some PWD cannot communicate well, and this affects their ability to access health care, including in emergency situations. As a PAR participant in Dili recounts:

> When my friend's wife was pregnant and she was experiencing difficulties, he called the ambulance. Because of the difficulty communicating, the ambulance didn't respond to him and hung up.

In another example, a health assistant was overheard speaking rudely to colleagues about a woman who was blind and who was pregnant, questioning her right to be a mother: "Oh people with blind eye. How can they also have baby or deliver a baby? How can they take care of your baby?" (Female PAR participant, Dili).

Discriminatory language is also used:

> T*he terms that they use to refer to disability people are not based on the existing terms for specific conditions of disabled people. They speak about people with disabilities without any dignity, such as blind, broken leg, and many others*. (PAR participant, Dili).

Other examples include being kept waiting and then being told to return the following day; being disrespectful and using bad language during delivery; and being told to buy information booklets for people with disability.

In Manufahi, a CHC participant mentioned the concerns of younger PWD: "The youth feel ashamed because they don't want to let health workers see their body."

There were concerns regarding dual stigma of disability and STIs including HIV, and participants emphasized their expectations for confidentiality by health workers:

> *As we know, if not kept secret, this kind of problem will affect us mentally. So, the better way that we can choose maybe is just to kill ourselves, because of the attitude of the community when they find out that we have HIV. I think Braille letters will be very important for us [on written materials] as we can then keep our secret."* (PAR participant, Dili)

PWD with STIs are reluctant to seek care, although a PAR participant in Dili shared a story about how she had gone to the health facility with her sister who was then able to serve as a go-between in seeking treatment. This helped to overcome shyness and worries about stigma.

Negative experiences disincentivize PWD from attending health facilities, although PAR participants also spoke of good and non-discriminatory care being provided in health facilities.

There remains an absence of resources to address the needs of PWD with specific impairments—for example, people who are visually impaired require materials in braille.

Women with intellectual impairments require support for family planning and may rely on others to ensure consistent utilization of medications. There are reports of women with intellectual impairments who fall pregnant due to inconsistent use of contraception, and also situations where the father is unknown. It may also be unclear as to how to manage the consent of the woman herself.

> *Mostly, families take decisions on reproductive health for disabled people, especially those with mental deficiency. When a woman with an intellectual disability unexpectedly gets pregnant, the family take the*

decision to bring her to the health center to access reproductive services, especially contraception. (PAR participant, Dili)

Women with intellectual impairments may also have certain fears, such as a fear of needles, that are difficult to overcome during situations such as deliveries.

PWD ACCESS TO HEALTH CARE AND RMNCAHN

PWD face higher levels of economic hardship, and so are more likely to be affected by lack of resources for transportation and other help. Special access and assistance are needed for PWD using public transport and where roads are poor.

At health facilities, challenges include limited access to water and sanitation, and these are harder to deal with for people with mobility and other impairments. Health facilities are not accessible for people with physical disabilities—for example, having stairs rather than ramps. To support PWD who cannot access health facilities, home visits are carried out by health assistants in some instances.

Apart from stock-outs of general medicines, shortages of drugs for patients with mental illness pose challenges for PWD and for the families who care for them. Families also seek alternate care arrangements, as a MHS participant in Dili observed:

> *The family wants to release the burden. They want us to take away their family member, they want us to take them away. Laclubar Hospital is a place for mental health people, but not all of them can stay there. Most of the families of people who are mentally ill want them to live there forever.* (KII participant, MHS, Dili)

POSITIVE EXPERIENCES, INNOVATIONS AND SOLUTIONS FOR PWD

PWD have a good understanding of health, including health responsibilities and autonomy:

> *I understand health is in our hands. If we take care and we protect ourselves, we take care of ourselves and stay healthy.* (PAR participant, Dili)

> *We always remind other people by sensitizing the community to understand the issues of PWD accessing the health center. We have our slogan which is "nothing about us without us."* (PAR participant, Dili)

RMNCAHN awareness includes understanding of the need for antenatal care, being knowledgeable about STIs, and being confident to ask questions at health facilities.

Health services at the municipal level identify PWD and provide support according to specific needs. This includes transfers to national hospitals for cases involving complex health issues and providing specific support in relation to RMNCAHN. PWD are reached through *SnF in communities, and then can be advised on how best to engage with health services.*

Women with disabilities who are pregnant are said to be supported by their husbands:

> *Yes, we have some pregnant mothers with disability here, and they are accompanied by their husbands to go to get the health services in the hospital. When the time comes to give birth, the husbands also take them to give birth in the hospital.* (FGD participant, CHC, Ermera)

There were various reports of positive and non-discriminatory experiences at health facilities including accessing contraception, removing *long-term methods such as implants or IUDs, and PWD receiving attentive guidance when being given medicines and dosages. These experiences are attributed to good training having been provided.*

> *The nurses delivered the medicine to me. They showed me the difference between medicines, and they showed me how to take it one time, three times, or two times per day. I have them show me how to identify the medicine that I should take in one day, two days, or three days. I think that was a very good attendance for me.* (PAR participant with visual impairment, Dili)

As a CHC member in Baucau emphasized: *"We always give treatment in an equal manner. Whenever people come, we always give equal treatment. We don't discriminate between all the patients."*

Emphasis on preventive health among health workers was appreciated, including in relation to reproductive health, STIs, cancers, and dengue—especially prioritization for children. Men have also been engaged through health assistants regarding the prevention of STIs, including HIV, and smoking.

In Ermera, the municipal health services have provided PWD with a booklet that can be shown during consultations, allowing for prioritized attendance. Medical statements and support are also provided to meet requirements and facilitate access for monthly support via the government scheme.

Some PWD rely on family members including husbands or wives to assist them in accessing health services, but help is also provided by health assistants and friends. PWD also access services independently, and motivational support is also received from others in communities. As a CHC participant in Manufahi observes:

> *We also have pregnant women with communication disabilities. She can't speak. She is married. Her condition during labor was normal. The treatment of people with disabilities by health workers is going well. Usually, their family brings PWD to do the consultation at the health facility when they get sick.*

The PAR discussions highlighted the importance of communicating normally with PWD, as they would with any other person: *"We're all normal people; the only difference is some people are disabled and some are not disabled."*

Priorities for SBC and RMNCAHN include improved physical access for health facilities; inclusive care and dignity for PWD; clear guidelines on non-stigmatizing language and non-discrimination in health care settings; improved care in rural health facilities; training of health workers to support PWD; improved communication for PWD; and written materials available in braille, including prescriptions.

It was recommended that families and caregivers of PWD receive information and training related to support, care, and dignity of PWD, including in relation to children with disabilities.

Community leaders should be involved in integrating PWD into community meetings, promoting support and dignity for PWD, and addressing concerns such as marriage, family planning, and childbearing, among others.

One participant, a village council member who identifies himself as LGBT said he was moved by the research activities and encouraged the inclusion of LGBT people in future studies:

> *I think as local leaders, we are ready to help to ensure PWD have access to health centers, ensure that there is no discrimination for the people—even protection and other things.… It is very important that the local leaders involve people in all of the activities or the events that happen in the community.* (PAR participant, Dili)

NUTRITION

Nutrition in Timor-Leste includes food production for subsistence and access to food from shops and other sources. Poor roads and rainy conditions limit the extent to which food can be transported to or from communities. Farmers are vulnerable to dry and windy conditions and other climatic factors that reduce agricultural outputs or destroy crops.

> *Most of us are farmers here, but we have a problem. For example, when we plant the corn or other food and the strong wind comes, we cannot do anything to stop it…it is the nature, and we cannot do anything to go against that.* (KII participant, Local Authority, RAEOA)

In some communities, locally produced crops are sold, and the proceeds spent on imported or processed foods instead:

> *We already advised that they should eat a lot of vegetables. Here they have beans such as mung beans. Yet, after the harvest, they bring all to the market and then they buy imported rice, imported cooking oil, instant noodles, and biscuits.* (KII participant, HP, Covalima)

Nutritionists based at health facilities address malnutrition and support nutritional health promotion. Partnerships with organizations such as the World Food Program also contribute to these objectives. Community awareness of malnutrition appears to be improving and supplementation is available through health facilities.

> *When some children or some babies are suffering of malnutrition, we give the supplement which is provided by the government and also remind them to give supplemental food. Apart from that, we remind them to give local food, full of nutrients to recuperate health as well as micronutrients.* (KII participant, MHS, Baucau)

Stock-outs of nutrition resources occur from time to time and this is frustrating for nutrition officers, especially when assistance cannot be provided to pregnant women, infants, and children.

> *We provide nutritional biscuits, and after a few months we can see an improvement in their condition. But now because we are out of stock, it looks like they have gone back to the bad nutrition condition as before.* (FGD participant, CHC, Covalima)

When women are concerned about the nutrition of their children, they may attend the health facility with their husbands. However, sometimes fathers are disengaged: *"The father only brings the mother and the child here. He sits outside and does not accompany the child into the doctor's room"* (FGD participant, CHC, Covalima). Living in remote areas affects nutrition of mothers and children, as they are not able to visit health facilities.

MALNUTRITION

Monitoring of nutrition on an outreach basis is challenging. For example, bulky equipment is not easily transported on motorcycles.

> *The equipment for the nutrition program is very complex and sometimes we need to weigh the pregnant woman, and we need to measure. And if you don't have the right equipment, you cannot do that.* (FGD participant, CHC, Covalima)

While breastfeeding awareness and practices are generally good, mothers or family members are sometimes impatient and introduce solid food prior to six months.

> *Sometimes the baby is two or three months old, and they give supplementary food. They think that when the baby is crying, the baby is hungry. So, after they breastfeed the baby, and the baby is till crying, they go and find some food supplement to give to the baby*. (FGD participant, CHC, RAEOA)

Feeding solid foods prior to six months may also occur due to mothers wanting to work.

Malnutrition of babies occurs irrespective of income level. Feeding infants solid foods in the first six months contributes to diarrhea and vomiting and leads to malnutrition. Sometimes children are malnourished because they are fed only plain porridge. Mothers may also be impatient with their children when they are eating, and their children eat less as a result.

NUTRITION AND PWD

Regarding nutrition, PWD, their children, and children with disability are more vulnerable to undernourishment. The main reasons are economic constraints and lack of support. Such challenges may be more prominent in rural areas:

> *In rural areas children may get discrimination from their parents and sometimes parents don't feed their children with disabilities properly. They may not have enough money to buy food for their disabled children. The most nutrition-vulnerable in the community are people with disabilities.* (PAR participant, Dili)

One PAR participant recounted the experience of her friend who has a child who is disabled. Following birth, she was unclear regarding feeding requirements and the child was fed solid foods early on. Other participants also shared examples of children with severe disabilities who were not fed well. It was also observed that in families where there are disabled and non-disabled children, those with disabilities end up receiving less food.

The subsidy provided by the government for PWD is $30 per month and not sufficient to buy healthy food. There are also complex administrative requirements to access such assistance.

Eating balanced or sufficient meals is said to be a challenge for PWD, simply because food is not consistently available. PWD with intellectual impairments also may be less able to ensure that they eat sufficient or balanced meals. As a result, PWD are more likely to experience hunger and malnourishment.

> *In the morning we eat one type of food. In the afternoon, we have a different type of food, and at night we eat a different type of food. It depends on the income, because those who have low income just eat*

the same type of food morning, afternoon, and night. I think the economic ability is very important to nutrition. (PAR participant, Dili).

NUTRITION AND CULTURAL CONSIDERATIONS

In some communities, it is customary not to eat certain foods, and health promotion advice is said to be overlooked:

> *Even though we gave them information during our promotion that peanuts, beans, and eggs are full of nutrition, the culture advises them not to consume it.* (FGD participant, CHC, Baucau)

When there is resistance to advice, health promoters do not force the issue, as they wish to maintain a trust relationship with community members.

While some foods are not consumed according to traditional beliefs—for example, fish, papaya leaves, cassava, moringa, chicken—it is possible to derive income from food production:

> *People who do not eat chicken meat can still raise chickens at home.* (PAR participant, RAEOA)

In some poor communities, allocation of resources is imbalanced. For example, money is spent on events such as funerals rather than on food; income during seasons when coffee beans can be sold allows for nutritious meals, but then people go back to their "normality" of eating potatoes; and local produce is sold, with the cash generated being used to buy imported or processed foods. Poverty and rising prices affect nutrition. Households consume what they have available but may also need to sell food for income:

> *They eat the local chicken and eggs, and also chicken meat. But it also depends on whether they have money. If they have money, they can have the chicken or the egg to eat in the household. If they don't have money, they have to sell the eggs of the chicken.* (KII participant, HP, Covalima)

IMPROVING NUTRITION

To support improved nutrition, CHC participants suggested (1) increasing the number of nutritionists at health facilities; (2) improving inter-government cooperation between the ministries of health, education, and agriculture; (3) increasing cooperation with NGOs; (4) reducing dependence and availability of imported and processed foods; and 5) expanding the promotion of nutrition in schools.

COVID-19

COVID-19 initially spread at a slow rate in Timor-Leste, with around 26 cases and no fatalities recorded by August 2020. A state of emergency was declared on 28 March 2020 and extended through to 27 May 2020. COVID-19 cases remained low through 2020 and into 2021, with the first wave developing in March 2021, reaching 5,811 cases and 41 deaths by August 2021. A vaccination campaign was launched in April 2021, and high uptake was achieved as the year progressed. By July 2022, there were around 23,000 cases and 133 deaths.[lvii]

DISRUPTION OF SERVICES

At the outset of the epidemic in the country, COVID-19 was perceived by communities to be political propaganda, but there was an increasing acceptance that the disease was serious—largely due to sensitization efforts. As a result, vaccination initiatives have been well accepted.

> *Our team in the CHC worked very hard to sensitize from hamlet to hamlet, and slowly the community became aware that the COVID-19 is real, and it is a global pandemic. At the moment we are focusing on vaccination of children in the schools. For the second dose we achieved more than 30%.* (FGD participant, CHC, Manufahi)

Deaths occurred across municipalities, mostly among older people and people with health conditions that increased the severity of COVID-19.

Health facilities continued to offer services during COVID-19 restrictions, although attendance was generally lower. Programs involving community outreach such as SISCa were discontinued. Coordination between health facilities and local authorities provided useful layers of support.

> *I think the coordination between the Health Post and the Local Authority is very good. Especially the campaign for COVID-19, where we relied on the mobilization from the village chief and the hamlet chief.* (KII participant, HP, Covalima)

There were some fears that health care workers had contracted COVID-19, and this discouraged health facility visits. There was also a drop-off in antenatal visit in some areas. In Covalima, a case was mentioned where a woman experiencing complications during labor was not allowed to go to the hospital due to her husband's concerns about COVID-19, and her baby subsequently died.

Health promotion in communities could not be delivered to scale during periods of COVID-19 restrictions, and this led to other diseases taking hold—for example, dengue was reported to have led to many deaths among children in Dili.

Cesta Básica (the food basket program) helped to support nutrition in some communities:

> *Because most of the women are unemployed, and caring for their households, Cesta Básica has really helped to support them economically, the family economy. In fact, most of the women were selling things in small markets, but during the pandemic with the rules of not interacting, they had to avoid COVID-19.* (PAR participant, Dili)

In Dili, it was suggested that food through this program was not fresh, or that it was inadequate. In Manufahi, it was felt that more emphasis should have been placed on preventing COVID-19 infections. In RAEOA, concern was voiced by Local Authority participants that food was not included in later periods.

RESISTANCE TO COVID-19 TESTING AND VACCINES

There was resistance to COVID-19 swab testing and vaccination in some communities. In RAEOA, health workers wore T-shirts that said "COVID-19," which contributed to community anxiety.

> *When we went to visit them, we wore the COVID-19 T-shirt, and they did not welcome us. They were afraid. They did not want to take the test, and also they did want to be vaccinated.* (FGD participant, CHC, RAEOA)

In Manufahi, there were suspicions that the COVID-19 vaccines were harmful, and it was claimed that people had died as a result, including pregnant women and babies. As a PAR participant in Manufahi suggested, vaccination should be voluntary: *This is the information that I want to share with you. Next time if the women during pregnancy don't want to accept the COVID-19 vaccination, then don't force them.*

In Baucau, health workers made communities aware that they themselves were being vaccinated, and this improved acceptance. There was also a growing interest among pregnant women and girls who were of child-bearing age and among people in RAEOA who wanted to travel.

POSITIVE EFFECTS OF COVID-19

A few positive effects of COVID-19 were noted. For example, handwashing has become more routinized; households received government subsidies, and food stamps were made available; wearing masks has become an established practice that now helps reduce the spread of other respiratory diseases; there is a greater appreciation for teamwork; and health workers received additional allowances to attend to COVID-19 cases, which has improved their personal financial circumstances.

COMMUNITY-LEVEL SBC APPROACHES

ADVOCACY

The promotion of breastfeeding has been successful, and communities are described as having "embraced" the information given. This is evidenced by women visiting health facilities when they experience problems with breastfeeding and need help to continue.

In Baucau, attendance at health facilities among pregnant women and women delivering babies has increased and this is attributed to advocacy:

> *By the promotion that we give to them, the community understands and considers the information whenever they have health problems. Some problems relating to pregnancy lead them to come to the health facility—specially for antenatal care because it will benefit their babies and their health.* (FGD participant, CHC, Baucau)

Cultural resistance remains in some topic areas. For example, speaking openly about sex and sexuality is challenging:

> *For them it is a taboo. This also makes it difficult for us to speak about sex openly. And when we talk about sex education, I think we face a lot of resistance.* (KII participant, HP, Covalima)

COMMUNITY ENGAGEMENT

Regarding the overall health response, and including SBC, PAR participants observed that the response to RMNCAHN should be "based on the reality of the community" and "bottom-up."

This includes deepening interaction and engagement between people in communities and health workers and incorporating active involvement of Local Authority structures:

> *If we want to have a healthy community, the Local Authority should be active and responsible.* (KII participant, MHS, Ermera)

To support this process, it is also necessary to engage village and hamlet chiefs.

Community engagement through health promotion is conducted by teams, which allows for multiple themes to be covered. However, it is noted that programs sometimes "get stuck in the middle" due to political and "higher-level" problems, which leads to interruptions. Nonetheless, successful outreach has contributed to increased uptake of health services.

PAR participants in Dili mentioned the importance of "willingness" of communities to change. This went hand in hand with interpersonal engagement with health assistants and sharing information through dialogue.

Engaging pregnant women prior to delivery, including through antenatal care and reminders, has improved preparedness for facility-based delivery. It is said that it is easier to convince younger women to deliver at the health facility. And younger women are also more likely to accept advice given following the birth. However, first antenatal visits are sometimes delayed because women don't realize that they are pregnant.

SOCIAL NETWORKS AND INFRASTRUCTURE

Although maternal mortality continues to be a pressing challenge, incidence is declining due to increasing numbers of deliveries being carried out at health facilities or hospitals. This is attributed to community engagement and health promotion activities, which include encouraging antenatal attendance. Training of health workers, including training through international agencies in emergency care, has also contributed to declines in mortality. Training has contributed to improving emergency care prior to transfer to a hospital.

In Baucau, there is a group called *Grupo Suporto Inan* (Mother Support Group) that identifies women who are ready to deliver, or who have babies and children who are malnourished or not vaccinated. The group works with health workers to improve linkage to care; it also promotes nutrition directly, including use of local produce:

> *The Mother Support Groups help us identify the people who did not bring their babies to get vaccination. They also ask the reasons why people don't bring the babies to the health facilities. The group is very useful for us because they give us assistance and they also promote good cooperation with us. This group has been established in all the territories, especially in our area, and in every village and sub village.*

CHC participants note that it will be beneficial to have youth leaders and men involved in engaging on issues related to men's health:

Men should lead the process to talk about STI. They can communicate easily with other males better than us. (FGD participant, CHC, Dili)

COMMUNICATION CHANNELS

Formal communication channels such as television and radio are trusted, as is information coming from health facilities, including information booklets and leaflets (especially with illustrations), and from community leaders. Social media and the internet are also communication sources, although not necessarily trusted. False information is also noted to reach widely over short periods of time through social media and cell phones:

People share information by phone very quickly, very bad information. (KII participant, MHS, Manufahi)

Another reason is social media. Now everyone has a smartphone. We don't know who is posting the information about health, but they are not doctors. They're not nurses. They are not midwives. Sometimes a person who has an elementary level, and they write something in Facebook and the other people read it and believe it. (KII participant, MHS, Covalima)

During COVID-19, information delivered through television was trusted as the information could be seen through "our own eyes." Authenticity was also corroborated through the voices of trusted announcers.

Staff at CHCs note that levels of literacy are very low. This includes historically low levels of education, as well as lack of interest in education, and school drop-out due to young people being drawn into work to provide for their families.

For example, if a child is 7 to 10 years old and they do not go to school, it is an issue because even if they do not know how to write or read, they know how to do business, they know how to provide for the family. They know how to earn money. (FGD participant, CHC, RAEOA)

While outreach visits are conducted to assist illiterate families, there is a need for other ministries to assist in overcoming the challenges of illiteracy.

Behavioral changes are complex to bring about and involve iterative processes. For example, regarding nutrition, it is said to be useful to make use of examples and make comparisons with neighboring households to motivate improvements. When information is given on how to treat malnutrition, benefits are observed quickly, and this supports recognition of the advice given by health workers. While there is general acceptance of the need to end open defecation, there is a need to ensure that this is possible by supporting households to build their own toilets.

SBC AND COMMUNICATION FOR PWD

PWD access information on RMNCAHN from diverse channels including radio, television, training offered by NGOs; from RMNCAHN–oriented national and international NGOs, civil society organizations, church; and from social media. The Ministry of Health's Facebook page is considered to be a trusted source of information, as is other information emanating from government.

Participants expressed interest in training as a way to receive information, as it allows for asking questions and discussion, which is not possible through other communication media:

> *I think the best way is from training, because through the training, if we don't understand some issues or something, we can ask the trainer directly.* (PAR participant, Dili)

It was also highlighted that when information is disseminated in the community, it is very important for local leaders to inform PWD, including parents of children with disabilities, to participate in the activity. Rural areas need additional emphasis for engagement with PWD. Parents, in particular, need information on caring for children with disabilities.

4. CONCLUSIONS AND IMPLICATIONS FOR SBC

Timor-Leste has some way to go towards improving key RMNCAHN indicators and targets, including maternal, neonatal, under-5, and dolescent mortality and various aspects of health care and service provision for women, men, infants, children, adolescents, and PWD, among other vulnerable sub-populations.

This study builds on previous research in Timor-Leste and provides comprehensive qualitative insights into RMNCAHN at district and community levels in Timor-Leste through the lens of people in communities including young people, men, women, PWD, health workers, municipal and district health personnel, traditional health providers, and local authorities. The findings of this study deepen understanding of many aspects of RMNCAHN identified in previous research, as well as providing new insights into health priorities. While the concerns of various vulnerable groups were explored, it was not possible to address the needs and concerns of LGBT people due to the study design.

General and interlinked findings include the following:

- Improvements in infrastructure such as roads, electricity, water, sanitation, and expansion of health facilities have improved opportunities for health care access in Timor-Leste. However, such development is continuing; lack of improvements in such infrastructure remains a barrier to health care access.
- Many aspects of RMNCAHN delivery and uptake are improving, including through health facilities and through various support programs. However, improvements have been uneven. There is a need to continue to increase the number of health facilities and improve RMNCAHN delivery and uptake.
- There have been improvements in gender equality in relation to health as well as in relation to work that can now be undertaken by women and women in leadership positions. Gender inequalities do, however, persist; these impede access to RMNCAHN—notably, that women require permission or are subservient to the authority of their husbands or families regarding accessing RMNCAHN and that girls and unmarried women are not able to access family planning methods. Such disempowerment includes health and life-threatening consequences—for example, regarding accessing antenatal care during pregnancy or accessing health facilities for delivery or dealing with the consequences of unwanted pregnancies. Access to RMNCAHN care by men is also sub-optimal.
- SBC delivered through various initiatives, organizations, and health personnel, as well as mass media and other communication, has contributed to progress in RMNCAHN. The findings of this study provide additional evidence to guide national and sub-national SBC strategies, to ensure inclusivity, and to support RMNCAHN at multiple levels.
- The importance of community engagement is well recognized. Community members are keen to be part of bottom-up processes to ensure health for all. Social networks and support

groups provide focused support and are an integral component of SBC and strengthening community health systems.

- Community leaders and local authorities have an important role to play in promoting aspects of RMNCAHN and supporting community dialogue and engagement. Such support can be expanded. This includes support for PWD and other vulnerable and underserved groups such as those identifying as LGBT.
- While the COVID-19 epidemic in Timor-Leste has not been severe, health services were constrained during lockdowns and other restrictions. Although there were drop-offs in health facility visits, it appears these have now resumed; uptake of COVID-19 vaccination also has been good. Certain positive effects were also noted including improved hygiene, attention to preventive health, and financial and other recognition of contributions by health workers during challenging times. There is a need to consider preparedness exercises for future pandemics and other crises that would affect health.

Overall, there is a need to intensify responses focusing on achieving key targets for the SDGs for 2030 and aligning with overarching national goals and policies. This includes building resilience and sustainability by ensuring integration at multiple levels; incorporating SBC approaches across RMNCAHN responses; strengthening health and community systems; supporting health providers, including traditional providers; engaging in partnerships, including with community leaders and groups; and emphasizing responsibility and accountability throughout health and community systems.

This section focuses on key themes as follows: (1) traditional and modern medicine; (2) maternal and infant health; (3) child and adolescent health; (4) PWD health; (5) male involvement; and (6) nutrition.

TRADITIONAL AND MODERN MEDICINE

Traditional health beliefs and health care–seeking from traditional healers and birth attendants are widespread in Timor-Leste. A recent study of hospital attendees in Timor-Leste found that 60% reported having used traditional medicine, including 32% in the past year.[lviii] Reasons for use included distance to health facilities, low cost, no side-effects, and recommendations from family and friends. A small-scale survey including urban and rural participants found that 73% had used traditional medicine, and 44% used it in combination with modern medical care, illustrating perceived complementary benefits of both approaches.[lix]

Studies show that use of traditional birth attendants in Timor-Leste is associated with challenges related to accessing health facilities and midwives due to poor roads, lack of transport, inadequate health services, restricted operating hours, lack of personnel, and family influence.[lx] Lack of privacy, poor communication, and rude or dismissive care are factors that diminish preference for delivery in health facilities.[lxi] These factors also contribute to delays in seeking care during delivery.[lxii]

The findings of the present study show that some traditional health practices are transitioning towards modern medicine, and also that traditional and modern medicine are viewed as mutually beneficial and complementary. Young people are more inclined towards modern medicine due to education and exposure to information including through the internet.

For the most part, health workers accept the merging of belief systems that accommodate traditional and modern medicine. They are comfortable negotiating for adoption of modern medicine practices in the context of traditional practices; for example, visiting women practicing the *sei* tradition soon after birth to administer vaccines to infants or engaging traditional healers and birth attendants to ensure that referrals occur in the case of emergencies or other health conditions. The most severe risks of prioritization of traditional care–seeking relate to antenatal care, delivery, and post-delivery due to complexities in reaching health facilities quickly given transport and other challenges. In a number of instances, it appears that traditional birth attendants have little capacity for foreseeing or managing obstetric and other emergencies.

Traditional beliefs are also influential in determining nutrition, including prohibitions of certain foods in general, or in specific circumstances such as pregnancy.

The findings show that people are more inclined to gravitate towards traditional healers and traditional medicine when various limitations of modern health care delivery are known or exposed. For example, when poor treatment is received, where privacy is sought (such as for treatment of STIs), or for conditions that are believed to be incurable through modern medicine.

To strengthen responses, including through SBC programs, the following approaches are recommended:

NATIONAL AND SUB-NATIONAL LEVELS

- Acknowledging belief systems that incorporate traditional and modern medicine as mutual and complementary approaches.
- Emphasizing the integration of approaches including knowledge sharing and focus on reducing and mitigating severe negative health outcomes related to health-compromising practices and the need for proactive approaches to emergency care.
- Conducting values clarification exercises for health workers to ensure the delivery of quality care that meets expectations of health facility users and to address challenges and barriers in the formal health system (including in relation to personnel, infrastructure, and resources) that undermine care-seeking.

MODERN AND TRADITIONAL HEALTH CARE LEVELS

- Including engagement with doctors, midwives, nurses, technicians, health promotors, pharmacists, traditional healers (*matan do'ok*), traditional leaders, religious leaders, community leaders, and community-based traditional birth attendants.

- Acknowledging complementarity of traditional and modern health care–seeking, including to address barriers that compromise health.
- Sharing examples of successful complementary use of traditional and modern health care and medicine.
- Engaging with traditional healers and traditional birth attendants to ensure that the potential needs for emergency care are foreseen and that referrals are made promptly.
- Engaging with communities through community leaders on universal access to family planning, including the need to address vulnerabilities and risks related to teenage pregnancy and childbirth, and health facility–based care-seeking in general.

FAMILY LEVEL

- Engaging with families regarding risks related to pregnancy, delivery, and postnatal care of mothers and infants, including to share examples of successful outcomes through health facility deliveries.
- Engaging with families regarding nutrition for pregnant women, infants, children, and adolescents in circumstances where nutritional intake is inadequate or impeded by traditional beliefs.

MATERNAL AND INFANT HEALTH

One of the most pressing concerns identified in this study is maternal and infant mortality. Participants shared numerous examples of negative outcomes, including deaths of mothers and infants related to the circumstances of home delivery, challenges related to transportation, and challenges at the health facility level.

Regarding maternal and infant emergency cases, specific circumstances include:

- Delayed or no attendance at health facilities for antenatal care and inadequate nutrition during pregnancy, which affects maternal and fetal health, and planning for delivery.
- Delayed or no attendance at health facilities for delivery due to constraints linked to traditional beliefs or other concerns imposed by partners or family members (or sometimes by traditional midwives) that result in deliveries at home.
- Lack of competence among some traditional midwives attending home births, including harmful techniques and practices, inability to manage emergency situations, lack of expertise managing the placenta or umbilical cord and other aspects of post-delivery care, and lack of attention or capacity in providing support to the neonate.
- Impassable or inadequate roads, exacerbated by weather conditions, that prevent transportation entirely.

- Lack of ambulances, ambulance drivers, or related resources that prevent or delay transportation to health facilities.
- Lack of suitable transport to convey health workers to communities to attend to emergency cases.
- Broken, damaged, or inoperable equipment, lack of access to clean water and adequate sanitation, and inadequacies related to staff training that limit effective care at health facilities.
- Lack of space, maternity beds, delivery kits, and other resources necessary to support delivery.

Maternal and infant mortality also are influenced by lack of access to contraception and decision-making by girls and women regarding childbearing and child spacing. Unmarried adolescent girls and women are not able to access contraception, and married women often require permission from their husbands or other family members to use contraception. Health workers are required to comply with guidelines and practices, and they fear negative outcomes if they transgress these expectations. In some instances, health workers have been required to remove long-acting contraceptive methods such as implants from women at the behest of family members.

Findings regarding the facilitators for improving the health of married women, pregnant women, and neonates include:

- Improved awareness and uptake of antenatal care, including timely and regular antenatal visits.
- Planning for transportation and accompaniment to health facilities for delivery.
- Timely attendance at health facilities for delivery, and neonatal care including vaccination.
- Feeding of newborns with colostrum.
- Merging of beliefs in traditional and modern medicine to support delivery at health facilities.

Findings from other studies in Timor-Leste identify the following factors related to maternal and infant mortality:

- Lack of transport, lack of essential supplies, poor infrastructure, lack of training, and gaps in information systems.[lxiii]
- Lack of privacy, poor communication, and unpleasant and embarrassing interactions with midwives in health facilities during delivery.[lxiv,lxv]
- Delayed or no attendance at health facilities due to the influence of husbands, lack of preparedness, traditional or physiological beliefs, and infrastructural and geographic considerations.[lxvi]

Recommendations include improving service provision by health workers, improving equipment and other resources at health facilities, and engaging with and improving skills and other capacities of traditional midwives.

To strengthen response through SBC, the following approaches are recommended:

NATIONAL AND SUB-NATIONAL LEVELS

- Highlighting the unacceptably high levels of maternal and neonatal mortality and committing to a pathway of intensified response towards aligning with and meeting the 2030 SDG targets through government, health system, and partner organization channels.
- Advocating for reproductive and maternal health including universal access to family planning methods, including for unmarried girls and women, and emphasizing the importance of planned delivery through regular antenatal visits, partner and family support, and managing limitations related to infrastructure such as transportation.
- Highlighting the "three delays" that contribute to pregnancy-related mortality—seeking appropriate medical help for obstetric emergencies, reaching health facilities efficiently, and receiving appropriate care at facilities.
- Addressing immediate resource gaps including transportation, health facility equipment and resources (including electricity, water, maternity beds, equipment, delivery kits), and staff training.

HEALTH WORKER LEVEL (INCLUDING DOCTORS, MIDWIVES, NURSES, TECHNICIANS, HEALTH PROMOTORS, PHARMACISTS, AND OTHERS)

- Promoting and supporting universal access to family planning methods irrespective of marital status.
- Highlighting the importance of addressing the three delays at the community level.
- Engaging and partnering with community-based midwives and traditional birth attendants to ensure managed care.
- Supporting transfer of skills for safe deliveries and neonatal care to community-based midwives and traditional birth attendants, including approaches to addressing obstetric emergencies by addressing the three delays.
- Attending to antenatal care, births, and neonatal care with dignity and respect.

TRADITIONAL HEALERS (MATAN DO'OK), TRADITIONAL LEADERS, RELIGIOUS LEADERS, COMMUNITY LEADERS, COMMUNITY-BASED MIDWIVES, AND TRADITIONAL BIRTH ATTENDANT LEVEL

- Recognizing the unacceptable high rates of maternal and neonatal mortality in Timor-Leste and the need to intensify efforts to meet SDG and national targets.
- Advocating for universal access to family planning methods.
- Recognizing the importance of facility-based antenatal care and advocating for adequate nutrition, safe activities, and health facility attendance throughout pregnancy.

- Improving skills in safe delivery and neonatal care among community-based midwives and traditional birth attendants.
- Understanding and planning for obstetric emergencies including advance planning by community-based midwives and traditional birth attendants to overcome the three delays.
- Advocating for and supporting availability of transportation for planned delivery at health facilities and emergency obstetric care.
- Attending to post-delivery care of the mother and neonate by community-based midwives and traditional birth attendants.
- Advocating for a full course of vaccinations for infants.

FAMILY LEVEL

- Engaging women, husbands, in-laws, and other family members on self-determination related to a woman's access to family planning.
- Sharing information with pregnant women, husbands, and other family members including in-laws on the risks of obstetric emergencies and the need for antenatal care and planned deliveries.
- Advocating for and promoting husbands and/or other family members accompanying women to antenatal care and to health facilities for delivery.
- Providing safe care and support to women and neonates after delivery.
- Advocating for and promoting adequate nutrition and safe physical activity for pregnant women.

CHILD AND ADOLESCENT HEALTH

The findings of the present study show:

- Children and adolescents are benefitting from improvements in infrastructure and wider availability of health facilities, which has increased opportunities for access to routine health care, vaccinations, nutritional support, and other care.
- Malnourished children are able to access necessary nutritional supplements and treatment for diarrhea and illnesses such as dengue.
- Adolescents are able to access health information through health workers, but also through access to the internet, and they can share such information with less literate, older relatives. However, they lack comprehensive information on RMNCAHN.
- Adolescents are shy to access health facilities for reproductive health matters including when they believe they are pregnant or for diagnosis and treatment of STIs. There is a lack of

adequate information and counselling for adolescent girls who are pregnant or who have babies.

- Adolescent girls remain vulnerable to early marriage and teenage pregnancy in some communities. They also may become pregnant when they are unmarried, as they cannot access family planning methods.
- Adolescents are exposed to alcohol and tobacco; smoking is said to be common among young men.
- There appears to be a lack of engagement between adolescents and their parents and caregivers regarding RMNCAHN concerns.

To strengthen response through SBC, the following approaches are recommended:

- Increasing care provision for infants and children to reduce malnutrition and under-5 mortality.
- Engaging with adolescents and sharing information on RMNCAHN concerns in schools and other community settings, including employing participatory approaches.
- Conducting values clarification exercises with health workers to support the provision of information, improved care, and support; ensuring health facilities are adolescent friendly.
- Assessing and improving sexual and reproductive health care provision for adolescents including providing universal access to contraception, including condoms to reduce unplanned pregnancies and STI transmission; addressing needs for antenatal care for adolescent girls who are pregnant (and providing links to social support services); improving care provision for STI diagnosis and treatment; and addressing other aspects of inclusive care.

PWD HEALTH

The rights, inclusion, and health of PWD are recognized and supported in Timor-Leste at a strategic policy level. However, PWD face numerous challenges in accessing health care in comparison to people who are not PWD. These challenges include stigma and discrimination, poorly configured or inappropriate services, infrastructural challenges, insufficient understanding on how to support PWD by health workers, inadequate or improper communication at the health facility level, and inadequate understanding of their needs related to RMNCAHN. People with mental health impairments tend to be socially excluded and are less likely to be able to access health care.[lxvii]

In addition, PWD face considerable economic challenges. They are less likely to be employed and may rely on family members and others for support.

The findings of the present study show:

- Although improvements in infrastructure, particularly roads, allow PWD easier access to health facilities, the facilities themselves are not well adapted to accommodating PWD with mobility challenges—for example, only stair access and challenging access to latrines.
- There are examples of health workers providing compassionate and dignified care for PWD, including home visits and other support. However, stigma and discrimination continue to occur in health facilities. This includes use of stigmatizing and disrespectful language, unhelpful attitudes, and dismissive behavior.
- PWD lack access to tailored information, including a lack of materials in braille.
- PWD are helped by their marital partners and other family members; but for some, this dependence includes having decisions made on their behalf by others. There do not appear to be suitable support structures for people with intellectual impairments in relation to RMNCAHN.
- PWD are committed to their autonomy through engaging with personnel at health facilities and prioritizing self-care.

To strengthen response through SBC, the following approaches are recommended:

- Conducting values clarification exercises with health workers to support the provision of respectful, dignified, and inclusive care for PWD. This may include engaging with PWD representatives and organizations to understand and address concerns and to provide collaborative support.
- Encouraging health workers to provide advice and issue requests for improvements to health facility infrastructure that will overcome challenges faced by PWD with mobility impairments.
- Providing training in tailored health care provision for PWD, including all aspects of reproductive health.
- Improving and expanding the range of communication materials available for PWD, including materials tailored to addressing PWD-specific RMNCAHN concerns.
- Establishing links with social services to support needs that go beyond what can be provided at health facilities.

MALE INVOLVEMENT

Male involvement is a vital component in family health, including maternal and child health, and men's health also necessitates emphasis on preventive health and care-seeking. Engaging men in general and engaging men and women together contribute to addressing gender inequalities. Health risks related to men in Timor-Leste include inadequate health knowledge, insufficient involvement in partner and family health, exposure to alcohol and tobacco use, and perpetration of intimate partner violence[lxviii,lxix]

Components of male involvement that are influential for health include sharing family and childcare responsibilities, supporting their partners during pregnancy and childbirth, supporting health of children, cessation of addictions, avoiding STIs, and care-seeking.

The findings of the present study show:

- Smoking is said to be common among men.
- There is a lack of involvement of men in household chores and childcare.
- Intimate partner and gender-based violence occur related to tensions in the household and alcohol use; prosecution is less likely to be pursued, with resolution sought through family dialogue instead.
- Exposure of men to STIs is said to be related to alcohol consumption and non-monogamous sex.
- Some men are accompanying their wives and children to health facilities for care and are supporting their wives when they access antenatal care and during delivery.
- Men dominate in decision-making regarding health care access and family planning. They can refuse access to contraception by their partners or deny permission to attend antenatal care or insist on home delivery. In-laws of women also can be influential.
- Nutrition needs of men are not well understood nor addressed.

To strengthen response through SBC, the following approaches are recommended:

- Prioritizing male engagement including for improving men's knowledge of health, including symptoms of conditions commonly affecting men; improving men's uptake of health care, including preventive health and testing for STIs; reducing male dominance of health care decision-making by women, especially in relation to care during pregnancy and delivery and with regard to accessing contraception.
- Encouraging and supporting men to attend antenatal visits with their wives; to plan for delivery, including ensuring arrangements are made to deal with pregnancy-related and obstetric emergencies; to be present during delivery; to support their wives in caring for infants and children; to support exclusive breastfeeding; to support postnatal care visits and infant and child vaccination; and to support child nutrition.
- Deepening men's understanding of nutritional foods available locally and family needs for balanced meals and vitamin supplementation.

NUTRITION

Food insecurity is a prominent challenge in Timor-Leste, and many households experience food shortages. There are high rates of malnutrition among children. Agricultural production is uneven,

insufficient, and vulnerable to changing climatic conditions. Poorer households can need to generate income to spend on food.

The findings of the present study show:

- Climatic factors affect agricultural production; even when production is achieved, poor roads and weather conditions impede distribution and marketing.
- In some communities, locally produced crops are sold instead of consumed in order to generate income to purchase imported foodstuffs.
- Nutritional supplementation helps to address malnutrition, particularly among pregnant women and children, but stock-outs impede efficiency and effectiveness of such initiatives.
- Monitoring of malnutrition is challenging, especially when it is conducted in communities, due to challenges transporting the necessary equipment.
- While there have been improvements in breastfeeding of infants during their first six months, feeding of solid foods prior to six months continues to occur.
- PWD are more likely to be malnourished due to economic disadvantages, and children with disabilities are more vulnerable to malnourishment than other children due to parental misunderstandings and negligence.
- Cultural beliefs and practices influence food selection, and some nutritious foods are disregarded due to such belief systems.
- Ways of improving nutrition include increasing the number of nutritionists at health facilities; building linkages among health, education, and agricultural initiatives; cooperating and partnering with NGOs; increasing consumption of locally produced foods; and promoting and supporting nutrition through schools.

  To strengthen response through SBC, the following approaches are recommended:

- Expanding community engagement on nutritional concerns, including through local leadership structures and groups.
- Improving understanding of cost and other efficiencies for nutrition derived from local subsistence farming and agricultural production, including by engaging with traditional and other leaders in communities.
- Engaging with PWD and families on nutritional needs and support for PWD, including children with disabilities; and strengthening links to support systems.
- Improving understanding of the vital importance of exclusive breastfeeding during the infant's first six months.

5. CONCLUSION

The findings of this study represent a comprehensive insight into RMNCHN in Timor-Leste through qualitative interactions with community members, health workers, traditional health providers and municipal and district health authorities. This report includes recommendations for SBC strategies, but the data also represents a rich source of information for reflecting on national and sub-national RMNCHN policies and strategies that have potential to be strengthened through these findings.

In the final analysis, considerable progress has been made in many aspects of RMNCHN response as well as underlying factors that determine the uptake of RMNCHN services. There are many opportunities to build on and strengthen this positive trajectory to improve the health of people throughout Timor-Leste.

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