

TIMOR-LESTE
HEALTH CARE SEEKING BEHAVIOUR STUDY
2009

FINAL REPORT

Authors: Anthony B. Zwi, Ilse Blignault, Diana Glazebrook, Veronica Correia, Catherine R. Bateman Steel, Elias Ferreira and Basilio M. Pinto

ISBN Number: 978-0-7334-2753-4

Suggested Citation:

Zwi, A.B., Blignault, I., Glazebrook, D., Correia, V., Bateman Steel, C.R., Ferreira, E. & Pinto, B.M. (2009). *Timor-Leste Health Care Seeking Behaviour Study*, The University of New South Wales, Sydney.

Available online at:

<http://www.sphcm.med.unsw.edu.au/SPHCMWeb.nsf/page/Timor-Leste>

Any enquiries or comments regarding this publication should be directed to:

Professor Anthony B. Zwi or Dr Ilse Blignault

School of Public Health and Community Medicine

The University of New South Wales

UNSW SYDNEY NSW 2052

AUSTRALIA

Email: a.zwi@unsw.edu.au or i.blignault@unsw.edu.au

Acknowledgements

We acknowledge the invaluable input of the Health Care Seeking Behaviour Study Steering Committee which played an important part in guiding the project planning, conduct and dissemination: Sra Madalena Hanjam Soares (Chairperson; Vice-Minister of Health) Sr Agapito da Silva Soares (Co-Chairperson; Director General of Health), Dr Erling Larsson (Senior Policy Adviser to Ministry of Health, MOH), Sr Marcello Amaral (Planning Department, MOH), Ms Tanya Wells Brown (Alola Foundation), Sr Manuel Mendonca (National Statistics Directorate), Sr Carlos Boavida Tilman (Institute of Health Sciences), Sr Valente da Silva (MOH), and Ms Natalie McKelleher and Sra Armandina Amaral (AusAID).

The support of the Minister of Health, Dr Nelson Martins, and all the staff of the Ministry is gratefully acknowledged. MOH personnel, along with those from a range of development agencies and organisations, generously gave of their time, insights and documentation. This project was funded by the Government of Australia through AusAID, the Australian Agency for International Development.

This study would not have been possible without the contributions of our research partners. At the Alola Foundation Ms Anne Finch (CEO) and Ms Tanya Wells-Brown (former International Program Manager, MCH) were generous with their assistance and encouragement. At the National Statistics Directorate, Sr Manuel Mendonca (Director) and Sra Cristina Dasilva-Cruz (Management Facilitator) were always helpful and supportive. Lourenco Soares, Americo Soares and Eduardo Ximenes assisted with data management, Silvino Lopes with programming and Silvina Soares da Costa with finances.

Many teams assisted. Alola Foundation field staff comprised Avelina Isabelita da Costa (interviewer, FGD facilitator); Lazaro Lelan Sila (interviewer, FGD facilitator); Justino Sarmiento Amaral (interviewer, FGD facilitator); Maria Fatima de Rosa (interviewer); Johana da Costa Gusmao (FGD notetaker); Zelia Maria da Costa (FGD notetaker); Marquito Soares (FGD notetaker); Francisca Ribeiro Fraga (interview notetaker, digital recording transcriber); Luis Soares da Costa driver); Pascoal R. Martins (driver); and Mafalda da Cruz Cabral (part-time administration). National Statistics Directorate field staff comprised: Team 1—Jose Belinho de Almedia (supervisor), Antonio do Rosario, Edelisa J. da Cruz, Filipina R. Vieira (interviewers), Salamao de Carvalho (data entry) and Luis Miguel (driver); Team 2—Rogerio Castro da Cruz (supervisor), Aleixo Barros Mota Smith, Honoria Edith da Cruz S, Domingas Fernandes (interviewers), Pedro Braga (data entry) and Antonio Ximenes (driver); Team 3—Anacleto Hornay (supervisor), Angelino A da Silva, Francisco G Rodrigues, Clarinha Soares (interviewers), Isabel da Costa (data entry operator) and Januario Soares (driver); Team 4—Martinha Sequeira da C N (supervisor), Amelia Maculada da Costa Augusto, Martinho da Costa, Ana Almeida D A Leong (interviewers), Josefina Fernandes Pinto (data entry) and Abilio da Cruz (driver); Team 5—Manuel G. dos Santos (supervisor), Domingas Daos, Jose da Costa, Celcia da Costa Pereira (interviewers), Estorinho Pinto Pedroso (data entry) and Didino da Costa Pereira (driver).

At UNSW Global we acknowledge Ms Cynthia Grant, the Project Manager, and Marianne Waxman. In the School of Public Health and Community Medicine, we especially wish to acknowledge the role played by Ms Stephanie North in assisting with the production of this report and the Sydney visit of the Timorese members of the team. We are also grateful for the support provided by the Head of School, Prof. Raina Macintyre, the former School Executive Officer Ms Vanessa Traynor, and the School Finance Officer Mr Bruce Long.

Professor Adrian Bauman, Dr Tien Chey and Dr Philayrath Phongsavan provided invaluable assistance in guiding the statistical interpretation and analysis of the HCSBS survey data and TLSLS health seeking data. We acknowledge the assistance of Michael Andersen and fellow UN Translation Cell colleagues for providing a half day's training for Alola District Support Workers in introductory interpreting skills. Michael Anderson translated the Tetum version of this report. Dr Babar Shaikh (Aga Khan) shared tools developed for a health care seeking behaviour study in Pakistan.

Acronyms

AusAID	Australian Agency for International Development
CEO	Chief Executive Officer
CHC	Community Health Centre
DHS	Demographic Health Survey
EA	Enumeration Area
FGD	Focus Group Discussion
HAI	Health Alliance International
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HCSBS	Health Care Seeking Behaviour Study
IUD	Intrauterine Device
MCH	Maternal and Child Health
MDGs	Millennium Development Goals
MICS	Multi Indicator Cluster Survey
MOH	Ministry of Health
NGO	Non-government Organisation
PSF	Promotor Saude Familia (Family Health Promoter)
SIHSIP	Support to the Implementation of the Health Sector Investment Program
SISCa	Servico Integrado Saude Comunitaria (Community Health Integrated Service)
STIs	Sexually Transmitted Infections
TAIS	Timor-Leste Integrated Health Assistance
TB	Tuberculosis
TBA	Traditional Birth Attendant
TLSLS	Timor-Leste Survey of Living Standards
UN	United Nations
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNSW	University of New South Wales
WHO	World Health Organization

Foreword

Honourable Minister of Health, Dr Nelson Martins

I welcome this report on health care seeking in Timor-Leste. It tells us about community attitudes and preferences in relation to health and health care, and informs us of community expectations. This research reinforces a commitment by the MoH to bring services closer to people's homes, and to deliver good quality care where people live.

The key issues which come out of this research relate to respecting and listening to the community, hearing what they say about health issues, and improving our management of services so we are continually improving quality and access to care. It is apparent that we need to communicate much more clearly, both with the community and between different parts of the health service.

This research provides us with insights into what community members see as health problems and their causes, and what they do in response. Do they deal with the problem on their own, within the family, or do they consult a traditional healer, or go to a government clinic or private provider? While choice may be constrained by time and distance, the research shows also that people's experiences of the health services greatly influences whether they use them again. If they are received with respect, empathy and care, they come back; if they are directly or indirectly criticized, or treated harshly, and their difficulties in accessing care are not acknowledged, they will not return.

There are challenges at every level – nationally we need to improve infrastructure and support to enable us to promote health and deliver services right across the country, and we need to work with our colleagues in the education sector to enhance awareness and understanding of health and its determinants.

The Ministry of Health has carefully developed our Strategic Plan and our Basic Services Package – these set out what types of services community members can expect to receive within the Timorese health system. We have good policies and now need to devote more attention to ensuring effective implementation, and that our services reach all community members. We need to enhance communication and improve the education and training of health workers to ensure that they have a respectful and supportive attitude to the community. Within our Districts we need to work together with community leaders to overcome the impediments to access. Extending our services through SISCa and providing access to multi-purpose vehicles in the sub-districts will help.

There are many challenges ahead, including decentralisation of services, management and decision-making. We will need to effectively integrate our colleagues returning from training overseas, especially those returning from Cuba. We will need to promote innovation, and reward excellence.

We thank our development partners, including the Australian government which funded this work, for support and engagement, and our research partners, notably the University of New South Wales, for asking difficult questions which stimulate us to improve our services and responsiveness to the community.

This research, and related training, contributes to developing our research capacity. It reinforces our desire to establish a research centre in Timor-Leste which will focus on health and health system issues. We need to ask questions about how we are doing, and search for answers and improvements. This will play an important part in building the health of our nation, in this our 10th year since the referendum on independence.



Dr Nelson Martins, MD, MHM, PhD
Minister for Health
Timor-Leste
April 2009

Table of Contents

List of Tables	7
List of Figures	7
Executive Summary	8
Section 1 – Introduction	13
1.1 Background and rationale	13
1.2 Research questions	13
1.3 Research context	14
1.3.1 Timor-Leste Census 2004	14
1.3.2 Timor-Leste Survey of Living Standards 2007	15
1.3.3 Timor-Leste Health Care Seeking Behaviour Study 2008	15
Section 2 – Literature Review	16
2.1 – International research	16
2.2 – Timor-Leste studies and reports	17
Section 3 – Methods	18
3.1 Design and approach	18
3.1.1 Survey	18
3.1.2 Qualitative	18
3.2 Focus and priority determination	19
3.3 Instrument development	19
3.3.1 Survey	19
3.3.2 Qualitative	20
3.4 Analysis	21
3.4.1 Survey	21
3.4.2 Qualitative	21
3.5 Ethics	22
Section 4 – Results	22
4.1 Participants	22
4.1.1 Survey	22
4.1.2 Qualitative	23
4.2 General health care seeking	23
4.2.1 Problems experienced and providers used	23
4.2.2 Physical factors	24
4.2.3 Economic factors	25
4.2.4 Socio-cultural factors	26
4.2.5 User-provider interaction	27
4.2.6 Equipment and staff	28
4.2.7 Medication	29
4.2.8 Referral	30

4.3 Seeking help for a child with diarrhoea.....	31
4.4 Seeking help for a difficult birth	32
4.5 Birth spacing.....	35
4.6 Serious illness.....	39
4.7 Prevention.....	39
4.8 Provider perspectives	40
Section 5 – Discussion	43
5.1 Limitations	43
5.2 Reflections on findings relative to what is known	44
5.3 Implications.....	45
5.3.1 Implications for the health sector	45
5.3.2 Implications for other sectors	47
5.4 Recommendations.....	47
5.4.1 Recommendations for the Ministry of Health	47
5.4.2 Recommendations for the Government of Timor-Leste.....	48
5.4.3 Recommendations for local government and communities.....	49
5.4.4 Recommendations for development partners.....	49
5.5 Further research	49
5.6 Other products	49
References.....	51
Appendices.....	53
Appendix 1 – Diarrhoea narrative	53
Appendix 2 – Birth spacing narrative.....	54
Appendix 3 – Difficult birth; extract from FGD.....	55
Appendix 4 – User-provider interaction during consultation; extract from user interview	56
Appendix 5 – User blame of provider; extract from FGD	58

List of Tables

All tables can be downloaded as a separate document at:

<http://www.sphcm.med.unsw.edu.au/SPHCMWeb.nsf/page/Timor-Leste>

Table 1- Health problems in the past 30 days (TLSLS sample)

Table 2 - Usage of health providers for health problems in the past 30 days (TLSLS sample)

Table 3 - Family planning method currently being used (TLSLS sample)

Table 4 - Currently used methods of birth spacing reported by men and women (HCSBS sample)

Table 5 - Reasons for not birth spacing (HCSBS sample)

Table 6 - Type of facility visited by sick person (HCSBS sample)

Table 7 - Beliefs about household practices that prevent people becoming sick (HCSBS sample)

Table 8 - Use of health providers by households in past 12 months (HCSBS sample)

Table 9 - Ideal spacing (years) between children (HCSBS sample)

List of Figures

All figures can be downloaded as a separate document at:

<http://www.sphcm.med.unsw.edu.au/SPHCMWeb.nsf/page/Timor-Leste>

Figure 1 - Research context

Figure 2 - HCSBS sampling strategy **Error! Bookmark not defined.**

Figure 3 - Health providers 'used' by households in previous 12 months for any illnesses (HCSBS sample)**Error! Bookmark not defined.**

Figure 4 - Chair used to transport sick person to nearest road or health facility

Figure 5 - Reported causes of diarrhoea

Figure 6 - Ideal time between children (HCSBS sample)

Figure 7 - Improving access, quality and management

Boxes

Boxes 1-14 can be downloaded as a separate document at:

<http://www.sphcm.med.unsw.edu.au/SPHCMWeb.nsf/page/Timor-Leste>

Executive Summary

Despite significant improvements, health status in Timor-Leste is poor. Low rates of use of public health services present a major challenge to improving the health of the people of the country. The Health Care Seeking Behaviour Study (HCSBS) was designed to improve understanding of the underlying issues and factors affecting the use of services, particularly in rural areas, and to provide an evidence base for future health policy, planning and programs.

This Study provides new and more detailed information about health care practices, including measures taken within the household, and preferences for health services at the village-level. It provides insights into the processes of decision-making and action in rural communities, including choice of particular providers or services—traditional and biomedical, and the various factors that influence those choices. In particular, the Study provides rich qualitative data in relation to three key scenarios: a child with diarrhoea, a difficult birth, and birth spacing. The Study also recorded, in some detail, provider perspectives, including the constraints experienced by government health service providers, as well as the views of users and providers on user-provider interactions. In addition to tables and figures, this Report seeks to present the voices of some of the research participants; these appear in boxes throughout the text and in the appendices where five slightly longer narratives are presented.

Methods

The HCSBS built on previous research in Timor-Leste, including national surveys and qualitative research, and drew on international studies and theoretical approaches to health care seeking. The Study employed a mixed methods research design and involved field work in all 13 districts.

The HCSBS survey drew a sub-sample from the Timor-Leste Survey of Living Standards (TLSLS), to facilitate subsequent data linkage. Health care seeking data were collected from 535 household heads and 771 individuals—404 women and 367 men from these households. The HCSBS qualitative component commenced with 13 entry interviews conducted with village heads (*xefe suco*). In three of the 13 districts, in-depth interviews were carried out with biomedical and traditional health care providers (32 in all) and health facility users (29). In the remaining 10 districts, focus group discussions were held with married women, married men, adolescent females and adolescent males (38 groups with a total of 261 participants).

Results

Long distances to health facilities discourage attendance, in particular for non-urgent conditions and preventive care, but also for severe conditions because the journey itself is perceived to contribute to deterioration in the patient's condition. During the wet season, even short distances can become impassable. In some cases the long journey stimulates collective action, for example in relation to groups of women walking together to facilities to support and protect one another. In the case of serious conditions, as well as during delivery, even short distances may pose significant obstacles.

Economic factors further complicate access to health facilities. Various costs are associated with health care seeking. Traditional providers may negotiate a payment (*kasu*) for positive outcomes. In relation to government health providers there was no evidence of routine charging of fees. Government health providers did, on occasion, charge for privately administering a service or for

offering services out-of-hours. Costs were also associated with obtaining medications (traditional or biomedical) and referral to another health facility, including procuring transport and accompanying the patient to the facility.

Family members are very involved in health care seeking; both making and then enacting decisions about when and where to seek help. Neighbours and local authorities may become involved; carrying or transporting patients to urgently required services. A husband's parents may be involved in decisions related to spacing children or using contraceptives. Relatives and community members are often involved in situations where ill-health was considered to be linked with traditional or custom matters.

Service users seek a number of elements within any consultation with government providers. Overall, they are looking for a comprehensive approach which treats them holistically and with respect. In addition, they have clear expectations about specific stages of the consultation process: reception/registration, examination, treatment (usually with medication) and referral. When they have travelled a long distance, they expect to be seen even if they arrive out of hours or without their registration card. In emergency cases, they expect to be seen when they arrive.

Users are discouraged from seeking help in the future by health worker anger and blame, and encouraged by demonstrations of empathy. In an examination, they expect to have a conversation about the history of the condition and to explore the possible causes and how to prevent this. In relation to treatment, users of health services had a number of expectations. These included being prescribed medication; having routine medications always available, especially for chronic conditions requiring repeats; receiving different medications for different symptoms; experiencing immediate effects; and receiving the same medication, if effective, when they next experience the same symptoms. Instead of completing the full course, patients may set aside some of the medicine obtained for use on a later occasion.

In deciding where to go for help, people appreciated facilities that were equipped with basic diagnostic and procedural equipment and staffed by qualified and well-trained staff; several indicated a preference for seeing doctors. A provider may recognise that the user's condition is beyond the capacity of that level of health facility to treat, and recommend referral. In general, users did not perceive this as a problem unless delay in getting to the facility of referral resulted in a negative outcome. Many actually expressed satisfaction that the provider had the institutional support to refer to a higher level facility to increase the likelihood of a positive outcome. Positive views of services are conveyed to others; so too are negative experiences.

Parents recognise many of the danger signs associated with childhood diarrhoea and increasing severity. The initial response is typically at household level (homemade rehydration and/or boiled leaves) and only if diarrhoea persists, is the child taken to a health facility. Where health facility treatment is not effective, the family often suspects custom factors as the cause. Health facility treatment may be resumed after the custom matter is resolved.

It is generally assumed that most births will be normal and, therefore, able to take place at home with the support and assistance of family. While a traditional birth attendant (TBA) may assist, women and men do recognise difficulties and complications that are beyond their skills. Late recognition of problems, however, results in delay in getting assistance. Custom-related issues and

social transgression by the husband, wife or family members were the most commonly perceived causes of difficult birth. Resolution of custom matters may be pursued concurrently while the woman is being taken to a health facility.

Women and men recognise the value of birth spacing in relation to the household economy as well as the health of the mother and child. Women usually receive information on methods from the health facility and inform their husbands. Where there is disagreement this is usually because women want to use, and men do not want to use, contraception. Disagreement can result in fighting, infidelity, and divorce. The husband's parents may influence decision making due to considerations regarding bride-price. Concern about potential side effects, often based on what they have learned about other's bad experience, and potential limitations on future fertility, discourages use of birth spacing methods.

Information about preventing disease was passed on mainly by health workers, and by *xefe suco*. Preventive behaviours by community members focused on avoiding contact with the sick, and the eating implements or sputum of the sick. Informants articulated considerable knowledge about hygiene and sanitation-related actions for diarrhoea prevention. A range of other health problems were also identified as preventable but most informants claimed they did not seek preventive health care. Some understood antenatal care as helping avoid difficulties, and had sought this care. In general, providers were aware of their preventive role and frustrated by the low level of community knowledge and preventive practice.

Health workers reported a range of limitations to delivering better services. Organisational and logistical constraints included lack of communication between facilities; delays in undertaking or providing outreach activities because of poor roads; unreliable drug supplies especially in the wet season; poor infrastructure including the lack of electricity for lighting and sterilising equipment; and the lack of training opportunities. Limitations in relation to provider-community interaction focussed on concern that providers may be blamed by community members in the case of a negative outcome; and frustration and anger at the perceived lack of community appreciation of the importance of prevention and early intervention. Some providers appeared to accommodate patient beliefs in custom as an underlying cause of illness.

Implications, recommendations and further research

Overall, the HCSBS underscores the often restricted range of health care choices available to rural communities given the impediments of distance, cost and infrastructure. Treatment at home with traditional and/or modern medicines and (sometimes simultaneous) consultation with local traditional providers could be regarded as a logical response to limited access to government health services.

The findings clearly demonstrate the pressing need for greater communication and understanding between those organising and delivering health services, and the communities for whom those services are intended. The research has implications for improving access to, and demand for, quality services and strengthening management and support systems as strategic priorities for the Ministry of Health (MOH). Assuring consistent delivery of good quality comprehensive services is essential to building trust in the public health system.

Recommendations are directed at a number of key institutions and agencies.

Recommendations for the Ministry of Health

- Strategies to improve the quality of service delivery should emphasise patient-centred care.
 - Government health workers should receive clear guidance on good practice in health services provision. Empathy, respect and clear communication should be more actively promoted and health care workers who are responsive to community members should receive recognition.
 - Achievements and good practice should be regularly communicated to the community locally and nationally. The MOH should develop mechanisms to reward health workers at all levels for effective and innovative service provision, including through an annual awards ceremony highlighting achievements and promoting positive media coverage and discussion.
 - Health worker education and training, for nurses, midwives and doctors, should be user and community-focused and should emphasise a holistic approach to health. This requires recognition of the mental, social, cultural and spiritual aspects of health, as well as the physical and biomedical aspects.
- Increase efforts to improve communication between service delivery and services, and community structures.
 - Pilot and carefully evaluate innovative means of enhancing the community-service interface. This should extend beyond an exchange of information to establishing genuine partnerships for service development and delivery.
 - Engage more actively with traditional birth attendants as they provide services to large sections of the community and would benefit from skills training and access to sterile equipment and supplies. Training TBAs to recognise problems, to refer early, and to avoid complications will benefit both mothers and children. Better planning for deliveries, and ensuring that skilled attendants are present, remains crucial.
- District managers should be given support and additional training to shape improvements in health care delivery and organisation. With the back-up of the policy and planning sections of the MOH, and regional advisors, these key personnel should focus attention on addressing the weaknesses within health care delivery. District managers should be empowered to ensure the availability of drugs, equipment and appropriate staff within services.
 - Improve the ability of rural health care staff to perform through providing ongoing training and support, and enhancing availability of transport and reliable drug supplies.
 - Identify ways to assist families to meet the costs associated with referral to facilitate access to appropriate levels of care.
- Capture lessons, adapt and scale up innovative and successful mechanisms to improve quality, access and acceptability of services, such as the triage system being developed at Guido Valadares Hospital in Dili and treating malnutrition using only local foods (Baucau).
- Health Promotion should play a stronger role in improving community understanding of prevention, the use of health care services, and the use of modern medicines. Community members should be encouraged to ask questions about their care and health providers should be trained to provide polite and informative responses. Promoting the engagement

of men in birth spacing and improving community understanding of effective use of medicines should be a priority. Education around prevention of common health conditions, and early interventions to reduce severity and complications, should be taken forward. The MOH, working with local authorities, schools and development partners, should invest in, and evaluate, pilot interventions to improve health literacy.

- The MOH should identify one or more persons to assess the implications of this research for the workforce, local and expatriate, and for identifying how the MOH and key educational institutions can address weaknesses through the selection and training of health workers.
 - This Report should be made available and used as a teaching and learning resource for health workers being trained in Timor-Leste, Cuba and other countries. Resources should be sought to translate this report into Spanish to facilitate discussion of its contents by Cuban personnel providing services or training in Timor-Leste and Cuba.
 - Educational institutions, with research and development partners, should explore questions raised by this research. Among these are questions related to the cultural and language competence of local and expatriate health care staff; improved understanding of the emerging private sector in health care provision, including pharmacists; and the need for detailed understanding of community responses to specific health problems and conditions in different parts of the country.
- The MOH should establish a research structure which will interface with researchers, play a major role in identifying research needs, and will ensure the integration of research findings in activities to improve policy and practice.

Recommendations for the Government of Timor-Leste

- Improve infrastructure – transport and communication – to assist with health, and other services, delivery.
- Ensure Ministry of Health and Ministry of Education collaborate on health-related curricula at schools and training institutions.

Recommendations for local government and communities

- Liaise with local and central government and development partners to develop strategies to facilitate access to services and improved transport for emergencies and referrals.
- In a number of pilot areas, work with Ministry of Health teams to identify innovative strategies to enhance health service – community interface and mutual respect.

Recommendations for development partners

- Support community and Ministry of Health initiatives to enhance respect and responsiveness to communities, and to improve access, equity and quality of services.
- Encourage innovation and evaluation of interventions to enhance health literacy and community participation and engagement in health issues.
- Provide support to MOH in acting on the recommendations above.

Section 1 – Introduction

1.1 Background and rationale

The Health Care Seeking Behaviour Study (HCSBS) was designed to improve understanding of the underlying issues and factors affecting use of health services in Timor-Leste and to provide an evidence base for future policy, planning and programs. A further objective was to build and enhance capacity for health-related research within Timor-Leste.

The HCSBS has been a collaborative effort between a team from the University of New South Wales (School of Public Health and Community Medicine and UNSW Global), the Ministry of Health (MOH), and two Timorese research partner organisations, sub-contracted by, and to, the UNSW—the Alola Foundation and the National Statistics Directorate. Its implementation was guided by a Steering Committee comprising representatives of the MOH, AusAID, Alola Foundation, National Statistics Directorate, and UNSW. The study was funded by the Australian government through AusAID, the Australian Agency for International Development.

Improving the health of Timorese people is a key goal of the Government of Timor-Leste [1-3]. Over the past few years the MOH has been developing health services, policies and the infrastructure required to enhance the delivery of quality health care. However, there is significant under-utilisation of health services by the community. The problem is pervasive and multifaceted. It is affected by factors on both the supply side (including infrastructure, health worker education and training, quality of treatment provided and service opening hours) and the demand side (including community attitudes and perceptions of illness and disease, social and cultural issues, and financial resources).

Recent population-based surveys [4-6], a qualitative study funded by the World Bank [7] and numerous local surveys and studies by non-government organisations (NGOs) [9-25] in Timor-Leste, have contributed to increased understanding of health care practices, including preventive practices, and health care seeking. However more information is needed about the factors that influence these behaviours and associated decision-making, including in-depth knowledge about community preferences and enhanced understanding of the relationship between health care providers and the community. Addressing questions which have some bearing on access, quality and management of health services is of particular value to the MOH.

1.2 Research questions

The Study sought to contribute to answering a number of questions:

1. What factors inform health care seeking behaviour and decision-making processes as they relate to households and individuals?
2. What are the reasons for use or non-use of health services? What are client expectations of service delivery?
3. What are client perspectives on service quality, performance of providers and satisfaction with services?
4. What are community attitudes to government and non-government providers?
5. How well do different models of service delivery meet community needs?

6. How do health service providers view their role in the community?
7. What do health service providers see as the enablers and barriers to effective and efficient health care?
8. How are providers connected to the community and how well do they understand community needs?
9. To what extent is preventive health care viewed as part of basic health service provision by both clients and providers?

1.3 Research context

Since the establishment of the United Nations Transitional Authority of East Timor (UNTAET) in 1999 and independence in 2002, several large national surveys with relevance to health have been carried out. Each provides some data that help construct a picture of health and health-related outcomes. Numerous qualitative investigations into aspects of health-care seeking have also been undertaken by the World Bank [7], HAI [9-16], TAIS [19-21], Care [8], OXFAM [18], HealthNet [17, 23-25], and UN agencies such as UNFPA [22] and UNICEF.

In 2001 the Poverty Assessment of Timor Loro Sa'e was conducted. This comprised two surveys. The first was an administrative census which collected data on the number of households at *suco* and *aldeia* level throughout Timor-Leste, and which provided a sampling frame for later national household surveys. The second was a household expenditure survey of a nationally representative sample of 1800 households.

The limitations of the *suco* sampling frame were reported later in the 2002 Multi Indicator Cluster Survey (MICS) [4], which noted a "tendency toward overstatement of both population and households in many areas, especially in Dili". The MICS was developed especially to meet the needs of developing countries lacking reliable routine sources of data and/or experience in carrying out household surveys to measure performance in relation to the World Summit for Children and, later, the Millennium Development Goals (MDGs) and World Fit for Children initiatives. Major topics included infant and child mortality, education, water and sanitation, child malnutrition and child health, HIV/AIDS and reproductive health.

In 2003 the first comprehensive assessment of the demographic, health and nutrition status of the population of the independent state of Timor-Leste took place [5]. However, as census data were not yet available, the *suco* survey population estimates from 2001 were retained as the sampling frame. The Demographic Health Survey (DHS) provided particularly valuable data on reproductive health, maternal and child health, fertility preferences and nutrition.

1.3.1 Timor-Leste Census 2004

The 2004 Census [26] was the first full national census after independence. It made use of Global Positioning System (GPS) technology and every household in the country was mapped and surveyed, thus providing an up-to-date sampling frame for future surveys. The Census collected vital demographic data as well as population data on social factors such as literacy, employment, household living standards and fertility.

1.3.2 Timor-Leste Survey of Living Standards 2007

The Timor Leste Survey of Living Standards (TLSLS) [6] was carried out to build on the modest living standards survey that had formed part of the Poverty Assessment in 2001. The TLSLS had two components, a cross-sectional sample of 4500 households, and a 'panel' component which followed up half (900) of the households surveyed in 2001. The cross-sectional survey drew on the sampling frame provided by the 2004 Census and collected economic and social data from a nationally representative sample drawn from five regions across the country. The health module included several questions on health seeking and health services utilisation, thus supplying baseline household-level data on these behaviours and their correlates. Other health data collected in the TLSLS included those issues related to immunisation, bednet use, birth spacing and pregnancy/child birth.

1.3.3 Timor-Leste Health Care Seeking Behaviour Study 2008

The HCSBS incorporated both a quantitative (survey) and a qualitative component.

The HCSBS survey sample was drawn from the TLSLS sample. This offered opportunities to link HCSBS data with social data collected previously in the TLSLS. The HCSBS covered different domains of health-seeking, and expanded on some domains included in the TLSLS. In particular, given the national focus on achieving the MDG targets, maternal and child health issues were prioritised. Unlike the TLSLS, the HCSBS survey sample was not designed to be nationally representative but, rather, to be typical of rural areas that are without ready access to hospitals.

The qualitative component of the HCSBS allowed exploration of the processes, beliefs and behaviours associated with health problems in order to better understand the factors influencing health care seeking.

Figure 1, shows the relationship between the Census, TLSLS and HCSBS (see attachment).

Capacity enhancement

Collaboration and capacity building were emphasised throughout the HCSBS.¹ The survey was carried out by the National Statistics Directorate (part of the Ministry of Finance), providing an opportunity to enhance links between it and the MOH. In addition, UNSW advertised for a local Timorese research organisation that would take responsibility, with UNSW support, for the qualitative fieldwork and collaboration on the analysis. Following a competitive tender process, the Alola Foundation was selected and provided the base for the qualitative team and the Timorese Senior Researcher. All training and research activities were designed as opportunities for further skills development and institutional strengthening. Survey structure and fieldwork was led by the National Statistics Directorate, and qualitative fieldwork and data collection by the team based at the Alola Foundation. UNSW managed the process through the Project Directors (Prof Anthony Zwi and Dr Ilse Blignault), Project Manager (Ms Cynthia Grant), Project Coordinator (Mr Basilio Martins Pinto) and Data Specialists (Dr Diana Glazebrook and earlier, Dr Catherine Bateman Steel).

¹ Further information about the capacity-building aspects of this Study can be found in the HCSBS Project Report.

Section 2 – Literature Review

2.1 – International research

A literature review conducted in preparation for the HCSBS aimed to consider similar research that had been carried out in other settings and to gain an understanding of the theoretical and methodological issues underpinning research in this field. Articles and papers reporting studies on health care seeking in developing countries were reviewed, with a focus on those that dealt with issues highlighted as important in Timor-Leste.

The bulk of health care seeking studies around the world have been descriptive, providing an overview of the patterns of behaviour and the choices people make in relation to their health and the services with which they interact. Some studies, particularly those which included a qualitative element, also offered explanations as why certain choices are made or certain behaviours occur; however many of them were limited to a specific illness or health topic.

Generally, patterns of health service utilisation and health care seeking were influenced by socio-economic status, maternal education, and cultural beliefs and perceptions of the causes, and scope for treating, different conditions. The main barriers to service utilisation were reported as long distances and poor transportation, health service factors such as staff attitudes and hours of operation, and the assessment of the benefits and costs by community members associated with use of available services.

TB, malaria and diarrhoea were commonly investigated [27-40], and some patterns of behaviour were similar across countries and settings. For malaria and TB, for example, home treatment was a common first step and only after this failed was help sought outside the home [30, 34]. Delay in treatment for diarrhoea was mainly related to lack of recognition of severity [28]. Rural living was a consistently a barrier to engagement with services, although this was not always simply a function of distance [41]. Factors such as lack of information and other health service factors also played a role. Satisfaction with services was difficult to assess, especially in settings where the features of ‘good quality’ services have not been articulated [40]. The range of studies on HIV were not reviewed.

On the theoretical side, research into health care seeking has been criticised as being a “somewhat over-utilised and under-theorised tool” [42]. Despite this there is an abundance of models and approaches on which to draw. Some authors [40, 41] have called for caution, noting the tendency for models to focus too heavily on individual level characteristics in explaining behaviour, rather than considering the broader picture. Hausmann-Mueler et al. [43] suggest that behind many models is an assumption that individuals make rational decisions to maximise utility and do not take into account emotional aspects, the symbolic value of actions, political forces, or social and cultural relations. Key factors identified are often considered in isolation from the context in which they occur, even for simple but important issues such as perception of severity of malaria being worse in some seasons. Similarly, MacKian [42] argues that to understand health seeking it is necessary to go beyond the individual and explore further the way the “local dynamics of communities” influence the process. This requires addressing two often neglected issues: the collective element of health seeking behaviour, and the interaction between individual and societies and health systems. The HCSBS drew on these ideas, together with a broad conceptual model developed by Kroeger, cited in [43], which has influenced several studies in other developing countries.

2.2 – Timor-Leste studies and reports

A range of development partners in Timor-Leste, including NGOs and UN agencies, provided reports on research they had done around health care seeking. In some geographical areas there has been extensive work focusing on specific health topics, such as child health practices, reproductive health and nutrition. Both HAI and TAIS, for example, have produced very detailed reports that shed light on health beliefs and practices related to maternal and child health, while UNFPA has conducted a situation analysis and qualitative research on reproductive health. In this section, we summarise only those studies that report on health care seeking in general.²

The 2003 DHS included several aspects of health-seeking behaviour, summarised by TAIS [19]. Approximately 1 in 10 households reported not using any health care provider when a household member was ill. Curative health care encounters occurred predominantly in community health centres (58.9%), about a quarter (24.6%) occurred in government hospitals, and 11.4% occurred in private clinics. Some people bypassed their community health centre and sought care at the nearest hospital instead. Mean travel time to the usual first health care provider was 35 minutes, with travel mostly by walking. Ever-married women who reported “big problems” in accessing health care for themselves identified the following difficulties: distance to health facility (63.6%), having to take transport (62.2%), not wanting to go alone (61.7%), getting money for treatment (59.3%), knowing where to go (26.7%), getting permission to go (17.9%), and concern about the absence of a female provider (4.4%). One or more of these specified reasons was reported by 75.9% of respondents.

In 2005 the World Bank funded a qualitative study [7] that incorporated focus groups with health service workers and users, and in-depth individual interviews, across 5 sub-districts. The study explored health care seeking behaviour, barriers to service utilisation and human resource issues. The major barriers to utilisation were found to be socio-cultural knowledge and practices, service quality issues and geographical distance. In addition, it was found that systems of ethnomedicine played a major role in health care seeking, with people tending to use traditional and biomedical health systems interchangeably.

A review of Timor-Leste literature from 2002–2006 conducted by TAIS (19) identified several cross-cutting issues that have the potential to negatively impact on use of health services and general health improvement. Service and service-quality issues included lack of running water and/or electricity, poor communication systems (with many facilities having no on-site radio), limited availability of drugs, lack of transport attached to most facilities (and low fuel budgets for those that do have it), and travel often hampered by heavy rains. Community factors included a general lack of understanding of the need for health care, a mistrust of services and strong beliefs in traditional medicine. Among the barriers to health improvement were damming of groundwater and sewer drainage to grow vegetables leading to proliferation of mosquitoes, and coffee cultivation taking the place of subsistence farming contributing to malnutrition. Barriers to the use of health facilities for safe delivery included lack of private space and resources needed to carry out traditional practices around childbirth.

² A summary of all Timor-Leste information on health care seeking collected (research findings and personal and organisational insights) is available on request.

Section 3 – Methods

3.1 Design and approach

The HCSBS employed a mixed methods research design and involved field work in all 13 districts of Timor-Leste. In addition to a household survey, in-depth interviews were conducted with village heads and health service providers and users, and focus group discussions (FGDs) were held with community members.

3.1.1 Survey

Sampling: TLSLS

The TLSLS used the 2004 Census Enumeration Areas (EAs; total of 1,163) as a national sampling frame. The TLSLS aimed to represent the population of Timor-Leste and therefore sampled a combination of rural and urban areas from across the country. The country was divided into 5 regions (by including a certain number of the 13 districts in each region) and each region into 2 strata (urban and rural). Nationally, therefore, there were 10 strata, from which 300 EAs in total were selected using probability proportional to size sampling. Within each EA 15 households were randomly selected, producing a total of 4500 households in the cross-sectional sample of TLSLS.

Sampling: HCSBS Survey

The HCSBS survey drew a sub-sample from the TLSLS sample. As there was interest in equal representation from all 13 districts when investigating health-care seeking, the HCSBS survey sample was stratified by district. The 300 TLSLS EAs were taken as the sampling frame and three EAs were randomly selected from each district. The sample was designed to be typical of rural areas without access to hospitals, therefore EAs that included a hospital were excluded. To avoid respondent fatigue we also excluded those that had been included in the 2008 TLSLS Extension survey. In each of the selected EAs, the 15 households originally surveyed in the TLSLS were re-approached for the HCSBS, allowing data linkage. In all, the HCSBS survey target sample comprised of 39 EAs and 585 households. Within each household, household-level data was sought from the household head, and individual responses were sought from one married man aged between 15 and 54 years and one married woman aged 15-49 years.

3.1.2 Qualitative

In each of the 13 districts, one of the three EAs included in the survey was randomly selected for further study. From this point on, the sampling was purposive. In three of the districts, one in each region, in-depth interviews were conducted with health care providers (biomedical and traditional) and users of government services. We chose Dili because it is the capital and Oecusse because it is so remote. Bacau was randomly selected from among the districts in the eastern region. In the remaining 10 districts the qualitative team conducted focus FGDs with men, women and adolescents.

Entry interviews were conducted with the village head (*xefe suco*) to identify the range of providers and services in each community. Information was sought about traditional providers and government or NGO health providers, either resident in the village or servicing the population of that village. Potential provider informants were located in this way and invited to participate in the study;

we aimed for 10 provider interviews in each of the 3 districts. For user informants, the village head was asked to identify one or two local residents who had recently had a consultation at the closest health facility (usually village health post). The research team then contacted the person directly to invite their participation and arrange an interview. Other users were identified using snowball sampling—each informant was requested to identify one other person who had recently made use of the health service. Again, we aimed for 10 user interviews in each of the 3 districts. Efforts were made to achieve a gender and age balance among service users (although women predominated).

In districts where FGDs were conducted, the village head was contacted in advance by the local Alola Foundation district support worker and requested to ‘invite’ (this often took the form of ‘identification’ rather than ‘invitation’) FGD participants who were ‘ordinary’ members of the community, i.e. no teachers, relatives of village head, traditional birth attendants or community health volunteers. Four FGDs were planned at each research site: married women, adolescent females, married men, and adolescent males. In response to lack of participation and contribution by married and adolescent women in FGDs, the criteria were adjusted to seek women who had some previous involvement in groups (e.g. church or youth groups) and were comfortable speaking in a group setting.

3.2 Focus and priority determination

The priority domains for enquiry were shaped through consultation with the MOH and other key stakeholders.³ A consultative stakeholders’ workshop was held in Dili. Input was sought at the district level from health service managers and providers and traditional birth attendants (TBAs). Initial consultations focussed on identifying gaps in current knowledge of health care seeking; a second round concentrated on refining the questions with domain experts.

It was agreed that, for users, the focus should be on general health care seeking and preventive health practices; maternal and child health, in particular child birth, postnatal and neonatal care and birth spacing; with limited attention to hygiene and hand washing. A better understanding of health service provider perspectives on barriers and enablers to service delivery and user-provider interactions was also considered important. There was general consensus that the focus should be at the most basic level of the health system, i.e. village health post rather than at community health centre or hospital. This was the level where PSF (*Promotor Saude Familia* or Family Health Promoters) were working and SISCa (*Servico Integrado Saude Comunitaria* or Community Health Integrated Service) was being established.

3.3 Instrument development

3.3.1 Survey

The first version of the survey questionnaire included an extensive list of questions in each of the identified priority areas. Many of these were taken, or adapted, from earlier surveys in Timor-Leste (DHS, MICS and TLSLS) and health seeking studies in other countries. The list was progressively refined through a process of consultation, deleting most of the questions for which ‘reasonable’ data

³ Multilateral and bilateral donors and advisors (World Bank, AusAID, SIHSIP), United Nations agencies (WHO, UNDP, UNICEF, UNFPA) and international and local non-government organisations (TAIS, HAI, HealthNet, CARE, World Vision, Water Aid, OXFAM, Plan International, Marie Stopes, and Fred Hollows Foundation).

already existed. Some questions were retained with substantially expanded response categories (e.g. barriers to attending a health facility), and new questions (for Timor) were added.

The overall survey structure was similar to the DHS, with household-level data from the household head supplemented by individual data collected from one married female aged 15–49 years and one married male aged 15–54 years (age groups chosen for consistency with the DHS, 2003).

Once the final set of questions was decided, they were translated into Tetum. Several iterations were required to agree on the words and expressions appropriate for use in rural communities. The instrument was then formatted, piloted during the field worker and supervisor training, and final adjustments made.⁴

The five survey teams, recruited and managed by the National Statistics Directorate, were comprised of personnel who had worked on previous surveys and spoke one or more of the local languages used in their assigned data collection areas, enabling them to draw on those language skills when necessary.

3.3.2 Qualitative

Qualitative instruments (guides for entry interviews with village heads, in-depth interviews with service users and providers, and FGDs) were refined during the training and early phases of data collection. Training activities provided opportunities to clarify the framing of questions, and probes for more information, as well as their sequence. Language received particular attention and nearly all words of Portuguese origin were replaced, where possible, with conversational Tetum. Technical terms in Indonesian were placed in text brackets alongside the Tetum expression where appropriate.

In-depth interviews with service users, and both traditional and government or NGO providers, were piloted in Aileu district. Sentence structure and language were further simplified in response to experience, and semi-structured interview guides were finalised for use in three districts.

Training for running FGDs used an initial guide which was further developed through role play and demonstration activities. Team members were trained in particular roles as facilitators, note-takers and observers. Feedback resulted in refinements to the sequence of questions and probes, and simplification of sentence structure and language. These tools were used in 10 districts with the team preparing transcripts of FGDs in the field for further clarification, analysis and coding.

Modifications to the FGD guide were made mid-way through fieldwork as data saturation became apparent in some areas. These questions were then removed, as were a small number of questions which had consistently failed to elicit meaningful responses. Probes that elicited vague responses were re-framed and some questions added in response to emerging areas of interest, such as the role of parents-in-law in relation to stopping fertility (rendering infertile)⁵ and birth spacing, and the types of difficulties with which a TBA can assist.

Qualitative team members spoke a range of languages (Baequeno, Makassae, Tetum Terik, Mambae, Fataluku) with varying degrees of fluency. An Alola district support worker fluent in the local language in each research site was recruited to interpret where requested by FGD participants or facilitators.

⁴ Copies of the questionnaire (English and Tetum versions) and other research instruments are available on request.

⁵ Mentioned as *halo para*.

3.4 Analysis

3.4.1 Survey

Initial analyses of both TLSLS and HCSBS datasets were carried out using *STATA 10* [44].

The cross-sectional component of the TLSLS only was included in the analysis, panel data was excluded. Health care seeking variables were analysed to provide prevalence rates for behaviours, beliefs and actions in the Timor-Leste population. Sample prevalence rates are reported here. As the design of the TLSLS aimed to represent the population, sample rates are likely to be indicative of national prevalence rates. Results are also available by district [6].

Sample prevalence rates for the health seeking behaviours included in the HCSBS survey are also reported here. As the sample was designed to be typical of rural areas, the results reported here are likely to be reflective of the rural population of Timor-Leste.⁶ This Study aimed to reflect rural experience generally, and did not seek to, and was not statistically powered to, analyse differences between districts.

3.4.2 Qualitative

Handwritten notes were made at the time of each interview and FGD, and were the same day typed into full notes with the aid of the digital recording. On average, each in-depth interview team (1 interviewer, 1 note-taker) completed 2-3 interviews per day, and each FGD team (1 facilitator, 2 note-takers) conducted and developed full notes for one FGD per day. Seventy-three in-depth interviews, including 13 entry interviews with village heads, were conducted and 38 FGDs. *NVivo8* [45] computer software was used to facilitate data management and analysis. Full interview records in Tetum were read together by the Timorese senior researcher and Australian data specialist, and following discussion, coded for emergent themes. Clarification was sought from the interviewer where the informant's response was unclear.

Coding reflected the key issues covered by the instruments (FGD scenarios related to difficult birth, problematic diarrhoea in a child aged 1-5, and birth spacing) as well as themes which were identified during the process of reading and coding interview records. Content that threw light on user and provider experiences and understanding of the three levels of delay⁷, the range and sequence of actions taken to seek help, and the elements that constituted a positive experience and outcome was also sought out. Use of traditional providers and perception of custom as cause of illness, and how these two factors impact on health care seeking behaviour, in particular use of government health facilities, was considered integral to the research.

Some content was also coded for general interest: locally used words to describe health and related conditions which were grouped into a glossary; and insights that may prove of value for teaching and training activities.

⁶ These data should be treated as preliminary.

⁷ First-level delay: decision to seek health care; second-level delay: getting to an appropriate health provider; third-level delay: receiving treatment in the health facility [2].

3.5 Ethics

Ethics approval was obtained through the Human Research Ethics Committee of the University of New South Wales, with the support of the Ministry of Health of Timor-Leste. Issues identified as warranting attention were the development of a response to any ill household members identified during the household survey. A local ombudsman was identified should there be any complaints regarding the conduct of the research. Verbal informed consent was required for all interviews; a simple verbal description of the research preceded signing. Verbal approval was digitally recorded for all FGDs as well as for all users and traditional providers, and signed informed consent forms for 13 entry interviews with *xefe* and all other providers.

Section 4 – Results

4.1 Participants

4.1.1 Survey

TLCLS

The TLCLS cross-sectional sample included 4,500 households, comprising 25,000 individuals. The sample was approximately half male (50.8%) and half female (49.2%). The ages of the household members ranged from 0–98 years, with an average age of 23 years. Half (50.6%) were aged 18 or over; among this group 61.9% were married, 27.9% never married, 9.2% widowed and less than 1% divorced or separated.

The most commonly reported mother tongue was Mambae (22.5%), followed by Tetum (17.7%) and Baequeno (14.2%). All other mother tongues were reported at rates less than 10%. Most people spoke Tetum (86.4%) even if it was not their mother tongue, and over a third (39.7%) spoke Bahasa Indonesian. A further 15.8% reported speaking Portuguese and only 4.6% spoke English. Consistent with the largely subsistence population of Timor-Leste, the main occupations cited were school student (25.4%), farmer (19.2%) farm labourer (17.4%) and housewife (16.5%), most of whom also worked in the fields.

HCSBS

The final HCSBS sample included 535 households, comprising 3,126 individuals. Similar to the TLCLS sample, the HCSBS sample was approximately half men (50.5%) and half female (49.5%). Ages ranged from 0–94 years, with 52.1% aged 18 or over. Most of those over 18 years (60.3%) were married, with 29.0% never married, 9.2% widowed and less than 1% divorced or separated.

In this sample the most widely spoken mother tongue was Mambae (28.1%) with Tokodete (8.4%), Tetum (7.8%) and Tetum Terik (7.6%) the next most common. A large proportion reported to be able to speak Tetum (83.4%), over a third spoke Bahasa Indonesian (37.8%), and slightly more than in the TLCLS spoke Portuguese (21.8%) and English (7.1%). Occupations were broadly similar to the TLCLS sample: school student (34.6%), housewife (12.5%) and farm labourer or farmer (15.9%, 7.1%), although there was a greater proportion of students in HCSBS.

Across all 13 districts, health care seeking data was collected from 535 household heads (equivalent to a 92% response rate based on a target of 585) and 771 individuals—404 women (69% response rate) and 367 men (63% response rate). Most of the missing households had declined to participate; a few had moved.

4.1.2 Qualitative

Thirteen interviews were conducted with village heads.

Thirty-two interviews were conducted with providers: 6 midwives, 5 nurses, 2 nurse assistants, 4 doctors, 2 PSFs, 1 pharmacy assistant, 1 clinic manager, 1 leprosy consultant, 1 kiosk medicine seller and 1 traditional medicine producer, as well as 5 TBAs (usually mentioned as *daia*, also *dukun*, *badaen liman*, *liman loos*), 1 healer-shaman (*matan dook*) and 2 bone setters (*ruin tohar*).⁸ One provider (kiosk medicine seller) withdrew permission to use his information at the conclusion of the interview.

Twenty-nine interviews were conducted with service users: 22 women, 6 men, and the parents of a sick child (interviewed together). The female users included 5 women accompanying sick children to the health facility and 1 woman attending for family planning.

A total of 38 FGDs were held across 10 districts, with a maximum of 8 and minimum of 4 participants in each group. FGDs for married women (10 FGDs with a total of 78 participants) and married men (10 FGDs, 75 participants) were better attended than those for adolescent females (9 groups, 56 participants) and adolescent males (9 groups, 52 participants). Overall, the level of participation and discussion was higher in the men's groups than the women's groups.

4.2 General health care seeking

4.2.1 Problems experienced and providers used

TLSLS

In the TLSLS 23.3% of the total 25,000 individuals reported that they had experienced a health problem in the previous 30 days. The most prevalent complaint was a cough (31.6%), which was more than twice as common as the next most prevalent complaint, a fever or “dengue fever”. Malaria (self-defined) was also commonly reported; other complaints included headaches, stomach ache, joint/muscle pain and cold (Table 1). Amongst those that had experienced a health problem in that time, 17.3% were unaffected in terms of capacity to work, however 50.6% missed 1–5 days of work.

Treatment for the illness was sought by 76.6% of those who reported a health complaint in the past 30 days. The primary reason for not seeking treatment was also ascertained and two reasons emerged as most important: “not serious enough” (45.6%) and “health facility too far” (36.7%).

⁸ This report translates ‘*matan dook*’ (literally eye + far) as healer-shaman (following the lead of the World Bank’s qualitative study into health service delivery and utilisation prepared by Alexander Edmonds). The healer-shaman was included as one of several traditional providers who are influential in relation to health care seeking. Where custom (*adat*) is suspected to be the cause of illness, a *matan dook* may be consulted to assist a household to determine the nature of the cause and facilitate the resolution of unsettled custom matters, thereby clearing the way for a traditional or biomedical treatment to relieve the person’s symptoms. In this sense, the HCSBS refers to the Timorese practice of consulting a healer-shaman as constituting a health care seeking action.

Other reasons, such as “health workers not present” (3.1%) or “no transport” (2.6%), were less frequently cited.

The health facility that was most often visited first was a public hospital, followed by a health clinic and a public health post.⁹ Cuban doctors were recorded a separate category and 12.8% said that they had visited a Cuban doctor first. In the TLSLS only 0.3% reported visiting a traditional practitioner first (Table 2).

The primary reasons reported for visiting a health facility were for a consultation (76.7%) or for treatment of illness (12.1%). The secondary reasons given were much the same: medications (75.2%) and consultation (12.8%). Visiting for other reasons, such as prenatal checks and immunisation, was rarely reported (<1%), but this may reflect the question about visiting facilities being asked in the context of a ‘health problem’.

HCSBS

The HCSBS survey enquired into all health providers seen in the previous 12 months by anyone in the household (see Figure 3 in attachment, also Table 8 in Appendix 6). Government providers featured most prominently, with over a third of all households using government health facilities. Private providers and traditional providers were consulted at similar rates. Family health promoters (PSF) and pharmacists were also consulted. The much higher reported use of traditional providers compared to the TLSLS may be a reflection of methodology, as the explanation given during the HCSBS, and the initial questions on home remedies and help-seeking within the family, made it quite clear that all sources of health care were of interest.

4.2.2 Physical factors

Long distances to health facilities discourage attendance, in particular for non-urgent conditions and preventive care, and also for severe conditions because the journey itself is perceived to contribute to deterioration in the patient’s condition. During the wet season, even short distances can become impassable. Communities deploy various strategies to overcome the physical barriers. In some cases the long journey stimulates collective action, for example in relation to groups of women walking together to facilities to support and protect one another.

In the HCSBS survey, travel time to a health facility for the most recent visit by a household member was under 1 hour in 44.9% of cases. Nearly a third of patients (29.2%), however, had to travel for over two hours, while 5.1% had to travel for over five hours. Most people (77.9%) walked to the facility; others went by motorbike (9.2%), microlet (3.8%), car (1.3%) or bicycle (1.7%).

In the qualitative work, distance was highlighted as having a major influence on health service usage. At one research site, informants said that when there had been a health post in their aldeia they attended ‘continuously’ (*beibeik*) for minor and serious complaints, but since the facility had been relocated elsewhere in the *suco* their ability to access services had greatly diminished.

Long distances (e.g. 24km round trip for villagers from Citrana aldeia walking to Baocnana sub-district, Oecusse) to health facilities discouraged attendance for non-urgent conditions and preventive activities such as antenatal care and immunisation. Informants claimed that the long journey, up- and down-hill, to the health post could cause deterioration in a person’s condition. For

⁹ Caution is needed in interpreting these data as rural Timorese may use the term ‘*hospital*’ as a generic term to refer to any government health facility. We found this to be the case in the HCSBS service user interviews and FGDs.

mothers carrying infants the journey could be exhausting (e.g. leaving an aldeia in Osso Ala at 3am to arrive at the closest health post located at Loilubo by 7 or 8am, in Baucau). Long distances also discouraged attendance for severe conditions as the patient was too weak to attend. This situation was described as *'hein deit atu mate'* ('just waiting to die'). An ill-person could only make the journey to a distant health facility when they had sufficient strength to do so.

Innovative responses to the long walk to services were also reported: women from research sites in Baucau, Ainaro, Aileu, Ermera, and Lautem mentioned walking together (*lao hamutuk*) with other women to obtain antenatal and neonatal care, as well as immunisation. For illness that emerged suddenly or was severe, a woman's husband, or older female relative usually accompanied the woman and her children. In Ponilala (Ermera) women formed groups to travel to the health facility out of fear for their personal safety.

During the wet season, flooded rivers and roads and slippery (*namdoras*) wet clay tracks reduced access to government health facilities even those nearby, and women typically relied on TBAs for delivery.

Communities deployed various strategies to gain access to health facilities. In situations where a person fell gravely ill, or a woman encountered difficult labour, relatives summoned health staff or procured an ambulance by borrowing a motorbike. In some cases they sought assistance with transport from the village head or police officer. In extreme circumstances, family and neighbours may carry (*hulan/leba*) a person on a bamboo stretcher wrapped in a cloth tube (*lipa*), chair, or push the patient in a two-wheeled cart usually used for carting water (*gerobak*), to the closest road or health facility. Carrying or stretchering a woman in difficult labour over a long distance was considered to be potentially dangerous, even contributing to her death (*iis kotu* = breath + sever). In some cases a husband was compelled to seek help for his wife in difficult labour, leaving her alone with many small children.

4.2.3 Economic factors

Economic factors further complicate access to health facilities. Various costs are associated with health care seeking. Traditional providers may negotiate a payment (*kasu*), for positive outcomes. In relation to government health providers there was no evidence of routine charging of fees. Government health providers did, on occasion, charge for privately administering a service or for offering services out-of-hours. Costs were also associated with obtaining medications (traditional or biomedical) and referral to another health facility, including procuring transport and accompanying the patient to the facility.

Traditional providers (TBAs, healer-shaman, bonesetters) may charge a fee for service, cash and/or in-kind, where the outcome is positive. *Kasu* is a type of ritual payment which compensates the provider for the treatment and is also meant to ensure that the cured person does not fall sick again. For example, a bonesetter in Baucau mentioned payment comprising *lipa* (cotton sarong), live chickens and \$US50. Others mentioned cooked meat from chicken, goat, or pig. It said that a TBA would expect *kasu* after successful delivery otherwise they may feel that they assisted the birth 'for nothing', i.e. without benefit (*saugati deit*).¹⁰ No situations were reported of government health workers routinely charging a fee for service. However, we were told of one provider who charged a

¹⁰ *Saugati* = free, gift.

fee for privately administering a family planning injection when the government supply had run out, and of a midwife who charged a fee for assisting with a difficult labour out-of-hours.

Government and non-government facilities were reported to stock different brand-name drugs. Some users preferred to attend private or church clinics and pay for drugs that they perceived to be more effective than those available at no cost through government health facilities. Others chose government facilities because medication was free.

In the TLSLS, the majority (80%) of those that visited health facilities reported that they did not pay for transport to get there. Some (11.7%) paid under a dollar, 7.3% paid 1-5 dollars and 1.1% paid over 5 dollars. In the HCSBS qualitative component, the cost of transport was mentioned as another barrier to access. Where a patient's condition is grave and they cannot walk or be easily carried to a health facility, household members may procure private transport. For example, one man paid US \$30 to hire a private vehicle to take a woman in difficult labour to hospital. The cash shortage experienced by farmers until the main harvest at the end of the wet season limits such solutions. In general, the cost of transport to a health facility was considered justified in the case of a positive outcome; if not, it was considered a waste of money that might have paid for children's education.

Referral to a government hospital with an in-patient facility (*baixa*) generates living expenses for accompanying family members. Where a patient is referred to a distant health facility for treatment for a chronic condition, the escorts may stay with relatives living nearby.

4.2.4 Socio-cultural factors

Family members are very involved in health care seeking; both making and then enacting decisions about when and where to seek help. Neighbours and local authorities may become involved; carrying or transporting patients to urgently required services. The husband's parents may be involved in decisions related to spacing children or using contraceptives. Family and community members were often involved in situations where ill-health was considered to be related to traditional or custom matters.

How community members respond to health problems reflects social and cultural influences. People who seek health care rarely act in isolation and are themselves members of households, extended family groups, and communities. All of these, as well as cultural, religious and political leaders and authorities, have an influence on individual decisions.

In Timor, women are connected to a geographical location and associated cultural traditions and language by virtue of their own and/or their husband's birthplace. Both sets of parents may be involved in decisions and actions to call a nurse or midwife to the home, or transport a sick woman to a health facility. Although most married women live with their husband's family, on some occasions, including the experience of difficult child birth, the woman's own parents may be included in the decision to seek assistance. This may be seen as sharing the risk and guarding against blame (*tau todan*) should something go wrong. Particularly when a woman's husband is absent or working outside of the sub-district, neighbours may be involved in procuring transport, and local authorities such as village heads may encourage the family to seek care or assist in conveying the patient to the health facility or fetching the midwife.

An elderly patient's children or a woman's spouse or in-laws may be involved in the decision to refer the patient to a larger facility, or to allow surgery. Concerns about the expense of transporting a

deceased patient home may be a consideration in deciding to send a very ill person away for treatment, given the cultural imperative for burial in the village of origin.

In Lautem, a woman's parents-in-law and sister-in-law may be involved in a woman's decision to space children or stop fertility (*halo para*) using traditional methods; this is related to bride-price (see also section 4.5 Birth Spacing). While the HCSBS did not specifically seek to look at perceptions of church doctrine in relation to contraception, or direct statements from religious officials, two informants mentioned these as influencing people's attitude towards taking up birth spacing.

Matters of custom were frequently brought up in relation to health care seeking. Custom was usually mentioned as *adat*. The process of determining and resolving the unsettled customary matter was usually mentioned as *hadea* or *hamos uma nia laran* (literally, to fix or clean the house). Custom factors may be suspected if the onset of illness is sudden (*derepent*) and severe (*todan*), or has not previously occurred (e.g. difficult birth experienced after several normal births), or where modern medicine does not effect a 'cure' (*kura*, or *pasa*). Custom factors reported included neglecting to contribute to maintenance of a ritual house, and failing to 'remember' deceased family members or negotiate bride price (*barlake*). Social transgressions mentioned included stealing, conflict with family members or neighbours, and speaking badly (*tolok*) to others.¹¹

Issues of custom do not necessarily delay seeking care as this may be sought and obtained at the same time as determining and responding to the custom-related factors. Sometimes custom-related issues are addressed after treatment has been obtained; at other times (e.g. where parents suspect custom from the outset) rituals may be carried out prior to seeking any hospital treatment. Parents, in-laws, and elderly relatives may all be involved in household-level actions to determine and resolve matters of custom. Local ritual specialists or healer-shaman (*matan dook*) may also be summoned to assist.

4.2.5 User-provider interaction

Patients seek a number of components within a consultation. Overall, they are looking for a comprehensive approach which treats them holistically and with respect. In addition, they have clear expectations about specific stages of the consultation process: reception/registration, examination, treatment (usually with medication) and referral. When they have travelled a long distance, they expect to be seen even if they arrive out of hours or without their registration card. In emergency cases, they expect to be seen when they arrive. Users are discouraged from seeking help in the future by health worker anger and blame; they are encouraged by demonstrations of empathy.

While health service users judge the quality of the service on the outcome, they are also concerned with the nature of the interaction with the provider during the consultation. Users expected providers to acknowledge the long distances they had travelled to the health facility and the fact that this may result in late arrival. In such cases, they expected to still be attended (examined and prescribed medication) even if they arrived outside of the usual registration hours (in some places reported to be 8 to 10am). Families also expected providers to be available out-of-hours for emergencies such as difficult labour.

¹¹ In Timor-Leste, illness in one generation may be the result of a social transgression/customary neglect carried out by another generation e.g. a deceased or living older relative.

Users were discouraged by anger (usually *hirus* sometimes *siak*) expressed towards them by health workers. This was conveyed by an angry facial expression *hatudu oin*, or yelling *hakilar*, both mentioned as *trata*. Users described providers being angry about late arrival and not washing before arrival, as well as for failure of a child to gain weight, for incomplete vaccination and for not exclusively breastfeeding. Health workers were sometimes angry if the parent asked directly for medicine.

Anticipating provider anger could cause people to delay, or not to use services at all. If a woman did not go to the health facility to deliver, against the nurse's recommendations, it was anticipated that staff would later be cross with her. Similarly, if a woman did not attend antenatal care, it was expected that staff would be reluctant to assist her in the event of difficult labour as she would not be 'registered'. One mother was discouraged by a nurse recommending consumption of fish for an underweight infant in a situation where the family lived far from the coast and had no access to this food (see Box 1). Another felt blamed for her child's condition.

Patients expected an examination process in which the provider asked about symptoms and elicited the history of the condition. Mention of possible causes was viewed positively, e.g. when a provider asked a patient suffering from itchy throat (*kakorok katar*) whether they had used another person's towel and soap which might have transmitted the sickness. Preventive advice was also viewed positively, e.g. in relation to foods to be eaten or avoided.

Patients appreciated being given priority in urgent cases, e.g. a knife injury with bleeding or a high fever. They also appreciated being asked to give permission for surgery, such as a caesarean section, before this was to be performed. They were also encouraged by providers 'serving' or looking after them (mentioned as *melayani*; see Box 2). Other positive examples included providers who invited the patient to sit down after a long journey, advised them to walk home slowly and rest on the way, or were willing to see them even if they had left their patient card at home (see Box 3).

4.2.6 Equipment and staff

In deciding where to go for help, people wanted facilities that were equipped with basic diagnostic and procedural equipment and staffed by qualified and well-trained staff; several indicated a preference for seeing a doctor.

Community members spoke of the need for scales (for weighing babies and adults with conditions causing weight loss such as TB), a stethoscope, an ophthalmoscope (to look into the patient's eyes), and laboratory equipment for screening blood for malaria and sputum (*kaben tasak*) for TB. In relation to screening for malaria, one user sought out a health facility that provided immediate test results.

Similar considerations were raised in talking about child birth. Families appreciated oxygen equipment for women with breathing difficulties, a sphygmomanometer (for monitoring blood pressure), drugs for stopping post-partum haemorrhage and transfusion equipment for severe haemorrhage. An intravenous drip was perceived as being able to restore the energy of a woman during a long labour.

Informants mentioned various birth difficulties that could not be assisted by a TBA and required formal health services, e.g. baby in breech position, long labour and haemorrhage (see also section 4.4). Some of these problems were identified as requiring surgical intervention, as in the case of an

episiotomy (mentioned literally as 'to cut' *koa* or *tesi*) or retained placenta. When a caesarean section was required most respondents recognised this as potentially saving the life of the mother and child, even though it caused suffering (*terus*) to the woman and was a potentially fatal operation that brought much worry to the woman's family (see Box 4). It was also remarked that an initial caesarean may result in subsequent caesareans and associated health problems for the mother and baby (*la hetan saude diak* = does not get good health), and that a woman incapacitated by a caesarean may be unfit to do heavy work again.

Several users recalled that they sought out facilities staffed by doctors. One said that a doctor would necessarily conduct an examination, whereas if there was no doctor staff may prescribe medication without doing this. Two users from Dili, where there was more ready access to doctors, suggested that doctors were able to prescribe more effective medicine and that a medical consultation was more likely to obtain good result (e.g. weight gain in a patient with lung problems, possibly TB; see Box 5).

4.2.7 Medication

In relation to treatment, users of health services had a number of expectations. These included being prescribed medication; having routine medications always available, especially for chronic conditions requiring repeats; receiving different medications for different symptoms; experiencing immediate effects; and receiving the same medication, if effective, when they next experience the same symptoms. Instead of completing the full course, patients may set aside some of the medicine obtained for use on a later occasion, by themselves, other household members or neighbours.

Nearly all users praised modern medicine (also mentioned as *ai moruk hospital* or *ai moruk malae*) for its efficacy in 'curing' (mentioned as *kura* or *pasa*) illness. One informant explained the potency of modern medicine as related to the fact that you drink it and it spreads quickly through the system for an immediate effect (*halo diak kedas*). Some claimed that traditional medicine (mentioned as *ai moruk tradisional* or *ai moruk Timor*), rather than modern medicine, 'suited' their body and was effective. Others claimed that, unlike modern medicine, it was not well understood which traditional medicines could be applied effectively to which illnesses, and some could be harmful. Whereas modern medicine is administered with standard doses, it was difficult to know the dose for traditional medicine (see Box 6).

Some users mentioned that traditional medicines may be effective initially (itchy body or *isin katar* was mentioned) but the condition returned later. Some users switched between modern and traditional medicine where symptoms persisted over an extended period of time, sometimes for many years. Neither modern nor traditional medicine was perceived to be effective against an illness caused by unsettled custom matters.

Where modern medicine did not relieve symptoms, some users claimed this signified custom as the cause, while others returned to the health facility to get different medicine. Some users expected an immediate effect (indicating that providers need to educate users about the delay). One user expected each symptom to be treated with a separate medication, and claimed that one medication prescribed for multiple symptoms (diarrhoea and headache) would not be effective. Others expected

to be prescribed the same medicine that had previously cured those same symptoms, and were less satisfied when prescribed a different, unfamiliar medicine.

Prescribed medication was fundamental to immediate patient satisfaction in the consultation process. Lasting satisfaction was achieved by a positive outcome such as cure or relief of symptoms. Users trusted (*fiar*) medicines that had cured a condition (headache given as example), and distrusted (*la fiar*) medicines where cure had not occurred (worms given as example).

Several users who lived a long distance from a health facility and without access to a pharmacy or kiosk, ensured their access to modern medicine by setting aside part of a course of treatment (mentioned as *rai* meaning to keep or to store) for use at a later stage (see Box 7). When a child subsequently fell ill (with such symptoms as diarrhoea, headache or itchy body), parents administered the medicine from the stored supply. Several informants mentioned obtaining the drugs from a relative or neighbour who had recently suffered the same illness and may have set some medicines aside, thus avoiding the long journey to the health post. These strategies highlight people's demand for modern medicine and the difficulties encountered by families in getting sick member (child or adult) to distant health facilities (see Box 8).

Drugs were also purchased from kiosks, obtained from teachers or village leaders, or from health providers (out-of-hours) at home. One village head mentioned a retired nurse who had established a small business selling medicine and administering injections for a fee. Where a health post was located nearby a market, and both were distant from the village, a few users and providers spoke of taking the opportunity to 'get medication' by visiting the service when they took their produce to market.

4.2.8 Referral

A provider may recognise that the user's condition is beyond the capacity of that level of health facility to treat, and recommend referral. Some users did not perceive this as a problem unless delay in getting to the facility of referral resulted in a negative outcome. Many actually expressed satisfaction that the provider had the institutional support to refer to a higher level facility to increase the likelihood of a positive outcome. Positive views of services are conveyed to others; so too are negative experiences.

There was general appreciation of the health service referral system, with capacity for addressing emergencies at higher levels. However, users resisted referral for elderly patients where they believed a negative outcome (death in hospital) would result. A doctor working in the national hospital also mentioned that providers need to better identify illnesses for which referral is appropriate and may result in a positive outcome. In the event of a negative outcome, particularly death of a patient, the provider may be blamed. (In cases other than death, it appears that provider responsibility may be partly mitigated if that they had been approached for help by the patient's family, as opposed to spontaneously offered their services).

Dissatisfaction by users following negative outcomes or poor interactions with staff were likely to be repeated at the village level and incorporated alongside other negative views of the services. One respondent indicated "if they take their child (to a health facility) and the final result is good, then they will boast about the health facility, but if the child is not cured and they must take him to

another health facility, and the child gets well, then they will talk badly (to others) about the results of the (previous) health facility".¹²

4.3 Seeking help for a child with diarrhoea

Parents recognise many of the danger signs associated with diarrhoea in a child and its increasing severity. The initial response is typically at household level (homemade rehydration and/or boiled leaves); only if diarrhoea persists is the child taken to a health facility. Where health facility treatment is not effective, the family often suspects custom factors as the cause. Health facility treatment may be resumed after the custom matter is resolved.

The TLSLS inquired into the presence and treatment of diarrhoea in children. Some 10.1% of children under 5-years old had experienced diarrhoea in the past 30 days, with the majority (70.8%) being 2 years or under. Nearly half (45.1%) of all children were given breast-milk during this time, but for those under one this figure was 75.6% and for those under two it was 55%. Over two-thirds (68.3%) of the children were given rice porridge (*sasoro*) to drink, including 53.7% of babies under 1 year. Over three-quarters (78.9%) were given oral rehydration solution, with a relatively similar rate across all age groups.

In the HCBSC user interviews and FGDs, various signs and symptoms of diarrhoea were mentioned: stickiness, odour, liquid only and motion mixed with blood. Symptoms indicating seriousness included diarrhoea and vomiting after eating, cold limbs, dazed, and dizziness, lethargy and becoming weak or soft-bodied. Other indicators included distended stomach; dry hair, lips and facial skin; runny nose; gums becoming white; stomach becoming reddened; no weight gain; deep-set eyes and sallowness.

A child with diarrhoea may demonstrate the following behaviours: crying (including crying while throwing their limbs around), screaming, drinking water only, passing diarrhoea during the night or on waking, sleeping fitfully, and being drowsy or nauseas. Diarrhoea accompanied by vomiting and diarrhoea that could not be cured by traditional medicine were considered especially worrying, while diarrhoea associated with teething in an infant was considered to be normal.

Many informants said that they tried boiled leaves first, proceeding to 'Oralyte' (rehydration medicine comprising a sugar and salt mix) if there was no change. Some understood the purpose of Oralyte to *aguenta* or 'hold' the symptoms during the night or over the weekend until the closest health facility opened. Others believed Oralyte could cure diarrhoea and waited to observe the outcome. Other actions taken within the household included a cold compress applied to stomach; pulverised candlenut or coconut oil rubbed on stomach; cutting child's nails; ash pressed to child's navel; and feeding child boiled banana, rice/sago porridge, or popped corn ground into flour. Traditional methods, such as holding (*kaer*) the stomach, was believed to be effective for a churning stomach (*kabun dulas*) where no diarrhoea was present.

There were four main groups of causes associated with diarrhoea, as detailed in Figure 5 in attachment: breastfeeding, contamination, foods eaten and seasons. Other causes identified

¹² 'Enquanto sira lori ba resultadu final hanesan diak berarti sira kontente, sira hanesan gaba tiha hospital ne'e. Mais enquanto sira nia oan la diak, hanesan lori fali ba hospital seluk, mak nia oan diak, ne'e diak bertaria sira koalia trata aat loos hospital ne'e nia resultado ne'e' (Adolescent woman, FGD, Viqueque).

included teething, incomplete vaccination, worms and *anin tama kabun* (literally: wind + enter + stomach).

Delay in deciding to take a child to a health facility may occur where parents perceive serious diarrhoea to be caused by custom (neglected customary duty or social transgression). Parents may suspect (*deskonfia*) that this is the case if they are aware of a pre-existing unresolved social matter, or they know they have neglected customary duties. In many cases, however, parents take a child to a health facility after home remedies do not effect a cure. If this treatment is also not effective (for diarrhoea due to custom neither traditional nor modern medicine will work), then they will carry out a ritual to determine whether custom is the cause.

Family members may carry out the ritual to determine the cause and then take steps towards resolving the problem themselves, or they may engage a healer-shaman (*matan dook*). Other actions reported that related to belief in custom as cause of diarrhoea included praying to God (*Maromak*) for help, or calling on (*hamulak*) the ancestors (*matebian*) to overcome the effect of the malevolent action, or attending the ritual house. Additionally, people may pray to God or the ancestors to make potent, or enspirit, the traditional medicine (root, bark, leaves) used to cure the child.

Interaction with health providers for diarrhoea

Where custom was not considered to be the cause, or had already been determined and resolved, and parents took a child suffering from diarrhoea to a health facility they were generally satisfied with the outcome. This resulted from rapid diagnosis and effective treatment relieving the symptoms.

However, if a child's symptoms were not relieved, or returned, and the parents took the child back to the facility, several informants felt that they were interrupting, even annoying (*satia beibeik*), the staff. In two cases, parents reported being asked to explain why they had come back with their child when they had been previously referred elsewhere. In the first, the parents of a 16-month old child with bloody diarrhoea (*tee raan*) took the child to a church clinic, were referred to a district-level health centre without positive outcome, and then returned to the church clinic. In the second case, a child with diarrhoea was admitted as a hospital in-patient without positive outcome, returned home to seek traditional medicine also without positive outcome, and was returned again to hospital.

Positive interactions and practices in relation to provider treatment of a child with diarrhoea were also related. For example, upon arrival to a district-level health facility an 18-month old child with bloody diarrhoea was given immediate attention with full examination and medication. The midwife then requested the mother to permit the infant to remain in the facility until the end of the day to allow observation of the effect of the medicine, and explained that the infant should be admitted overnight if its condition had not improved, otherwise they could return home. Positive experiences of this sort instilled in the community a sense of trust and support for the health system.

4.4 Seeking help for a difficult birth

It is generally assumed that most births will be normal and therefore are able to take place at home with the support and assistance of family. While a TBA may assist, women and men do recognise difficulties and complications that are beyond their skills. Late recognition of problems results in delay in getting assistance. Custom-related issues and social transgression by the husband, wife or family members were the most commonly perceived causes of difficult birth.

Resolution of custom matters may be pursued concurrently while the woman is being taken to a health facility.

Birth rates are high in Timor-Leste, and maternal and neonatal mortality continue to be extremely high. In the TLSLS, 48.9% of married women aged 15–49 had given birth during the previous two years. In most cases these births were attended by a TBA (28.3%) or a midwife (27.8%). Relatives or friends were also commonly in attendance (19.0%), however a doctor was present for only 7.9% of births.

Within the HCSBS, in the eyes of the community, a delivery considered to be unproblematic requires only one's husband to assist (or mother-in-law, or mother, or elderly female relative), with a midwife or nurse consulted for postnatal care only. In the case of a normal birth the baby is described as soft headed (*ulun mamar*) as opposed to the hard-headed baby (*ulun to'os*) of a difficult birth. Here, soft and hard refer to the baby's willingness to be delivered or not, resulting in prolonged and difficult, or unproblematic labour.

For an unproblematic birth at home, a woman may or may not call a TBA to assist. Many informants used the term 'trained TBA' (*dukun terlatih*) to distinguish those TBAs provided with training and resourced during the Indonesian period from those TBAs who have never been trained. Several said that TBAs are able to determine an incorrect (antenatal) position of a baby mentioned as 'lying wrong' (*toba salah*), and re-position or turn (*fila*) the baby manually by 'holding and pushing' (*dudu kaer*) or, during labour, by 'holding the sides of the stomach and pushing down to correct' (*kaer husi kabun sorin dudu tun no halo los*) (see Box 9).

A few informants (and several government health providers) mentioned infection resulting from the TBA cutting and tying the umbilical cord.

Informants described various actions taken within the household in the event of difficult birth. These included applying hot compresses, giving hot water to drink, elevating the woman's legs by tying them up with cord to reduce bleeding, giving traditional medicine (e.g. certain leaves kneaded (*dulas*) into a ball and applied to the stomach), providing a bottle into which the woman could exhale or blow, and suspending a rope from the ceiling by which the woman could support herself. (Many of these household-level actions are probably taken also for births considered to be unproblematic.)

A TBA may be called to assist a difficult birth when the labour takes place during the night, when the health facility is far and there is no transport, or when the road to the health facility is cut by flooding during the wet season. Difficulties mentioned for which a TBA could not assist, and for which exhaustive efforts were then taken, sometimes unsuccessfully, by family members to call a midwife to the house or transport the woman to a health facility included haemorrhage, baby's arm or leg first, long labour, retained placenta, woman has no energy to push, and excessively large baby. Help was also sought from midwives if waters broke early or labour began prematurely. One married man observed that, in the context of a difficult birth, the doctors (i.e. health workers) "know what is inside, we can only see outside".¹³

Informants mentioned almost 30 forms of difficult birth, with the most common being retained placenta, baby's arm or leg delivers first, long labour, position of baby, twins and stillbirth. Other

¹³ 'Tamba inan isin rua ne'e ita hare deit husi liur maibe laran ne'e ita la hatene lolos doctor sira mak hatene nebe lori ba iha doctor sira hodi koko' (Married man, FGD, Manututu).

difficulties included those related to the mother (first birth, very young mother, old mother) and those occurring in the pregnancy (e.g. spontaneous miscarriage, premature labour or early rupture of membranes, anaemia and heart-condition). Problems arising during delivery included blue baby, mother breathless (*iis la to'o*) and/or too weak to push, excessively large baby and/or large head, arms and legs of woman without strength (*mamar*), placenta delivers first, or 'white blood' (*raan mutin*)—fainting or light-headedness or swelling to the eyes believed to result from the woman becoming cold after delivery and white blood rising to the head. *Raan mutin* is usually treated with a hot compress or warmed palm wine/*tuak* to drink. Problems following delivery included infection as a result of cutting and tying the umbilical cord, postpartum haemorrhage, and malaria in the newborn.

Several advantages of calling a midwife to assist a difficult labour, or delivering in a health facility, were mentioned. It was said that a health provider (unlike a TBA) could advise the right time to push, preventing premature pushing (*hakas-an demais*) leading to exhaustion.¹⁴ Second, in a health facility environment a woman is free to pace up and down, whereas at home she is confined to the house (due to not wanting other people to know that she is in labour as it is considered a private matter). Third, where a provider is unable to manage the problem identified at that level, they are able to refer to a higher level health facility. A few informants perceived that a facility-based delivery would be quicker than delivery at home.

Women could be discouraged from calling a midwife or delivering in a health facility where they anticipated *trata* from staff such as being yelled at (*hakilar*) when they screamed out early in the labour, or where they arrived to hospital without washing, or in one case, shaving (*koi*) their pubis. Additionally, some women mentioned that they felt embarrassed to scream out during labour in a health facility, or deliver in the presence of many people. Some also mentioned that it was not good to scream during a home birth as one's neighbours could hear.¹⁵

Custom-related issues and social transgression by the husband, wife or family members¹⁶ were the most commonly perceived causes of difficult birth. Other reported causes, in order of frequency, were a lack of antenatal care, the woman working too hard or walking up- and down-hill too much and poor nutrition. Malaria, incomplete vaccination in the mother, too many people in the house (baby would choose to be born only when they had left) and lying down to give birth (causing the placenta to be retained) were each mentioned by one person.

When a difficult labour is believed to relate to a neglected customary matter, the family may carry out a ritual to determine the cause and take steps to resolve the problem in order to facilitate delivery, or they may sit and discuss problem with family members, or go to the ritual house. Determining and resolving the problem does not always require that the woman herself be present; such actions may be taken prior to her leaving for the health facility or while she is making the journey. One informant said that, if a woman faces difficulty in labour and is far from a health facility,

¹⁴ '*Nia hanesan mai koko oras too ona labarik ne nia mesak sai deit, inan nia labele hakas an demais*' (Married man, FGD, Viqueque).

¹⁵ Making loud noise in labour is not so much a source of shame but considered to be something private, not for others to hear or see. Additionally, to scream out during labour is believed to deplete the woman's energy, causing exhaustion.

¹⁶ Cases mentioned: man refuses to acknowledge paternity; conflict over bride-price; infidelity; premarital sex; person deliberately causing sickness in another; previous conflict between husband and his parents, or wife and her parents; theft of a sacred or taboo object; woman curses (*hotar*) a close family member; and woman wilfully damages her own possessions.

it is better to carry out a ritual then carry (*leba*) her to the health facility, rather than risk her not delivering at the facility and then carry her home to settle custom.

The two cases presented in the box below each demonstrate a sequence of actions that combines traditional and biomedical interventions to deal with difficult labour (see Box 10).

4.5 Birth spacing

Women and men recognise the value of birth spacing in relation to the household economy as well as the health of the mother and child. Women usually receive information on methods from the health facility and inform their husbands. Where there is disagreement this is usually because women want to use, and men do not want to use, contraception. Disagreement can result in fighting, infidelity, and divorce. The husband's parents may influence decision making due to considerations regarding bride- price. Concern about potential side effects, often based on what they have learned about other's bad experience, discourages use of birth spacing methods.

TLCLS

All married women between the ages of 15 and 49 years in the TLCLS sample (n=404) provided information on birth spacing. Family planning was currently being used by 22.1%. Amongst those not using family planning, the main reasons cited were wanting children (40.9%), concerns about side effects (14.4%) and not being comfortable with it (11.8%). Some women reported not using family planning because it was not available (9%) or because their husband disagreed (8%).

A large proportion of women using family planning were having an injection (63.0%). The next most common practice was the calendar method (12.3%). The oral contraceptive pill (8.9%) was also used but only one of the 733 women reported use of condoms (Table 3).

The level of education achieved by women was significantly ($p=0.003$) associated with usage of family planning methods. At university level 51.9% were using family planning compared with 23.5% who ceased schooling at primary school level.

HCSBS

In the HCSBS survey, the ideal number of children most commonly reported by both women (25.4%) and men (19.9%) was four. Having 5 (women 14.7%, men 10.5 %) or 6 children (women 16.1%, men 16.2%) were the next most common responses, but a significant proportion chose 7 or 8 as the ideal number (women 19.3%, men 21.3%).

The ideal time between children, according to both men and women, was 2 years. There were very few responses outside the range of 1-3 years, and 3 years was more commonly cited than one year as the 'ideal' spacing (Figure 6, also Table 9 in Appendix 6).

In the HCSBS FGDs, among those participants who supported birth spacing, the ideal time between children was commonly mentioned as 3 years. The metaphor *escada* (ladder) was commonly used to refer to un-spaced children; 1 year apart, their decreasing heights are like the steps of a ladder. Many informants explained this in terms of infant development. For example, pregnancy should be avoided until the youngest child can feed itself with a spoon, walk unaided, has started school, or is

able to help the mother with a newborn baby (e.g. fetching clothing or water). Some informants used the mother's health as a reference, i.e. she should wait until her body has regained its strength and weight before becoming pregnant again.

Survey respondents expressed a high level of interest in spacing children (women 67.8%, men 68.9%). This could be facilitated by providing more information about family planning (response given by 13.8% women and 17.7% men), greater availability of family planning methods (women 22.3%, men 21.6%), and greater support from their spouse (women 38.9% women, men 31.9%).

In the previous 12 months, 43.3% of women and 40.2% of men had talked about birth spacing or family planning, mostly with their spouse (women 47.2%, men 46.2%) or a health provider (women 32.7%, men 33.6%). Most respondents (>70%) stated that they would prefer to get information and obtain family planning methods from a health provider, preferably a midwife or a nurse (women 77.1%, men 88.8%).

As shown in Table 4 in attachment, contraception was being used by just over a third of survey respondents (women 38.0%, men 36.7%). Injection was by far the popular method among women, followed by withdrawal and the oral contraceptive pill. No women, and only six men, reported using condoms. The decision to use family planning was reported as usually being made jointly by a couple (women 81.6%, men 80.7%).

The HCSBS qualitative component shed light on some of the reasons behind contraceptive choices. Injectable (*sona* or *suntik*) methods were said to cause weight gain, disinterest in sex, thinning of the uterus (*oan fatin neé ema dehan mihis ona*), even death. The pill was regarded as risky as it had to be taken on a daily basis and could easily be forgotten, and women perceived that men did not like using condoms. The calendar method, usually promoted by church clinics, was considered unreliable as it depended on mutual abstinence. Some informants preferred natural or traditional methods based on root, bark or leaves. In relation to permanently preventing conception, traditional medicine was mentioned but not neither vasectomy nor tubal ligation.¹⁷ Breastfeeding as contraception was mentioned as a natural practice of the past.

Several informants mentioned switching methods, specifically the pill and injection, when side effects were experienced (see Appendix 2 for birth spacing narrative). Providers mentioned limitations in offering implants due to user fear (Oecusse) and lack of training (Baucau).

Among survey respondents who were not currently using family planning, the main reasons were that they "liked babies" and "heard of other's bad experience" (Table 5). Among all men and women (contraceptive users and non-users), the main worries or concerns resulted from hearing about other people's bad experiences, it being against traditional or religious beliefs, and having their own previous bad experience.

Decision making around birth spacing

In general, wives were more likely to seek to use a spacing method than their husbands; disagreement usually occurred where husbands rejected using a method. Where a husband did not

¹⁷ A TBA, or other person knowledgeable about medicine that can stop fertility, may speak to the medicine (*hamulak*) to call on its power.

agree, no contraception was used. Some FGD participants said that no spacing method would be used if *either* husband or wife disagreed. There was a tendency for adolescent men to be more open to birth spacing than married men.

Most informants in Lautem and Viqueque said that a man's parents (*banin*) should be involved in decision-making regarding birth spacing. Furthermore, it was anticipated that they would not support use of a spacing method by their daughter-in-law since this would reduce the opportunity to 'recuperate' the loss associated with bride-price (*barlake*) through *both* male and female offspring. In Lautem, because a man's sister's bride-price has contributed towards her brother's wife's family, she may also be involved in the decision-making. Several, mostly female, informants, in five other sites (Aileu, Bobonaro, Covalima, Liquica and Manufahi) also mentioned that bride-price could be influential. If a man has submitted bride-price but does not demonstrate responsibility towards his wife and children, a woman's parents may encourage their daughter to decide to use a method without informing her husband (Bobonaro, Aileu). Others suggested that a man's parents would assess their daughter in-law's health and the economic capacity of their son's household. In Alas (Manufahi) and Lacló (Manututu), some informants claimed that *barlake* was not customary and, therefore, parents-in-law were not involved in such decisions.

There was a tendency for women to be critical of a husband's parents involvement in decision making. Occasionally, where a husband and wife agreed to use a spacing method but expected opposition from the husband's parents, they did not inform them. In Lautem and Viqueque, some women spoke openly about using contraception without telling their husband for reasons of poor health, advanced maternal age or a weak household economy. Several men and women said that if a man was not economically responsible (mentioned as 'not responsible' *la iha tanggung jawab*), or at night went out alone to gamble (*joga futu manu*), drink (*lanu*) or 'hang out' (*buka lemo-lemo*), then his wife was justified in using a method without letting him know.

Most informants referred to the norm that husband and wife ought to come to an agreement and should share the same position (*liafuan ida deit*). Both men and women indicated that while women should follow their husband's position, this could lead to underlying discord, e.g. 'the woman follows the man because the man does not want [to use a method] so the woman just follows [but] the problem remains'.¹⁸ Discord may result in husband and wife physically beating each other (*baku malu*), infidelity (*selingkuh*) by either partner but usually the male, divorce and/or the husband taking a new wife.¹⁹

Some informants felt the matter of discord was a secret (*segredu*), something that demonstrated weakness (*kelemahan*) or was a source of shame/embarrassment (*moe*) and, therefore, should not be shared with family members as other people could not be relied on to keep this secret. Some claimed that they would seek assistance from a 'local authority'; others said that the husband's parents, or both sets of parents, should be involved in discussing and resolving the problem as it was a matter related to custom.

Reasons for birth spacing

The scenario in the HCSBS FGDs related to 'spacing' (*fo spasu*) and not 'family planning' (*KB*²⁰).

¹⁸ *Feto tuir mane tamba mane lakohi feto mak ba deit nee problema sei iha* (Adolescent male, FGD Aileu).

¹⁹ Taking a new wife and/or divorce was commonly mentioned as a normative response in Lautem and Viqueque.

²⁰ Acronym in Bahasa Indonesia for *keluarga berencana*, family planning, socialised in Timor-Leste by the Indonesian administration.

However, participants tended to use the term *KB* to cover both practices: some using it to refer to spacing between children, others referring to stopping rather than spacing, e.g. saying they would use contraception when they had reached their desired family size.

Health-related reasons mentioned for not using any spacing or family planning method focused on bleeding: heavy bleeding²¹ that caused extreme weakness, frequent menstruation, clotting (*kafuak*), no menstruation perceived to result in blood rising to the head and causing headaches. Several informants, male and female, mentioned that using spacing or *KB* could result in being unable to conceive or subsequent miscarriage.²² It was said to be safer to use family planning after several children in case it affected conception. Another reason for not using was desire for more children, possibly determined by desired sex ratio; for example, at least one female child to bring bride-price (*Lautem*), or sons to carry on the family name, inherit wealth (*riku soin*) or look after the ritual house (*uma lulik*).

Factors of time and household economy influenced decisions regarding spacing. Spaced children allow mothers time to attend to the needs of existing young children (e.g. feeding, dressing and clothing, bathing, schooling, taking care when they are crying or ill, and keeping children free of sickness and healthy weight) and the needs of the household (e.g. carting water, procuring food, washing clothes, sweeping). Where spacing has been practiced, an older child is capable of assisting its mother, otherwise a woman considers herself to be alone (*mesak*), as her husband is absent during the day and all children are as yet too young to assist. Spaced children allowed women to 'work' (*servisu*) such as picking coffee that generated income. Many mentioned the importance of being able to afford to educate existing children to provide for their future.

Women's health also influenced decision to space. Married men were articulate about health effects of not spacing: constant pregnancy and breastfeeding could weaken a woman's body and lead to malnutrition, low body weight and vulnerability to illness (see Box 11). Further, breastfeeding while pregnant could cause sickness in the infant as the milk is perceived to be dirty (*foer*). Additionally, the uterus could become thin (*tipis*) from frequent pregnancy and labour, infection or wounds (*kanek*). Adolescent women mentioned using spacing or family planning in order to delay childbirth where they were afraid of difficult birth or maternal death.

Many women and some men mentioned that spacing allowed women both mobility and sociality, otherwise they were confined continuously to the house. The effect of this was disabling and meant "loss of one arm" (dedicated to holding the baby; *liman ida nee sorin mate tiha ona*).²³ Sexuality was also mentioned: if a husband and wife want to sleep together then they should use a method if they don't want to become pregnant. Not sleeping together is a matter of secret between husband and wife as it signifies marital problems. Sleeping separately may be achieved by sleeping children between husband and wife in the same bed. Sexual appetite or desire mentioned as *nafsu* (in this study usually referenced men) was mentioned as a reason for using spacing because sleeping separately without using a method required mutual abstinence and a man could not be relied upon to abstain.

²¹ A married woman from Bobonara claimed that the local priest informed his congregation that women may use a method and suddenly experience haemorrhage (*raan fakar*). Scant reference was made to the church in terms of people's decision not to use contraception: one person mentioned *kelonggaran* meaning transgression in the context of the church; another said that fertility was the right (*direitu*) or plan (*planu*) of God.

²² A male respondent stated that using traditional medicine as modern contraception caused infertility (Covalima).

²³ Married man, FGD, Bobonara.

Health workers were proactive about informing women about spacing during immunisation and infant weighing, when women present with reproductive-related or other health problems, or arrive to a facility with many unspaced children. Some mentioned that health staff informed women about the risks and benefits of using a method, and advised them to tell their husbands. No informant mentioned being pressured to use contraception. People may be influenced by other people's stories to start thinking about spacing. A woman may get information about family planning from a health centre returning home to re-tell what she learned over and over to other women.

4.6 Serious illness

When serious illness is present, most people access government health care services and seek medical treatment. Home treatment is also common, and traditional remedies are also commonly sought. Sick adults usually make their own decision about whether to visit a health facility; spouses are involved in about a third of cases.

The HCSBS survey investigated processes and steps that the community follow when dealing with serious illness. Data was gathered on 285 individuals reporting a serious or significant illness in the past twelve months, approximately equal numbers of men (52.3%) and women (47.7%) aged from 0–94 years. The most commonly reported illnesses were fever (16.3%) and malaria (15.2%). Home treatment was common, with 63% being given biomedical treatment (often paracetamol, 32%) and 28.2% trying a home remedy. Almost one quarter of households (22.4%) reported consulting a traditional healer-shaman (*matan dook*) for the illness and 28.8% reported taking traditional medicine. The use of a traditional healer is substantially higher than was reported in answer to an earlier survey question about the range of health providers used (14.9%), but is more consistent with the qualitative findings.

Almost all of those reporting serious or significant illness (95.4%) visited a health facility, most (67.5%) after one day of sickness. The decision to go to the facility was most commonly made by the sick person (34.3%) or their spouse (30%); sometimes by another household member (13.0%). Facilities visited included subdistrict health centres (35.0%), health posts (20.1%) and SISCa posts (15.9%). Very few reported visiting a private clinic (Table 6).

4.7 Prevention

Information about preventing disease was passed on mainly by health workers, and by xefe suco. Preventive behaviours by community members focused on avoiding contact with the sick, and the eating implements or sputum of the sick. Informants articulated considerable knowledge about hygiene and sanitation-related actions for diarrhoea prevention. A range of other health problems were also identified as preventable but informants almost unanimously claimed they did not seek preventive health care. Some understood antenatal care as helping avoid difficulties, and had sought this care. Providers were generally aware of their preventive role and frustrated by the low level of community knowledge and preventive practice. Nearly all providers spoke about delivering antenatal care.

In the HCSBS survey, the majority of household heads (87.9%) reported that household members generally washed their hands with soap, boiled water before drinking (84.9%) and almost all households (97.6%) washed their eating utensils (Table 7). The small proportion of households that reported they did not have soap (<2%) all cited lack of money to buy the soap as the main reason.

Preventive behaviours described by community members in the qualitative study focused on distancing oneself (*hadook-an*) from the sick person, and avoiding contamination. Contact with people with the following symptoms was avoided: coughing blood (*mear raan*), skin fungus (*panu*, also hena mutin – literally fabric+white), boils (*fisur*) or red eye/conjunctivitis (*matan mean*). All of these symptoms were mentioned as being able to be transmitted (*daet*) to others. Also mentioned was avoiding contact with the cups, plates, forks, and clothes of these people, and avoiding contact with the sputum (*kaben*) spat out (*tafui*) by a person coughing blood. The practice of spitting arbitrarily (*nar-naran deit*) was viewed negatively in this context.

In FGDs, participants demonstrated considerable knowledge about actions to prevent diarrhoea, such as boiling drinking water, covering cooked food, washing hands after defecating and before eating food (soap was not mentioned), using a toilet area for defecating, and keeping the toilet area clean. Tethering goats and pigs to avoid faecal contamination was also mentioned. Information about preventing disease was passed on by health workers, and by *xefe suco* who took responsibility for socialising their constituency about prevention, particularly hygiene and sanitation.

Community members identified a range of other health problems as also being preventable: indigestion (*estomagu*), lung disease, itchy skin (*isin katar*), leprosy, fever, malaria, coughing, high blood pressure, and goiter.²⁴ However, when asked whether they sought health care for preventive reasons, community members responded unanimously that they did not. Typical responses included: “No, when I am sick I go, if I am not sick I don’t go because we need to see to our work” and “I come only when I am sick, if not sick we don’t come arbitrarily because it is far.” Some community members, however, did understand antenatal care as helping avoid difficulties through, for example, identification of incorrect position for delivery, estimation of due date, and distribution of antenatal vitamins. Providers were generally aware of their preventive role and frustrated by the low level of community knowledge and preventive practice demonstrated, for example, in low or no attendance at immunisation outreach clinics (see Box 12). Nearly all providers spoke about delivering antenatal care: weighing pregnant women, distributing iron tablets, giving advice about nutrition during pregnancy, checking the position of the baby in the womb, promoting immunisation (e.g. against tetanus) for pregnant women and newborns, offering advice on postnatal birth spacing, advising about breastfeeding (colostrum and exclusive breast feeding), and advising about avoiding malaria in pregnancy. Postnatal preventive care offered by providers included advising about the risk (to baby and mother) of smoke from sitting close by the fire (*haneruk ahi*) in the period of seclusion after birth, advising about worming and vitamin A for infants, weighing infants to check weight gain or loss, and distributing supplementary feeding such as ground maize.

4.8 Provider perspectives

Health workers reported a range of limitations to delivering better services. Organisational and logistical constraints included lack of communication between facilities; delays in undertaking or providing outreach activities because of poor roads; unreliable drug supplies especially in the wet season; poor infrastructure including the lack of electricity for lighting and sterilising equipment; and the lack of training opportunities. Limitations in relation to provider-community interaction focussed on concern that providers may be blamed by community members in the case of a negative outcome; and frustration and anger at the perceived lack of community appreciation of

²⁴ In addition to these, providers also mentioned TB, HIV/AIDs, STIs, conjunctivitis, worms, dengue, mouth disease - oral hygiene.

the importance of prevention and early intervention. Improvements to the availability of MOH health promotions materials, development of a queuing system for seeing patients, and improved communication systems at facilities would enhance services and build trust.

Limitations to health services

Difficulties recounted by village-level nurses and midwives related to physical factors, equipment and services, and delayed presentation by patients. Many of these factors were also articulated by users as difficulties related to accessing quality health services.

In rural areas, female health workers are sometimes obliged to travel in pairs to remote locations without communication equipment or transport, at times walking for hours in order to conduct mobile clinics. Even where transport and fuel are provided, poor roads can cause them to arrive late or not at all, disappointing waiting clients. Specific mention was made of transportation of nurses and midwives and their equipment and drugs as being necessary to conduct SISCa outreach activities.

An already unreliable drug supply is made worse in the wet season which blocks road access. In Oecusse this resulted providers sending the patient or members of the patient's family to Indonesia (Atambua) to seek medication. In Baucau community members may carry medicines in preparation for a mobile clinic on foot from the closest access point to their own road-inaccessible village.

Infrastructure mentioned as lacking by provider informants included electricity to village-level health posts for adequate lighting,²⁵ equipment to sterilize instruments,²⁶ a drugs storage facility for village-level health posts, carrying containers to secure equipment for outreach work, training facilities for health staff, and provision and maintenance of accommodation for health workers at the village level. Also mentioned was the need for SISCa to provide a private space for examination of pregnant women, and other women with internal reproductive-related problems.

Midwives and nurses reported that the lack of communication between village-level health posts and sub-district and district level health facilities, made referrals difficult. They highlighted the need for increased access to doctors at the sub-district level, as well as ongoing training opportunities for themselves.

Many commented on staffing level as being insufficient to meet the number of patients attending, thus contributing to delays. Sometimes patients waited all day to be seen, only to be sent home at the end of the day with a request to return the following day (Madre clinic, Venilale). Some non-government providers became frustrated with users who came to them rather than attending a government facility closer to their home as this led to increases in patients and long delays. The absence of a queuing system also generated problems for providers, with patients quarrelling with staff for attention, and pushing each other aside to get to the front.

A subdistrict level midwife stressed the value of 'official' MOH resources dealing with prevention, such as in relation to causes of malaria, as they claimed users did not trust the word of the provider alone (see Box 13).

²⁵ TBAs mentioned torches so that they could attend night deliveries and examine the woman's body in houses that are dimly lit by candle or kerosene wick.

²⁶ TBAs mentioned scissors and thread for cutting and tying the umbilical cord, otherwise they deploy scissors used for cutting hair and thread used for weaving *tais*. They also requested gloves for delivery as they perceived that gloves reduced tearing.

Provider perspectives on interactions with patients and community members

Most government providers were not stationed in their village of origin, but were usually working in their sub-district or district of origin. Their social integration was made easier by the fact that they spoke the language of service users, and were often married to a person born in the village or sub-district. Some participated proactively in the religious and agricultural life of the village, others participated only when invited to do so.

Several government providers mentioned tensions with local community sometimes resulting in the provider being transferred. Such tensions had arisen when the community blamed and threatened the provider over the death of a patient, and provider perception that a member of the community had deployed custom to curse them or cause sickness.

Some providers disclosed that they reacted angrily (*hirus*) when users did not follow advice on preventive matters such as ante-natal attendance and immunization. Other issues that made health workers angry included failure to follow advice on planning to give birth in a government facility, exclusively breastfeed, or follow advice on strategies to increase the weight of the child or ensure TB drug compliance.²⁷ Some providers explained that they did so out of frustration and concern for the health of the woman or child.

No providers reflected on the effects of their anger on the patient. Reports from some users indicated a reluctance to call a midwife in the event of difficult labour, anticipating the midwife may be angry if she was called late and the condition of the woman in labour was already grave.

While a patient may seek assistance when their condition is already grave and arrive late at a facility, invoking health worker anger, their family might blame the provider who treated them in the event of the patient's death. Delay in seeking assistance can also generate a sequence of events which may lead to a patient's death, something which the provider might then be blamed for. For example, after a two-day labour, a TBA was called and she assisted the delivery of the baby, and also cut the cord, and then the woman bled heavily and experienced retained placenta [*kaan la mai*]. As the TBA was unable to deal with this complication, the following morning – already delayed – the family called a midwife who was unable to assist with delivery of the placenta but inserted an IV drip and administered an oxytocin injection and arranged for a NCBA (Coffee Co-operative clinic) vehicle to take the woman to Dili national hospital where she died two hours later. The community alleged that the midwife was to blame (*dun sala*) and the midwife had to be subsequently transferred to another sub-district.

However, it was also mentioned in relation to blame (*fo sala*) that where a provider had been called (*bolu*) to a patient's home by their family, and where a negative outcome resulted, the family of the patient must take partial responsibility for the outcome because they had called the provider. A nurse gave the example that three weeks after a TBA delivered a baby (first baby of mother) it developed swelling to the head [*ulun bubu*] and the family took the baby to the CHC where it was examined by a doctor. The respondent (nurse) then said to the family: "Something has happened and who can you blame [*fo sala*] because the TBA who assisted was not obliged to assist, but you called her to assist". The nurse went on to explain that a TBA is only concerned with the baby being born and not concerned about any health effects of unclean instruments being used, such as tetanus, and that for first birth especially, assistance should be sought from a midwife.

²⁷Time constraints could constrain providers from conducting preventative activities.

The risk of a provider being blamed for a negative outcome may have implications for spontaneous outreach activity, e.g. where a provider initiates a home visit rather than having been invited by the family to attend. (See Appendix 5 for FGD extract on ‘blame’.)

Further in relation to delay, some providers understood factors that caused patient delay such as long distance and lack of transport, belief in custom (*adat*) causing the illness, and use of traditional medicine first. In relation to transport, one provider mentioned that communities should be more proactive in assisting ill people or women approaching the period of labour to help ensure access to a health facility. Providers understood that first level delay was often caused by user views that the illness may be caused by custom factors, such as neglect of customary duties, or social transgressions, and required a customary response to determine and resolve the cause (see Box 14). A range of conditions were at times associated with custom factors – including appendicitis, severe diarrhoea and difficulties encountered during labour.

Some community members appreciated health care staff allowing family members to take the patient home temporarily when the hospital treatment did not appear effective as in these cases a custom-related cause was thought to be probable and needed to be resolved first before the patient could return to hospital for treatment (Bobonaro). Some traditional providers such as *matan dook* acknowledged the efficacy of hospital treatment, and claimed to send people to local health facilities after they had determined and resolved any custom-related causes.

Some providers expressed frustration that patients and their families located far from Dili, such as in Oecusse, refused to be referred to Dili for necessary surgery as the family perceived that the local facility had necessary equipment and staff. The requirement for family agreement, particularly the support of male family members, for referral was another cause of delay mentioned by a Dili-based midwife. One provider explained that rejection of a referral for caesarean by a woman’s husband had resulted in the death of his wife. In relation to third-level delay (receiving treatment in the facility), regulation to prioritise patients based on severity was suggested.

Section 5 – Discussion

5.1 Limitations

Both the survey and the qualitative component of the HCSBS had limitations. Time in each area was a major constraint given the requirement that the study be truly national and carried out in all districts. Development of research instruments and training of field staff took longer than anticipated but was an essential part of local capacity building and central to achieving the research outcomes. More detailed ethnographic study was not possible, however this Study has identified a number of areas in which such in-depth work would be of value (see 5.4, below). The concurrent conduct of the two components of the study did not allow for subsequent quantification of behaviours and preferences identified through the qualitative work.

The survey covered three enumeration areas in each of the 13 districts; some randomly selected enumeration areas were unable to be included because they had recently been surveyed as part of the TLSLS Extension Survey and household heads have begun to report dissatisfaction at repeated survey activity with little discernible improvement in services. The interviewers were not always able

to access both a man and woman in every house, due to absence of household members and restricted opportunities for prior communication about interviewer visits. The response rate for individual interviews (69% for women and 63% for men) was below the target rate of 80% but was deemed acceptable given the resource and logistic constraints.

Some FGDs were not as effective as others; in particular those with adolescent and unmarried women proved somewhat disappointing. In Timor, few young women have had the opportunity to share their ideas or experiences in a group. They are thus somewhat shy in situations of group discussion; all the more so where some of the topics may be deemed personal and sensitive. Midway through qualitative data collection, the criteria for women's FGDs was altered to target married and adolescent women with previous experience with groups (e.g. church or youth groups). An effort was still made to ensure that such women were no more educated or had any special status relative to other women in the community.

Two additional factors may have affected women's participation. First, *xefe suco* tended to delegate, rather than to invite, FGD participation, thus making it difficult for them to decline. Second, married women in rural areas are not necessarily fluent in Tetum, as their activities tend to be more localised than men and conducted in the local language. Use of skilled local interpreters to routinely interpret all FGD questions and probes, as well as all responses from FGD participants, would have allowed women to contribute in their local language. While such a person was on hand for all FGDs, they only interpreted when requested to do so by participants, rather than routinely throughout the discussion.

Although 21 government/NGO health service providers, 8 traditional providers and 2 others (kiosk/pharmacy) were interviewed, this represents relatively few in any particular category. The study was unable to give detailed attention to any particular category of health care provider: TBAs, Cuban doctors, pharmacists, midwives, PSFs and others – all of whom would benefit from further examination and analysis.

A number of health sector initiatives are currently underway in Timor-Leste; this research provides some insights into many of these initiatives but is not focused on any one intervention. SISCa activities, for example, are only beginning to be more structured and organised. Although the HCSBS demonstrates the value of initiatives directed at the interface between community and health service, the Study was not geared to evaluating this unfolding program.

5.2 Reflections on findings relative to what is known

The HCSBS was designed to build on previous research in Timor-Leste, adding depth to available knowledge and insights regarding health care seeking, particularly in rural areas with limited access to hospitals, and drawing on and contributing international literature in this field. From the outset, we endeavoured to give due consideration to the collective element of health seeking behaviour and the interaction between individual, society and health systems, as well as the socio-cultural and linguistic complexity present in Timor-Leste. This report provides an overview of some of the main findings; additional details will be provided in subsequent peer-reviewed publications.

The HCSBS emphasises the role of the family and community in decisions to seek health care, and around the issue of birth spacing. It also highlights the degree to which cultural beliefs, attitudes and practices vary across the country, e.g. bride price (*barlake*) had a significant influence on use of contraception in Lautem and Viqueque, but this was less in other districts.

The HCSBS sheds light on the ways in which quality of health care is assessed by community members and, in particular, indicates how sensitive they are to the ways in which they are treated by health workers. They appreciate effective examination and history-taking, the availability of diagnostic and procedural equipment and medication, and the opportunity for referral should the provider believe that more effective care is available from a higher level facility. Community members take careful note of the empathy and sensitivity of health service providers. Where providers are seen to be harsh and unsympathetic, or inflexible in how they run their services, such as being unwilling to see patients who arrive after registration for patient attendances has been closed, this has a strong negative influence on use of government health services.

Hearsay and 'second-hand' experience were also extremely influential, with other people's negative experiences being one of main reasons given for not using contraception in both the survey and the FGDs. More generally, one person's experience of health care, whether negative or positive, is likely to be noted by others and form part of the narrative about that individual provider and/or service, with ongoing influence through telling and retelling of stories and experiences.

5.3 Implications

Overall, the HCSBS underscores the often restricted range of health care choices available to rural communities given the impediments of distance, cost and weather. Treatment at home with traditional and/or modern medicines and (sometimes simultaneous) consultation with local traditional providers could be regarded as a logical response to limited access to government health services. Efforts to identify and resolve underlying issues of custom (*adat*) were clearly described to the Study team.

The research findings have implications for the health sector, and beyond.

5.3.1 Implications for the health sector

The MOH is committed to ensuring that all people in Timor-Leste, irrespective of gender, age, place of residence or socioeconomic status, enjoy equitable access to good-quality health services provided in (and beyond) facilities that are well equipped and staffed. The MOH also seeks to ensure that the community has access to information that empowers them to make informed choices about matters affecting their health and wellbeing. The Ministry has identified improving access to, and demand for, quality services and strengthening management and support systems as strategic priorities [3]. Figure 7 shows how the HCSBS findings can be related to each of these goals.

The many dimensions of access—physical, financial and socio-cultural—all play an important part in determining what services are used, where and when. Community members want health services that are readily available, affordable, and socially and culturally acceptable. Having to transport a sick person, or a pregnant woman, to distant services is costly in many ways and is a powerful disincentive to service utilisation. Family members have an important say in the decision to seek assistance, or accept referral to another health facility. Around issues of child birth and fertility, a woman's in-laws may also be influential. These barriers need to be addressed, for example by improved transport and communication (not only a matter for the health sector) and culturally-sensitive outreach models. SISCa, which is currently being developed and extended, may contribute to improving access.

Community members at the village level have clear expectations of government health services and how they should be delivered. They expect to be treated with consideration and want acknowledgment of the efforts they have made to seek assistance, especially if they travelled far. They expect to have the history of their condition carefully assessed and to be properly examined, with the use of relevant tests and equipment. They expect to be treated with medication, to be referred to a larger health facility if necessary, and to be given personal advice on prevention. They are, however, often disappointed with one or other aspect of the services provided. Assuring consistent delivery of good quality comprehensive services is essential to building trust in the government health system.

Much of the dissatisfaction experienced by users—patients and their families—was due to limitations of the system: lack of infrastructure, equipment and drugs; lack of qualified staff; and, in places, restricted facility opening hours. Access to health workers out-of-hours in emergencies, such as during a difficult birth, was a common concern. In some cases, dissatisfaction resulted from a lack of understanding and appreciation by users of what the health service can and cannot do, and the role of individuals, families and communities in maintaining health and well being. There is a clear need for patient and community education, even basic information about commonly prescribed medications and their effects, such as how long different drugs take to work and the importance of completing the full course prescribed, rather than stockpiling them for later. Carefully considered health literacy campaigns, designed with community and stakeholder participation, are required to challenge widespread beliefs that treatable medical conditions are due to custom or social transgression, and to reinforce the importance of early intervention and prevention.

A major source of user unhappiness and reluctance to use health services, however, related to dissatisfaction with the user-provider interaction. Users were discouraged from seeking help early, and in some cases from seeking help at all, by health worker inflexibility, anger and a tendency to blame community members for their poor health. Negative experiences were shared with others in the family and community and affected their behaviour too. On the positive side, users were encouraged by demonstrations of empathy. Community members do appreciate the efforts of health workers when their demeanor and behaviour convey respect and care, even when ‘cure’ does not occur.

Where health providers are unable to offer the service needed by the patient, or the severity exceeds the competence of the health worker, there is appreciation of the fact that referral to a higher level of service is possible. When referral takes place, support in meeting the associated costs, such as transport and food for accompanying family members, and support in returning a body should the patient die, are also important.

Community members, in general, see a birth as a ‘normal’ event, hence one that can take place at home. It is only when complications are identified that the help of a TBA or a qualified health worker is sought, but this is often too late. In part because they are local and so easily accessible, TBAs are usually approached first.

Almost all the issues explored in the TLSLS health module and the HCSBS have implications for MOH management systems. In particular, departments such as health promotion, maternal and child health, community health services, as well as hospital services and district health teams, could benefit from careful review of the HCSBS, alongside discussion about how best to ensure responsive services.

5.3.2 Implications for other sectors

Improving roads and bridges, and transport would immediately improve community access to health facilities and other services. This would also support outreach activities and community-based interventions like SISCa, as well as facilitating supervision and support for isolated health workers and improving the regular supply of drugs to the rural and remote areas. Enhancing communications—radio, telephone and, ultimately, the internet—will help communities to access timely assistance and health workers to access timely advice.

Improving access to water, sanitation and electricity will benefit village health facilities, enhancing their acceptability to users, and households, contributing to reduction in disorders such as childhood diarrhoea.

Education of women is a particularly valuable intervention for all health outcomes and it is clear that acceptance of birth spacing is related to educational achievement of female household members. Improving engagement of men in discussion on birth spacing is also important.

5.4 Recommendations

Recommendations are directed at a number of key institutions and agencies.

5.4.1 Recommendations for the Ministry of Health

- Strategies to improve the quality of service delivery should emphasise patient-centred care.
 - Government health workers should receive clear guidance on good practice in health services provision. Empathy, respect and clear communication should be more actively promoted and health care workers who are responsive to community members should receive recognition.
 - Achievements and good practice should be regularly communicated to the community locally and nationally. The MOH should develop mechanisms to reward health workers at all levels for effective and innovative service provision, including through an annual awards ceremony highlighting achievements and promoting positive media coverage and discussion.
 - Health worker education and training, for nurses, midwives and doctors, should be user and community-focused and should emphasise a holistic approach to health. This requires recognition of the mental, social, cultural and spiritual aspects of health, as well as the physical and biomedical aspects.
- Increase efforts to improve communication between service delivery and services, and community structures.
 - Pilot and carefully evaluate innovative means of enhancing the community-service interface. This should extend beyond an exchange of information to establishing genuine partnerships for service development and delivery.
 - Engage more actively with traditional birth attendants as they provide services to large sections of the community and would benefit from skills training and access to sterile equipment and supplies. Training TBAs to recognise problems, to refer early, and to avoid complications will benefit both mothers and children. Better planning for deliveries, and ensuring that skilled attendants are present, remains crucial.

- District managers should be given support and additional training to shape improvements in health care delivery and organisation. With the back-up of the policy and planning sections of the MOH, and regional advisors, these key personnel should focus attention on addressing the weaknesses within health care delivery. District managers should be empowered to ensure the availability of drugs, equipment and appropriate staff within services.
 - Improve the ability of rural health care staff to perform through providing ongoing training and support, and enhancing availability of transport and reliable drug supplies.
 - Identify ways to assist families to meet the costs associated with referral to facilitate access to appropriate levels of care.
- Capture lessons, adapt and scale up innovative and successful mechanisms to improve quality, access and acceptability of services, such as the triage system being developed at Guido Valadares Hospital in Dili and treating malnutrition using only local foods (Baucau).
- Health Promotion should play a stronger role in improving community understanding of prevention, the use of health care services, and the use of modern medicines. Community members should be encouraged to ask questions about their care and health providers should be trained to provide polite and informative responses. Promoting the engagement of men in birth spacing and improving community understanding of effective use of medicines should be a priority. Education around prevention of common health conditions, and early interventions to reduce severity and complications, should be taken forward. The MOH, working with local authorities, schools and development partners, should invest in, and evaluate, pilot interventions to improve health literacy.
- The MOH should identify one or more persons to assess the implications of this research for the workforce, local and expatriate, and for identifying how the MOH and key educational institutions can address weaknesses through the selection and training of health workers.
 - This Report should be made available and used as a teaching and learning resource for health workers being trained in Timor-Leste, Cuba and other countries. Resources should be sought to translate this report into Spanish to facilitate discussion of its contents by Cuban personnel providing services or training in Timor-Leste and Cuba.
 - Educational institutions, with research and development partners, should explore questions raised by this research. Among these are questions related to the cultural and language competence of local and expatriate health care staff; improved understanding of the emerging private sector in health care provision, including pharmacists; and the need for detailed understanding of community responses to specific health problems and conditions in different parts of the country.
- The MOH should establish a research structure which will interface with researchers, play a major role in identifying research needs, and will ensure the integration of research findings in activities to improve policy and practice.

5.4.2 Recommendations for the Government of Timor-Leste

- Improve infrastructure – transport and communication – to assist with health, and other services, delivery.

- Ensure Ministry of Health and Ministry of Education collaborate on health-related curricula at schools and training institutions.

5.4.3 Recommendations for local government and communities

- Liaise with local and central government and development partners to develop strategies to facilitate access to services and improved transport for emergencies and referrals.
- In a number of pilot areas, work with Ministry of Health teams to identify innovative strategies to enhance health service – community interface and mutual respect.

5.4.4 Recommendations for development partners

- Support community and Ministry of Health initiatives to enhance respect and responsiveness to communities, and to improve access, equity and quality of services.
- Encourage innovation and evaluation of interventions to enhance health literacy and community participation and engagement in health issues.
- Provide support to MOH in acting on the recommendations above.

5.5 Further research

Additional research is warranted in several areas which have been identified but not fully explored here. A number of provider groups deserve additional attention and study. These include the Cuban Medical Brigade which was minimally covered here; TBAs and other traditional providers; NGO services and private sector providers, in particular general practitioners and pharmacists who operate primarily in urban centres. The ready availability of a wide range of health care providers in these centres is likely to influence both identification and response to health care needs. Access to skilled health care workers will change substantially when the first cohort of Cuba-trained Timorese professionals begin to return home to practice in 2009.

Timor-Leste is a country with large and growing populations of children and young people. Their views on the acceptability of health services are important, as are their suggestions for youth engagement in service development and policy. Innovative approaches to youth-centred input to health promotion and to enhancing understanding of the determinants of health, the importance of effective prevention, and the need for early intervention, deserve attention.

5.6 Other products

The HCSBS has developed a number of resources alongside the primary research tools and project reports. Two deserve particular attention: a glossary of health care terms in Tetum, and the identification of material which may be of value to those responsible for training health care workers.

The glossary has emerged from in-depth interviews with service users and providers, and focus group discussions with a large number of informants. Terms describing health conditions, traditional health care providers, and remedies and solutions to health care problems, have been identified and coded. These are focused primarily on three areas (diarrhoea, child-birth, and child-spacing) but are not limited to these. Building this resource for Timorese and expatriate (*malae*) health providers is of potential value in improving understanding and communication with service users. The HCSBS

team hope that a mechanism can be developed to build up this glossary by combining it with other earlier documentation, and enhancing it over time.

The HCSBS team, department heads and district health teams also identified a number of scenarios that could form the basis for discussion and training by health care workers, MOH department heads and district health teams. Some examples have been highlighted in the text and appendices of this report. These vignettes can be further built up to stimulate and elicit debate around the implications for policy and practice, and in so doing can play a part in enhancing the appreciation and responsiveness of providers to the health concerns of the community.

References

1. Government of Timor-Leste. National Development Plan; 2002.
2. Ministry of Health Timor-Leste. Basic Services Package for Primary Health Care and Hospitals; 2007.
3. Ministry of Health Timor-Leste. Health Sector Strategic Plan 2008–2012; 2008.
4. Timor Leste Multiple Indicator Cluster Survey - Report 2002; 2002.
5. Timor Leste Demographic and Health Survey - Report 2003; 2003.
6. Timor Leste Survey of Living Standards - Report 2007; 2007.
7. World Bank. Health Service Delivery and Utilization in Timor-Leste: A Qualitative Study Dili; 2005.
8. Foote D. Nutrition and Health Survey of Children and Pregnant Women In Timor Leste: Covalima, Bobonaro, and Liquica Districts: Care; 2006.
9. Health Alliance International. Report into Cultural Practices and Beliefs Relating to Pregnancy, Birth and the Post-Partum Period in Timor-Leste; 2003.
10. Health Alliance International. Key health education messages for mothers and newborns in Timor-Leste; 2003.
11. Health Alliance International. Strengthening Maternal and Newborn Care in Timor-Leste. Focus Group Discussions with Midwives -Aileu, Ermera, Liquisa and Manatuto Districts; 2004.
12. Health Alliance International. Summary Report of Results from HAI Evaluation of Bibi Bulak Community Drama; 2005.
13. Health Alliance International. Strengthening Maternal and Newborn Care in Timor-Leste: Assessment of Health Services (Health Facilities and Staff) Relevant to Maternal and Newborn Care - Aileu, Ermera, Liquisa and Manatuto. 2005.
14. Health Alliance International. Strengthening Maternal and Newborn Care in Timor-Leste: Qualitative Community Assessment Aileu and Manatuto Districts; 2005.
15. Health Alliance International. Child Spacing Baseline Community Assessment Report, Districts of Aileu and Manatuto; 2006.
16. Health Alliance International. Feto Nia Funo: Report on film viewings and community discussions throughout the districts of Aileu, Liquica, Manufahi and Ermera; 2007.
17. HealthNet International. A Survey on Accessibility of Health Services and Health-seeking Behaviour in Liquica District; 2001.
18. OXFAM. Underlying Causes of Gender Inequity in Covalima, Timor Leste; 2003
19. Timor Leste Asistencia Integrada Saude (TAIS). Cross-cutting Issues for Improving Child Health Services in Timor Leste - a literature review 2002-2006; 2006.
20. Timor Leste Asistencia Integrada Saude (TAIS). "Community Consultation" on Child Health Practices in Timor-Leste; 2007.
21. Timor Leste Asistencia Integrada Saude (TAIS)-MOH. Situational Assessment Timor Leste Literature Review. Key Behaviours and Sub-behaviours for Improving Child Health; 2006.
22. UNFPA-MOH. Timor Leste National BCC Strategy for Reproductive Health, Family Planning and Safe Motherhood; 2007.
23. Webster J, Pacheco C. Efficacy and Cost of Insecticide Treated Mosquito Nets in East Timor: Health Net International; 2001.
24. Webster J, Pacheco C, Pinto L. A Situation Analysis of the Market for Mosquito Nets and Insecticide in East Timor: Present Situation, Potentials for Expansion and Barriers to Overcome. 2002.
25. Webster J, Pacheco C, Pinto L. Report on the distribution of Insecticide Treated Mosquito Nets to Pregnant Women through Health Facilities; 2002.
26. Timor Leste Census of Population and Housing; 2004.

27. Beiersmann C, Sanou A, Wladarsch E, De Allegri M, Kouyate B, Muller O. Malaria in rural Burkina Faso: local illness concepts, patterns of traditional treatment and influence on health-seeking behaviour. *Malaria Journal*. 2007;6(1):106.
28. Bojalil R, Kirkwood BR, Bobak M, Guiscafre H. The relative contribution of case management and inadequate care-seeking behaviour to childhood deaths from diarrhoea and acute respiratory infections in Hidalgo, Mexico. *Tropical Medicine & International Health*. 2007;12(12):1545-52.
29. Eastwood S, Hil P. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in The Gambia, West Africa. *The International Journal of Tuberculosis and Lung Disease*. 2004;8(1):70-5.
30. Enato EFO, Okhamafe AO. A survey of anti-malarial activity during pregnancy, and children's malaria care-seeking behaviour in two Nigerian rural communities. *Scandinavian Journal of Infectious Diseases*. 2006;38(6):474-8.
31. Hoa N, Thorson A, Long N, Diwan V. Knowledge of tuberculosis and associated health-seeking behaviour amongst rural Vietnamese adults with a cough for at least three weeks. *Scandinavian Journal of Public Health*. 2003;31(1):59-65.
32. Kaona F, Tuba M, Siziya S, Sikaona L. An assessment of factors contributing to treatment adherence and knowledge of TB transmission among patients on TB treatment. *BMC Public Health*. 2004;4(68).
33. Kasse Y, Jasseh M, Corrah T, Donkor S, Antonnio M, Jallow A, et al. Health seeking behaviour, health system experience and tuberculosis case finding in Gambians with cough. *BMC Public Health*. 2006;6(143).
34. Malik E, Hanafi K, Hussein Ali S, Ahmed E, Mohamed K. Treatment-seeking behaviour for malaria in children under five years of age: implication for home management in rural areas with high seasonal transmission in Sudan. *Malaria Journal*. 2006;5:60.
35. Ndyomugenyi R, Magnussen P, Clarke S. Malaria treatment-seeking behaviour and drug prescription practices in an area of low transmission in Uganda: implications for prevention and control. *Transactions of the Royal Society of Tropical Medicine and Hygiene*. 2007;101(3):209-15.
36. Ndyomugenyi R, Neema S, Magnussan P. The use of formal and informal services for antenatal care and malaria treatment in rural Uganda. *Health Policy and Planning*. 1998;13(1):94-102.
37. Pérez-Cuevas R, Guiscafré H, Romero G, Rodríguez L. Mothers' health seeking behaviour in acute diarrhoea in Talaxcala, Mexico. *Journal of Diarrhoeal Disease Research*. 1996;14(4):260.
38. Pronyk PM, Makhubele MB, Hargreaves JR, Tollman SM, Hausler HP. Assessing health seeking behaviour among tuberculosis patients in rural South Africa. *The International Journal of Tuberculosis and Lung Disease*. 2001;5:619-27.
39. Selvam JM, Wares F, Perumal M, Gopi PG, Sudha G, Chandrasekaran V, et al. Health-seeking behaviour of new smear-positive TB patients under a DOTS programme in Tamil Nadu, India, 2003. *The International Journal of Tuberculosis and Lung Disease*. 2007;11:161-7.
40. Uzochukwu B, Onwujekwe O. Socio-economic differences and health seeking behaviour for the diagnosis and treatment of malaria: a case study of four local government areas operating the Bamako initiative programme in south-east Nigeria. *International Journal for Equity in Health* 2004;3(6).
41. Thompson R, Miller N, Witter S. Health-seeking behaviour and rural/urban variation in Kazakhstan. *Health Economics*. 2003;12(7):553-64.
42. MacKian S. A review of health seeking behaviour: problems and prospects: University of Manchester - Health Systems Development Programme; 2003
43. Hausmann-Muela S, Ribera JM, Nyamongo I. Health-seeking behaviour and the health system response. *DCPP Working Paper 14*; 2003.
44. Stata Corporation. Stata Statistical Software: Release 10.0, College Station, Tex; 2008.
45. QSR International Pty Ltd. NVivo qualitative data analysis software; Version 8; 2008.

Appendices

Appendix 1 – Diarrhoea narrative

The following diarrhoea narrative illustrates multiple health care seeking actions, belief in custom as cause, and delay in getting to a health facility. The first action taken by the mother is to prepare a traditional remedy at home because the closest health facility is far. By implication, if the facility had been closer she may have taken the child there first. The next action is to take the child to a health facility and here we learn about delay due to distance from health facility, and the cost of transport – during the three days she approaches relatives to borrow money and tries to sell chickens, but she is unsuccessful. Another action potentially taken involves custom. The mother explains if the medicine prescribed by the doctor had not been effective this would signify that another cause was at play i.e., unsettled matter of custom. The father would carry out the ritual to settle custom at home while the mother would return to the CHC to get medicine. We learn that after the custom matter has been settled, the mother again seeks hospital medicine which is now effective, and the child gets better. This reinforces belief in the importance of settling *adat* matters.

In this community, what symptoms are considered to indicate diarrhoea that is problematic?

At 8 months old [my daughter] was quite healthy but suddenly she got diarrhoea with vomiting. On the first day I looked at the child's poo. I didn't know why the child's poo was like this. The second day I wondered why is there still diarrhoea. The third day I saw the child was very weak. The community health centre was very far so I made a herbal cure.

Then I went to the CHC ... When I arrived there the nurse asked me how long had the child been sick and I answered three days. She said [with angry tone – nada siak]: “why didn't you bring this child with diarrhoea quickly?” I replied: “I wanted to bring the child quickly but there was no transport and no money [to pay for transport]” ... We asked our relatives for money to bring the child to hospital but they could not help. Even though our child had been sick for three days we could not go. What could we do? I asked relatives for money but they did not give me any, so we waited, but if we wait then our child will die. My husband has no job, he is a farmer, so we have no money. I tried to sell chickens [to raise money for transport] but no-one bought them. [At the CHC] I asked the ‘doctor’ for medicine to give to the child. I gave the medicine to the child. After three days the child's poo was already dry. So this was the way the child was affected.

However if I saw the child was still not well [after CHC visit] I would return again and ask my husband and the family: “how is it that this child still has diarrhoea - I have taken the child to hospital. I have tried herbs. Something may have happened, something may have caused this child to get diarrhoea.” So our family comes together and thinks about this thing. Maybe something has caused it. We try to think about whether custom (*adat*) might be the cause. The child's diarrhoea is not because of sickness but because custom caused it. They speak, they kill a small rooster, and try and identify the cause of the sickness. The sickness is like this or that – this is why the child is like this. I cannot wait any longer at home – I have to go to the hospital to collect the medicine to cure the diarrhoea. At home they must continue to carry out the ritual. When the custom cause is settled, the child then drinks the medicine and becomes well. This is my experience.

Married woman, Focus Group Discussion, Lautem District

Appendix 2 – Birth spacing narrative

This narrative illustrates several aspects in relation to using a spacing method. This includes disagreement between husband and wife over using (unusually, husband wants to use, wife does not), receiving information about spacing during immunisation, switching methods resulting from side effects, conception/pregnancy occurring while following the calendar method, and expressed satisfaction with using a method due to economic reasons: being able to assist her husband with agricultural work in order to sell surplus produce to raise income.

Where and to whom did you visit for birth spacing method or information?

Mine is [like this] with my second child my husband obliged [me], you should follow family planning, I refused, if I use it may cause me to be infertile, you must [said husband], then when my baby reached two months and I attended immunization, he obliged [again], I was not convinced, after vaccination I took my baby outside [husband asked] 'did you get family planning or not?'. I replied 'not yet'. He asked me to return, no problem because you [husband] want me to use so then I used the pill, I received pill then they explained to me [how to take it] take like this, and like this. I followed it [instruction], I took it for two days only and had bleeding for two weeks, excessive bleeding that made my face pale, and made me very weak, very weak. Then I returned [to CHC] I blamed my husband 'it is because of your attitude that this has happened. The child is still little, now what is going to happen, you take me back to hospital [CHC]. [Then they] took me to hospital [CHC]. [Health staff said] no problem, take medicine to stop the bleeding. One week after the bleeding has stopped, return again. I took the medicine and the bleeding stopped. After one week I returned and was given an injection, the injection suited [me] but I was like a man, my body was very big, why I am as big as this. After the fourth child I refused [to use injection any more]. He [husband] obliged me but I refused to follow family planning, I used calendar [method] and why, I don't know, suddenly I fell pregnant [respondent laughs]. I said after delivery I will try to go back to the clinic. People said even bleeding might occur but if you are careful it will be fine. So after delivery I intended to go to [health facility] to use family planning again. But my younger child is now 2 years and 3 months and I am 3 months pregnant [again]. I'm not feeling very happy about it - my husband is a farmer, how are we going to survive? We live from agriculture, if he [husband] goes to the garden [if we don't have young children] we can help him in the garden to plant and then buy soap, kerosene. If we are pregnant and nursing children continuously it is a problem. I think family planning is good for us. We like it.

Married woman, Focus Group Discussion, Lautem District

Appendix 3 – Difficult birth; extract from FGD

The sequence of responses in this FGD discussion illustrates several aspects related to difficult birth. The TBA is unable to assist with retained placenta and it is imperative to urgently get the woman to a hospital. In this case, this requires the assistance of the local authority. There is recognition of the need for a trained midwife or doctor to assist.

I ask you again, at the time of delivery what was the problem that caused you to call a vehicle from the hospital?

#1. Delivery is a problem when women give birth for example after giving birth the previous night a woman may be affected by two things: sometimes she gives birth but not completely, like the baby's objects [sasan] from the mother's stomach are delivered but probably not completely, for example the baby has come but the placenta like the string of the placenta or it can be said that the placenta does not come. If a TBA holds on but still [the placenta] does not come we will go quickly to the hospital as the hospital knows how to handle it, the doctor is the one who knows the gravity of this.

#2. Here like my brother in-law said, [after] the baby has been delivered, and the cord cut, then if the placenta is very delayed in coming it obliges us to cut the cord and then clean the baby then cover her vagina [fatin lulik] because the placenta has not yet come out. We should take the mother quickly to hospital because the TBA is not able [to assist] because it is complicated. An ambulance should be called to take the woman to the hospital so that the doctor can determine whether to perform surgery or remove the placenta.

Whom is involved in the decision making?

#1. Because in the hamlet, the hamlet head has the following motivation: he does not want someone to die in his hamlet. Because of this he has the right to be involved and give his opinion to the child's father [woman's husband]. So, the hamlet head also has a right ... to go to hospital, to call a car to transport the woman to hospital ... because the TBA is unable [to assist] ... the doctor knows whether [the difficulty] is severe or minor.

When you went to the hospital what was the outcome?

#1. [We] went to the hospital because TBAs have faith in their medicine [or technique] that they apply to the [woman's] stomach but if it is not effective then the TBA's capacity is only to this stage, so it's better to go to hospital. It is not that we are Timorese that we consider our traditional medicine to be good, but we were born from there [traditional medicine]. Nowadays because various illnesses exist, upon delivery a baby can get a fever immediately, in this [case] the doctor is knowledgeable. When the child is born the doctor can give an injection immediately because they are knowledgeable about this. We should go to hospital - if people from a household don't move themselves to go [to hospital], the hamlet head may also take that decision [for them]. If you do not decide to take [the person] to hospital, if the person dies you are the one who will be responsible. We are also fearful of this so we take them to hospital.

Two married men, FGD, Bobonaro

Appendix 4 – User-provider interaction during consultation; extract from user interview

This narrative highlights issues of trust and communication emerging in a consultation setting and resulting in the patient being discouraged from attending the health facility. The mother is upset that the provider asks her whether she is feeding her child, and the provider is upset that the mother does not appear to have taken his advice (which she cannot follow because the foods he has chosen to recommend cannot be procured locally). The narrative also flags the issue of physical distance to the health facility discouraging preventive care in that the mother perceives that her child's condition will deteriorate during the course of the journey.

Did you get what you expected in your consultation with a health provider earlier?

I went there [village-level health post] to have my child weighed as the nurse spoke about the baby's weight. At the time of weighing if the child's kilograms do not increase I feel upset and embarrassed. I feel [this], sometimes others call me to go [to the health post] and I am breastfeeding so I can't prepare breakfast, when they call I have to go, the baby's kilograms do not increase.

What do you mean by upset/embarrassed?

Upset that the child's weight does not increase, we worry that the child will be sick or something. We're scared, worry because it is far, and we must leave to walk [to the health post] at dawn, the fault is with us as mothers, at dawn the child has not yet done wee or poo, not yet eaten and this causes no weight gain.

According to you, if the child has not eaten this is what causes the child not gaining weight?

Because leaving at dawn causes this. The child has not yet done wee or poo, food has been given to the child but the child has not eaten and is just taken and must endure the journey.

What did you understand that the nurse told you?

One month the child's weight increases, the next month it decreases. The nurse asks: did you feed the child, or not? [He says] if the child does not eat, give vitamins. The nurse says this month the baby's weight has decreased, did you feed the child or not.

How did the provider treat you?

They indicate that they accept me well enough, when the child's weight does not increase [they are] angry. [They ask] Where did you go that you did not feed your child?

Did you want the provider to treat you differently than they did?

I am just thinking about my child, if your child does not eat, what can you do? You can cook leafy greens and eggs so that the child's grams can increase. It is the nurse who directed me if there is fish, give to the child. Not continuously through the month but weekly. The child's weight decreased. This month I was going to return [to the health post] but I didn't go because the child's father was busy. The nurse directed me to go to the health post but the child's father was busy so I did not go.

Did you follow what the nurse said?

When I have these things, I can follow the instruction. I raise chickens but there is no fish. I have tomato and greens ... [unfinished sentence].

Do you plan to return?

The long distance makes me reluctant, but when a child falls ill despite this reluctance, I must go.

CONT.

What makes you believe in a provider?

I believe in them when the child's weight does not increase and they tell me what to feed the child. This is the reality: a person who has strength can go, but especially for pregnant women the difficulty is that they don't have the strength to go, some have good health, some don't.

If you go it's good but when the consultation is over, we must make the return journey which makes us sick due to the long distance.

When you give food is there a difference in the baby's weight (grams)?

We don't give everything [that is instructed]. If there is money we can buy, if there is no money, we just have chicken and in the rainy season leafy greens - amaranth and kangkung.

Did the nurse inform you that this food would more or less increase the child's kilograms, or what?

The kilos would not increase, but the grams would.

In-depth interview with service user, Baucau

Appendix 5 – User blame of provider; extract from FGD

This FGD extract elaborates the issue of user blame of provider although in this case the provider is a person knowledgeable in traditional medicine (*ai moruk nain*). The contributions elaborate that blaming a provider for a negative outcome is an enduring Timorese cultural response, and that a traditional provider at least will wait to be invited to attend to a sick person, rather than initiate treatment. The implication is that if a negative outcome results, the fact that a provider was called by the family of the patient may lessen the blame directed at the provider, whereas if the provider themselves initiated treatment resulting in a negative outcome the blame is greater. (Note however that there is also argument that intervention by any provider whether called or not that results in the death of the patient results in the same accusation of blame by the family of the patient towards the provider.)

So, who made the decision to take the woman to deliver at the hospital after four days [of labour]?

#1: Sometimes people who are knowledgeable about traditional medicine give medicine that does not cure, that causes more suffering for the ill person/child and causes anger [e.g. in the parent]. They say: 'it was you who gave your medicine and made the child like this, if you hadn't given the child would not have become like this.' Actually, it is like this, we ask for help and trust in them [knowledgeable people] and then you call them [the parent of the ill child], another person cannot call them [to attend your child]. This is something [results in] casting blame.

#2: So, this is bad Timorese practice [it is as though] your child was OK but because you brought them and had this bad treatment it caused them to become like this and then we suspect one another, quarrel, and use sorcery [*habuan malu*] against each other. We store a grudge: supposing that person did not go and call that person and they did not come – it was the medicine which caused the child to become like this. Whereas the person [a knowledgeable person] went there to help the child become well but because of something you gave, and did not cure the child, you then blame that person and you store a grudge against that person because of that. Sometimes this happens and because of this if a person does not call [a knowledgeable person] they will not come because if the child [or ill person] dies of something then this results in a quarrel til death. Like healers, if you don't call them they are not brave enough to come

Two married men, FGD, Covalima