UNDERSTANDING THE HEALTH-SEEKING BEHAVIOR OF PEOPLE WITH *LAY-NGAN-YAW-GAR* (STROKE)

In Bago Township, Myanmar

Aung Zaw Moe

Understanding Myanmar's Development | RESEARCH REPORT **No. 11**

RCSD | IDRC | CRDI

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Copy Editor: Tom Fawthrop
Cover Photo: Aung Zaw Moe
Design and Layout: Jeff Moynihan

Published in February 2018 by:
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Foreword

Myanmar is undergoing an exciting and often unpredictable time of transformation on many fronts after decades of isolation. Outsiders have only a limited understanding of the complexities, dynamics and the depth of change taking place—affecting the social, environmental, economic, and governmental spheres, and directly impacting the livelihoods and practiced culture of the peoples of Myanmar. How are they actively taking part in their country's developmental process, and in the face of what obstacles? In this pivotal moment, Myanmar's need for both mind- and manpower to help fill the gaps of data and research on critical development issues has never been greater.

RCSD has established the Understanding Myanmar's Development (UMD) Fellowship program, supported by the International Development and Research Centre (IDRC), Canada, to enhance the knowledge of Myanmar's development, strengthen the research capacity of Burmese researchers, and encourage them to become actively engaged in the study of development policy and practice. The fellowship seeks to promote sustainable academic exchange and dialogue among researchers from Myanmar, Thailand, and other GMS countries. Under this program, 30 fellowships have been awarded to mid-career researchers in their respective areas of social and economic change, agriculture, environment and climate change, health and health care systems, and social media and innovations.

Myanmar has a long and rich history of traditional medicine. The role of traditional medicine retains great influence, and has been the main provider of health-care for the vast majority of people

throughout history. While many Western medical studies have been published both in and about Myanmar, there is much less documentation of traditional medicine and other health-care practices at the community level within the country.

This study uses an anthropological approach to analyze social issues linked to health care in Myanmar. Conducted over a year, this research touches on many facets of the social lives of patients afflicted by *lay-ngan-way-gar* (stroke), health care providers, and the tension between individual and communal beliefs. With the rapid changes taking place in Myanmar, the health care sector should be viewed through different social and anthropological lenses. This study is an initial step to explore and understand health-care seeking behaviors at the community level, and the larger cultural and socio-economic factors that influence the health care choices of Myanmar's people.

Chayan Vaddhanaphuti, PhD
Director, RCSDS

Acknowledgements

It was my honor to be a research fellow in the Understanding Myanmar's Development (UMD) Program with the Regional Center for Sustainable Development (RCSD) at Chiang Mai University. I had a great opportunity to learn both theoretical and practical aspects of social research.

First, I would like to express my gratitude to Professor Ajarn Chayan for his guidance, courage and support that enabled me to progress as a social scientist specializing in anthropological research. Also, without the supervision and mentoring of Associate Professor Sasitorn Chaiprasitti, I would not be able to complete this course. Ajarn Sasitorn has shown a keen interest in medical anthropology and gave me step by step guidance throughout my study. Her visit to field villages also showed me the linkage between theoretical and practical aspects of conducting field research.

Being a medical doctor with a quantitative background, it was hard for me to adapt to qualitative social study. However, all the professors and mentors shared their wealth of knowledge to transform me into a well-equipped social science researcher. I owe many debts of gratitude to all who shared their knowledge, experience, and insights.

Many thanks are to Ajarn Jennifer Leehey, coordinator of the UMD Program. Jennifer worked with all the research fellows and inspired me. Also I give my thanks to the RCSD office team who handled arrangements for schedules and teaching programs so effectively, and my sincere thanks to the funding agency IDRC for supporting the UMD program.

It is my pleasure to be a part of research fellow family with four other Myanmar fellows. I love the way our research fellows have supported and learned from each other, so I extend kind regards to all of them For my field work, I could not finish my study without the help of Ms. Wut Yi Win who helped me with data collection, appointments with different villagers, elders, care providers and cases.

Last, but not the least, my study is filled with the wisdom and insights of all the cases and various health care providers that I had interviewed and visited. Every field visit has a significant meaning and learning point for me. The association of people with *lay-ngan-yaw-gar* (stroke) helped to provide me with new insights about life and health. In conclusion I must give deepest thanks to all those people who cooperated and contributed to produce this book and wishing them all the best.

Abstract

Although *lay-ngan-yaw-gar* (stroke) is a common public health issue in Myanmar, the majority of studies focus solely on biomedical aspect of stroke, viewing the subject mainly from a Western medical perspective.

This study fills a knowledge gap and tries to understand how people with *lay-ngan-yaw-gar* in rural villages seek medical attention based on diverse influences derived from their community leading to interaction with various health care providers.

It is a qualitative study based on grounded theory using the ethnographic approaches. The author uses a conceptual framework adapted from Arthur Kleinman to guide their research—to question and explore various insights, belief, meanings, explanations and feelings of community people with *lay-ngan-yaw-gar*, and to understand different stages of the conditions of illness and patterns of health-seeking from the patients' perspectives.

Individual in-depth interviews were done using guidelines. Interviews focused on individual cases, health care providers and the family members in order to get the various social perspectives

The author also observed the situation of how people with *lay-ngan-yaw-gar* interact with different providers, rituals and events related to *lay-ngan-yaw-gar.* It is obvious that based on individual belief in the causation of *lay-ngan-yaw-gar*, people seek health care from different providers. It was found that health seeking patterns are also related to socio-economic background, as well as religious beliefs.

A major contribution of this study to the existing knowledge is that health seeking is not merely communication between the patient and the provider. It also has social, cultural, religious, spiritual and psychological aspects.

In conclusion, this study provides real life experiences of people with *lay-ngan-yaw-gar* and their pattern of health-care seeking behavior, decisions and explanations of their illness, and evaluation of the treatment of different health care providers, both in the folk sector and biomedical sector.

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INTRODUCTION

In Myanmar, stroke is a leading cause of death comprising 3.6% of all deaths in 2011 (Heath in Myanmar, 2013). *Lay-ngan-yaw-gar* or "wind disease" is a common chronic illness that impacts on the socio-economic life of people. *Lay-ngan-yaw-gar* is the Myanmar term for neurological weakness caused by stroke from a biomedical point of view.

The biomedical perspective explanation is that *lay-ngan-yaw-gar* (stroke)is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. (WHO, 2014)

Unlike the biomedical explanation, the cause of *lay-ngan-yaw-gar* has several different explanations according to traditional beliefs in Myanmar. Practitioners of the traditional medical system explain the cause of *lay-ngan-yaw-gar* in other ways. According to the Ayurvedic system of medicine, *lay-ngan-yaw-gar* is caused by the imbalance of wind, phlegm and bile causing illness.

The Buddhist perspective considers the cause of *lay-ngan-yaw-gar* to "*Karma*",based on an actions committed by an individual in his past or present life. Astrologers take the view that the cause can be discovered by calculating the zodiac of stars, planets and the time of birth and age (Heath in Myanmar, 2013).Therefore, different schools of thought, arrive at different interpretations of what causes *lay-ngan-yaw-gar* in Myanmar.

Although stroke is a common public health issue in Myanmar, the majority of studies conducted focus solely on biomedical aspect of stroke, mainly viewed from the point of Western medical perspective.

This study will fill a knowledge gap about understanding how people in rural villages of Bago with *lay-ngan-yaw-gar* seek medical attention based on their worldview, and explore the different perspectives to be found in the traditional health sector.

Before going into the details of my study, I would like to clarify some conceptual things related to the term "health-seeking". MacKian (MacKian, 2013) pointed out that the term "health-seeking" is not well defined in most of the studies.

There are studies which emphasize the '*end point*' (utilization of the formal system, or health care seeking behavior); secondly, there are those which emphasize the '*process*' (illness response, or health seeking behavior). Here in this study, I will place more weight on the second part, the process, in which people interact with the various health care systems in the case of *lay-ngan-yaw-gar*.

Research Objectives

The general objective of this study is to understand the health-seeking behavior of a community people with *lay-ngan-yaw-gar* in Myanmar.

Specific objectives are

1. to explore the definition, classification, causes and effects of *lay-ngan-yaw-gar* from the patient point of view,
2. to understand the pattern of health-seeking behavior of people with *lay-ngan-yaw-gar* and the different providers during various stages of the illness
3. to understand and provide evaluation of people of different treatment outcomes and the treatment furnished by a diverse health providers with *lay-ngan-yaw-gar.*

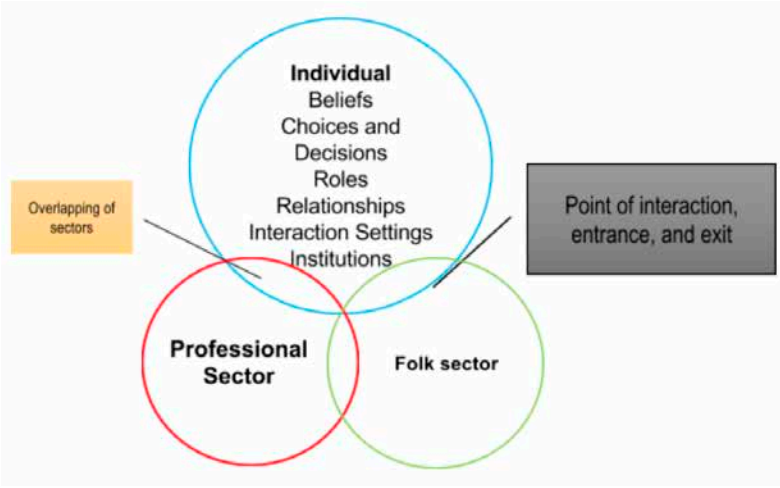
Research Questions

- How do people with *lay-ngan-yaw-gar* define and classify *lay-ngan-yaw-gar*?
- What are peoples' beliefs about the causes and effects of *lay-ngan-yaw-gar*?
- How is the decision made to seek a particular type of health care in the context of different forms of of *lay-ngan-yaw-gar*?
- How do people with *lay-ngan-yaw-gar* evaluate the treatment outcome of different providers?
- How do people with *lay-ngan-yaw-gar* explain the interactions of different health care sectors?
- What are the available health care services for *lay-ngan-yaw-gar* in the context of community?

Methodology

This is a qualitative study based on grounded theory using ethnographic approaches. I use the conceptual framework adapted from Kleinman (1980) to guide my research theme to explore various insights, belief, meanings, explanations and feelings of community people about *lay-ngan-yaw-gar*, and to understand different stages of illness conditions and patterns of health- seeking from the patients' perspectives.

Figure 1 Conceptual framework of local health care system (Kleinman, 1980)



In this framework, individual belief, choices and decisions are embedded in family, social network and the community. It is the lay, non-professional, non-specialist, popular culture arena in which illness is first defined and health care activity commences. (Kleinman, 1980)

The professional sector comprises the organized healing profession, mostly modern scientific medicine, while folk sector emphasizes traditional and indigenous healers.

In the case of illness and disease, individuals may seek health with different sectors based on their belief and choices. The stages of disease and severity of illness will also be a factor to take into before the decision taken.In some cases, the individual may seek health simultaneously (both in folk and professional sector), and sometimes sequentially (one after another). In such conditions, the overlapping of health sector might create patient-provider and provider-provider conflicts, an interaction that might affect the treatment outcomes and the health- seeking pattern (Hardon, et al., 1995).

Conduct of the Study

12 months- from October 2014 to September 2015

Area of research

Three villages: Kamarnut, Shanywargyi, and Saiti in Bago Township, Myanmar, were selected.

Tools

To obtain research objectives, individual in-depth interviews (IDIs), were done using guidelines. Interviews focus on individual cases,health providers and the family members, to get the various social perspectives and a good understanding.In-depth interviews explore various health-seeking patterns of individuals and their family members in a particular social context. Before the interview, I had a preliminary field visit to project villages, in order to get basic information about the number of people with *lay-ngan-yaw-gar,* and different providers available in the villages. The survey data showed that there are 54 cases in 6 villages; however, I deliberately selected only 8 cases to undergo in-depth interviews. Here in this paper, 3 out of the 8 cases have been selected

I have also observed the situation of how patients interact with different providers, rituals and events related to *lay-ngan-yaw-gar*.

Informants

Three cases (individuals, family and providers) were selected for In-Depth Interviews (IDIs). The study focuses on the age group between 15 to 70 years old, residing in Kamarnut and Saiti villages.

Data analysis

Collected data were reviewed and transcribed at the end of each day to undergo content analysis. To ensure validity, researcher and research assistants independently read and re-read the transcripts, repeatedly listened to the interview recordings, as well as cross-checking as a team to produce consistent findings. After the content analysis, several major themes were identified and the findings arranged in terms of major themes and sub-themes.

2

BACKGROUND

Field Site Description

Bago

Bago is the capital city of Bago Division and surrounded by over fifty villages. Bago (formerly spelt *Pegu*) was formerly known as *Hanthawaddy* (*Hongsawatoi* in Thai).The earliest mention of Bago in history is by the Arab geographer ibn Khordadbeh around 850 AD (Encyclopedia Britannica, 2016) Bago has undergone many historical events related to spread of Buddhist, Mon and Burmese religious beliefs, cultures and wars.

With regards to health care services, Bago has a 200-bed government hospital and an Urban Health Center. Diverse traditional care providers are commonly found in Bago. The traditional sector is comprised of *nat-ga-daw* (spiritual mediums), monks, astrologers, palmists, indigenous medical practitioners, traditional birth assistants, traditional bone setters, and fortune tellers.

Village Profiles

Kamarnut

Kamarnut is a peri-urban village with a population of over 7,000 and it is also my native village. It has direct road access to Bago

just four kilometers away.Most people are Buddhist in the village with a few devotees of Hinduism. Nearly every household has a picture or symbol of a spirit. The economy of village is mainly agricultural involving both sexes, while home- based tobacco(cheroot)- making industry employs women. Nearly ten percent of villagers are working in Bago as day laborers, garment factory workers and construction workers.

There is a government rural health center in Kamarnut run by one health assistant (who is one of the cases in this study), and one midwife. Kamarnut also has two private biomedical clinics. Notable people in the village include the monk (astrologer), a spiritual medium who can communicate with spirits and dead people, and a traditional birth assistant. There is a community clinic where I sometimes volunteer to provide primary health care, and a pharmacy shop where villagers can easily buy self-medication.

Saiti

Saiti is a small village with over 1,000 population. It is located at a distance of three kilometers to the south of Bago. In the past road access to Bago was poor.

A new concrete road was constructed in 2012, and transportation has become smoother. The economy is similar to Kamarnut village. A private doctor provides health care and there is one mid-wife assigned by the government. The village monk is famous for astrology, and some traditional masseurs operate here.

Shanywargyi

Shanywargyi is a remote village located six kilometers from Bago. The estimated population is about 2,600. It has no direct road to Bago, but is located near a railway line to Bago. The majority of the people are farmers, with women mostly employed in the tobacco industry. There is a mid-wife who leads the sub-rural health center under the Ministry of Health. The village has a so-called doctor, traditional birth assistant, astrologer, fortune teller, and a small pharmacy for health care. The village came onto the electricity grid in 2012, changing the lifestyle of villagers. Road access to village was also renovated in 2013 and communication became improved with a much greater flow of goods and products.

Religion and Traditional Culture in Popular Understanding of Health and Illness

The majority religion is Buddhism, while Christianity, Islam and Hinduism accounts for 2-3 % of the population. Bago is famous for monasteries where young monks receive training and study Buddhist literature. Among the various teachings, *abhidhamma* (Mon, 1995) is the most difficult literary and conceptual part of Buddhism. The essence of *abhidhamma* is embedded in the daily life and culture of Buddhist people. Knowing some basics about *abhidhamma* will be useful for individuals studying healing derived from Burmese traditional culture.

Abhidhamma postulates four types of ultimate reality, namely *citta, cetasika, rupa,* and *nibbana*. *Citta* is the consciousness of the sense or awareness of an object. *Cetasika* refers to mental factors or mental concomitants. They depend on *citta* for their arising and they have influence on *citta*. There are 52 kinds of *Cetasika*. The combination of *citta* and *cetasika* is called *nama*. *Rupa* is also known as matter or corporeality. *Nibbana* is the elimination of suffering or absolute lasting peace (Mon, 1995).

Health and illness from a Buddhist perspective

The teaching of *abhidhamma* provides an understanding of health and illness from a Buddhist perspective. *Rupa* may change its state, form and color as a result of the influence of heat and cold, just as matter does. There are 28 derivatives of *rupa*. Each unit of *rupa* has four major elements namely *pathavi* (earth), *apo* (water), *tejo* (fire) and *waryaw* (wind). These four elements modify the presence of *rupa*. The imbalance of these four elements results in disease from the *rupa* perspective. This assumption arises from four determinants that modify *rupa*. They are karma (actions in terms of physical action, speech or thought in both the past and present life), *citta* (mind), *u-tu* (climate: hot and cold conditions) and *ahaharra* (nutrition and food for body and soul).

Buddha believed that our body is composed of *nama* (mind) and *rupa* (body) and these two units are very tiny.We cannot even see it with an electron microscope. We can only know this gradually at an abstract level when we practice meditation, until we reach

the stage of enlightenment. The degenerative process of *nama* and *rupa* is changing at all time.

Every second, the formation, decay, death of *nama* occurs over a hundred trillion times and *rupa* change occurs when *nama* is changed seventeen times. We cannot change this process. However, one can modify the sequence of change in *nama* and *rupa* by therapy that modifies the four major determinants.

The modification of four determinants can be done in several ways. For better karma we can make merit and do good-deeds (physical action), prayers (verbal action or speech) and meditation (intellectual action or thoughts) according to Buddha's teaching.

Astrologers, spirits, and fortune-tellers

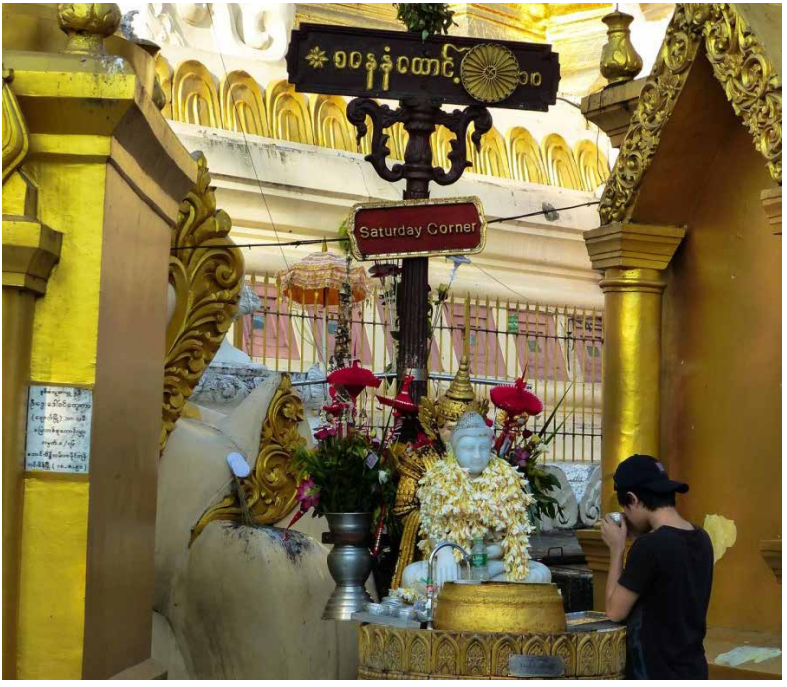
In Myanmar, karma is also translated as *kan,* meaning luck or fortune. People believe that spirits and ghosts can influence and make a person sick if that individual suffers from bad luck or ill-fortune. With such bad luck, an astrologer or fortune teller can foresee what will happen to a sick person. An astrologer or fortune teller may advise the sick person to make merit, obtain charms or perform rituals to bring relief from bad luck.

The astrological concept is based on Hindu concepts and is linked with eight creatures. For example, if born on a Sunday, it is a bird that is the creature of influence, while if born on a Saturday, a dragon is the symbolic creature (as shown in the figure below). The symbols of such creatures are widely seen in the corners of every pagoda in Myanmar.

A spiritual medium can predict which spirits have taken possession of the sick person and provide advice about rituals that can restore health. In addition, the fortune teller and a spiritual medium may also encourage the individual to consult with a particular health-care provider, or to consume certain type of food to counter ill fortune, or possession by evil spirits.

However the Buddha discouraged the belief in spirits and astrology in his teaching when explaining the four ultimate realities.

Figure 2 The "dragon" corner of the pagoda for those born on Saturday



Another type of modification is improving the mind (*citta*) For instance, one can meditate to reduce stress and sufferings, so that the body will have a good recovery. Consultations with astrologer, fortune teller or a spiritual medium,can explain what is happening with the disease, and provide advice on what to do. This may create a kind of psychological motivation and a psychosomatic recovery. After doing merits or rituals, people feel relaxed and think that bad luck and ill-health will soon disappear, and they will soon be able to return to normal health.

During illness, the presence of family members, beloved ones, relatives and other person may also contribute to positive or negative psychological influence on the patient.

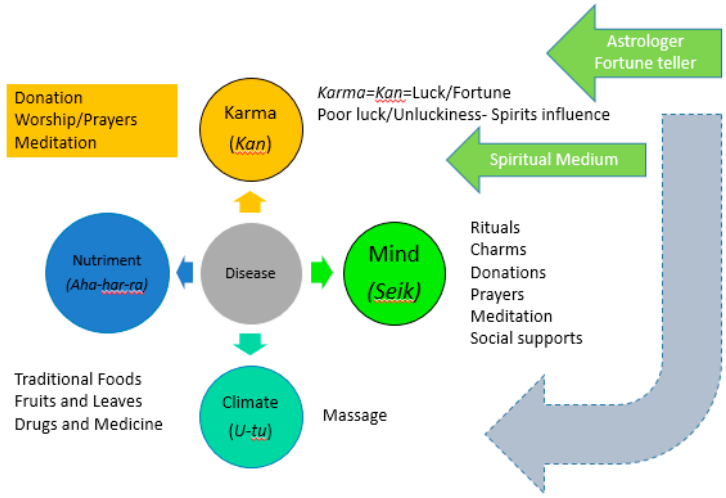
The third determinant that influences our body is *u-tu*. Here, *u-tu* means the nature of heat or cold condition, rather than hot or cold temperature. In fact, *u-tu* is combination of four basic elements. Deficit in such elements are categorized as disease. In traditional medicine, diseases are classified into two groups: cold diseases and hot diseases.

Recommended remedies include massage therapy that can reverse the reaction of cold or hot condition, or eat nutritious food, fruit or fresh juices, the kind of advice that maybe all health providers would agree with, even though they have radically different understandings of the causes and explanation of illness.

Ahaharra (nourishment) is the fourth determinant of health from Buddhist perspective. Here nutriment has two kinds; physical foods for body, and mental nourishment for the mind. Foods or drugs are used not only for nutriment, but also for maintaining health in both traditional and western medicine.

The following figure shows how health can be maintained through the modification of four determinants.

Figure 3 Modification of the four determinants of health



Along with the Buddhism, the culture of worshiping spirits (*nats*) is very common and deeply-rooted in Myanmar for centuries. People celebrate and worship the spirits twice a year; early monsoon before the paddy growing, and late monsoon after the harvesting time. Bago is well-known for "*Bago Mae-daw*" (the Buffalo Mother or Lady Buffalo, *Bago Mae-daw* is believed to be a goddess of the Mon people, representing the Mon cultural identity and the history of Bago (figure 4) which is one of the 37 spirits in the culture.

Figure 4 The Bago Mae-daw (Buffalo Mother or Lady Buffalo)

Figure 5 Spirits that people put in a shrine to worship

Myanmar traditional medicine vs. other traditional health providers

The definition of traditional medicine in Myanmar is by practitioners who offer treatment with medicinal herbs and plants. To be a traditional medicinal practitioner, one must attend proper training and receive a certificate from the Department of Traditional Medicine under the Ministry of Health.

However, traditional massagers, bone-setters, local midwives, spiritual mediums, monks and astrologers are not classified and

not registered as traditional medicine practitioners in Myanmar. These categories belong to the folk sector or informal sector of Myanmar health care system, and they received less attention from both researchers and policy makers.

Modern Medical Perspective

From the biomedical perspective, *lay-ngan-yaw-gar* is termed as "stroke": a condition where the supply of blood oxygen to the brain is interrupted. There are two pathological classifications: ischemic stroke (blockage of vessel) and hemorrhagic stroke (rupture of vessel). Many causes of stroke are related to a chronic health conditions such as: heart disease, diabetic mellitus, smoking, hypertension, alcoholism, blood disorders, use of oral contraceptives and so on.

Treatment options of stroke depends on the severity and type of stroke. It ranges from observation to hospitalization for various medical and/ or surgical interventions. Medical doctors carry out various laboratory tests (blood, urine, spinal fluids) and procedures (X-ray, ECG- electro cardio graph, MRI- magnetic resonance imaging, CT computerized tropo- scan) to identify the cause of a stroke. The decision to take such tests are solely determined by the doctors, and the cost of these tests are sometimes very expensive for poor people. This is one factor that leads people to avoid western medicine and health-care.

In addition, diagnostic tests and procedures are complex. It is never explained to the patient or their relatives why doctors have to perform these tests, or how the tests can help to establish the cause of the stroke. Western doctors usually advise regular exercise, a balanced diet, as wellas treatment of existing chronic disease. They will also recommend life-style changes for the prevention of stroke, and the rehabilitation of stroke patients.

Impact of Socio-economic Change on Stroke and Chronic Disease

In the area of study rapid urbanization after 2010 has resulted in changes in life-style with the arrival of the national electricity grid

and improved road access. Starting from 2012, many telecom companies emerged, village people were able to use mobile phones and internet.In addition a free flow of commodities, access to markets and improved communications was witnessed after 2013

Bago is located in the center of lower Myanmar on a major highway from former capital Yangon. This has facilitated the flow of commodities and trade from neighbouring countries including Thailand , India and China.

The local dietary pattern has also changed over the years. Villagers report that now they are using ready-made foods such as instant noodles, dried French fries, deep-freeze chicken and imported snacks, with an increased use of seasonings (Mono Sodium Glutamate-MSG).They also have gained easy access to alcohol, beer, the increased use of insecticides and a decline in the consumption of locally-made foods, vegetables and snacks.

Access to internet and various media channels has connected local people with the outside world and exposed them to other cultures Thai, Korean and Chinese. Eating Thai style or Korean style food has been absorbed into popular culture Many traditional snacks have been replaced by plastic -coated colorful ready-made snacks and sugary drinks. Posters and vinyl sheets carry advertisements promoting sugary drinks and ready-made foods, are now visible along the streets also in villages. The consumption of alcohol is widespread, and linked to the popular pursuit of eating barbeque,often accompanied by beer parties. Alcohol is culturally accepted and served in social gatherings, such as weddings and donation ceremonies in villages. Despite the government bans on artificial seasonings, many food companies mix these seasonings with curry powder, and with chicken essence.

With extensive marketing through television channels, FM radios and web pages like Facebook, local people have better access to the food and drug market. Local people are now able to read a variety of newspapers and journals In the past it was a dream for people to read daily newspapers and journals.

With good electricity supply nearly every household can possess a television, and get e information about various food dishes,drugs

and the social activities in neighboring countries. Village people also enjoy improved access to health care service information from radio, television, journals and the internet. With a better information and access to media, villagers have more options and more choices for health care treatment from diverse care providers.

Transportation has vastly improved for villagers in recent times. In the past most villagers had to walk or travel by bicycle. The importing of motor-bikes has made travel much easier but it has reduced the amount of daily exercise from walking or cycling. Bago is a center for motorbikes imported from Thailand and motorbikes have increasingly replaced bicycles or walking.

Improved road transportation and telecommunication assists villagers in seeking out a range of health care providers. In the past, one had to get up early, go by bicycle or on foot to get treatment from a medical doctor or traditional healer that might be located from 10-20 miles away from village. Furthermore in the past the patient would have to wait for hours the clinic or healer's home until their name was called. These days they can book an appointment n have advanced booking from home,that saves time and energy to seek healthcare.

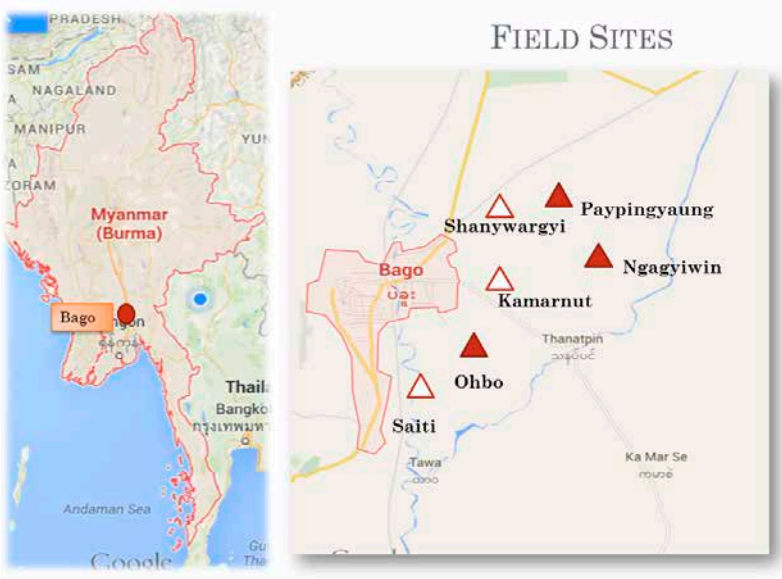
The healthcare system in Myanmar does not provide any health insurance system by the State or by private bodies, but there are some State funded health care facilities. Payment for health care is a major burden for many people.

Civil society organizations, recognizing the hardship faced by the general public, have intervened by setting up special community clinics providing free health-care and humanitarian assistance. Some community clinics emerged after the cyclone Nargis in 2008, and these clinics operated free services. Among the villages in this study, Kamarnut has one community clinic but other villages have no free clinic.

The health system suffers from a lack of research and knowledge about the traditional health care sector.

Field Work

Figure 6 Map of study villages (field sites)*



** All triangles (red and white) are study villages; white triangles are villages of selected cases*

Project advocacy with village leaders

In November 2015, I went to six project villages and explained to village leaders and administrators about my study on "*lay-gnan-yaw-gar*" with a view to collecting village data such as: population, major livelihood, health care services and so on.

Figure 7 Advocacy meeting in progress (in Kamarnut village)

In addition to the introductory meeting, I took the opportunity to meet with village youths (8 to 15 youths in each village) and discussed about my study. I facilitated the Participatory Learning Action (PLA) tools, and I was given the village map, seasonal trends and the location of village health care providers. This PLA tool; mapping and seasonal trends, helped me a great deal in getting to know more about the background of the village: seasonal trends of livelihood, means of transportation in villages, location and access to the health care providers via villagers. Table 1 describes basic information about the villages.

Figure 8 Village mapping with youth in Ngagyiwin village

Table 1 Brief information about study villages
Source: survey of Lay-ngan-yaw-gar in villages

Village Name and basic information	Road access to Bago	Health care facility	Health service providers
Kamarnut Population: 7,173 Households: 1,314	direct bitumen road access to Bago (15 min drive)	Sub-center (Govt) Free community clinic (NGO)	Doctor Nurse Mid-wife Health assistant Pharmacy Astrologer Monk Traditional masseur Traditional birth assistant Spiritual medium
Shanywargyi Population: 2,630 Households: 589	Laterite road access (45 min drive)	Sub-center (Govt)	Mid-wife Pharmacy Astrologer Quacks Traditional birth assistant
Paypingyaung Population: 1,300 Households: 263	No direct route, pass through Shanywargyi (1 hr drive)	No	Astrologer Quacks Traditional birth assistant Monk
Ngagyiwin Population: 900 Households: 220	No direct route, pass through Paypingygung and Shany-wargyi, 1.5 hr. drive	No	Astrologer Quacks Traditional birth assistant Monk
Saiti Population: 1,089 Households: 225	Direct laterite road access to Bago (45 min drive)	Sub-center (Govt)	Doctor Mid-wife Pharmacy Astrologer Monk Traditional masseur Traditional health assistant
Ohbo Population: 1,835 Households: 351	No direct road access (45 min drive)	No	Auxiliary Mid-wife Pharmacy Astrologer Monk Traditional masseur Traditional health assistant

I conducted a short survey to identify people with *lay-ngan-yaw-gar* in 6 villages. The aim of the survey is to get the approximate number of people with *lay-ngan-yaw-gar* in project villages, and to obtain the background information for the selection of specific cases for study.

For this survey, I received help from village youths and got the list of people suffering from *lay-ngan-yaw-gar*. The survey is just a brief collection of case details. The the survey included Name, Age, Gender, affected part of body due to *lay-ngan-yaw-gar* ,and treatment option they had taken.

This survey worked out well as I not only obtained the list of cases, but I also received visual map of village roads and streets,and secured the social engagement of the villagers Within November 2014, 54 people were identified in six villages. Among 54 people, 50% (27 people) are male, and 50% are female. The range of this group is between 51 years to over 60. Age range distribution of people with *lay-ngan-yaw-gar* is shown in table 2 and figure 9.

Table 2 Age group distribution of people with *lay-ngan-yaw-gar*

Age Group	Number of cases
Less than 30 years	2
31-40 years	3
41-50 years	9
51-60 years	11
over 60 years	29
Total	54

Figure 9 Age group distribution

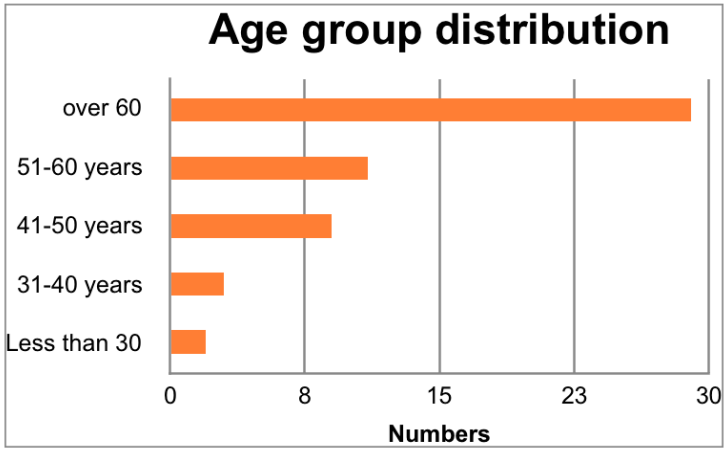


Figure 10 Body parts affected by lay-ngan-yaw-gar

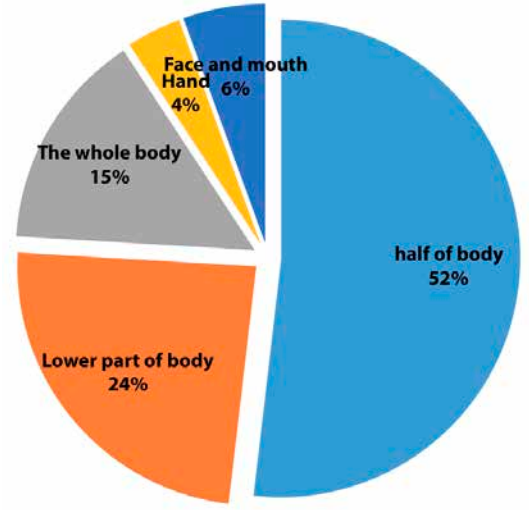
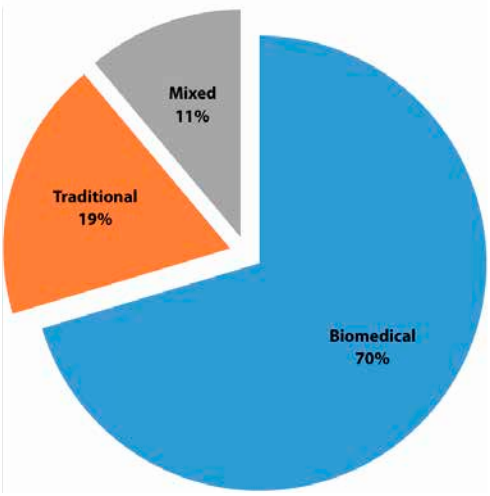


Figure 10 illustrates the body parts affected by *lay-ngan-yaw-gar*. Majority of cases are affected on one half of the body.

Regarding the health care treatment options, 70% seek medical care with biomedical treatment, 19% received health care by traditional care providers (astrologer, traditional massager, monk, traditional medicine practitioner, spiritual medium) and 11% seek health in combined approach of both biomedical and traditional sector as shown in figure 11.

Figure 11 Treatment options



Interviews

After the survey I interviewed several different cases in their villages. I introduced myself and explained the purpose of my study and requested their verbal consent before starting the interview. All photos were taken after getting consent from patients and family members.

Summary of cases

I interviewed eight individuals for my study and their characteristics are summarized in the table below.

Table 3 Survey of stroke cases

Case	A	B	C	D	E	F	G	H
Age (year)	31	41	50	40	15	19	70	38
Sex (M-male, F-female)	M	F	M	M	F	F	F	F
Duration of illness (year)	1.5	1	1.5	1.5	6	6	2	6
Affected Body parts at onset	All 4 limbs	Right hand and leg	All 4 limbs	Left hand and leg	Right face, hand and legs	All 4 limbs	All 4 limbs	All 4 limbs
Affected Body parts at present	Left hand and leg	Right hand and leg	Left hand and leg	Left hand and leg	Right hand and Leg	Right hand and leg	Right hand and legs	Right hand and legs
Marital status	Married	Single	Married	Single	Single	Single	Married	Married
Occupation	Farmer	Dependent Mentally ill	Carpenter	Health Assistant	Student	Day labor	Farmer	Street vendor

Table 4 Diversity of health care providers

Case		A	B	C	D	E	F	G	H
Health care Provider	Biomedi-cal doctor	+++	-	+++	+++	++	+	+++	+
	Traditional Masseuse	-	-	+++	++	++	+++	+	+++
	Spiritual Medium	+	+	-	+	+++	-	-	-
	Astrologer	+	+	+	-	-	-	-	-
	Monk	+	-	+	+	+	+	+	+
	Fortune teller	-	-	+	-	-	-	-	-
	So-called village doctor	-	+++	-	-	-	-	-	-

3

RESEARCH FINDINGS

This section will discuss the combination of field work: interviews, observation and health within the local cultural context. Here I try to explain the situation, local conditions and significant life experiences of individual cases in a social and cultural context looking at how patients experience *lay-ngan-yaw-gar* rather than as just medical cases. I will also include some of my research experiences which provided insights and understanding about the different circumstances of people suffering with *lay-ngan-yaw-gar*.

Based on the interviews with different cases, four major themes emerged :

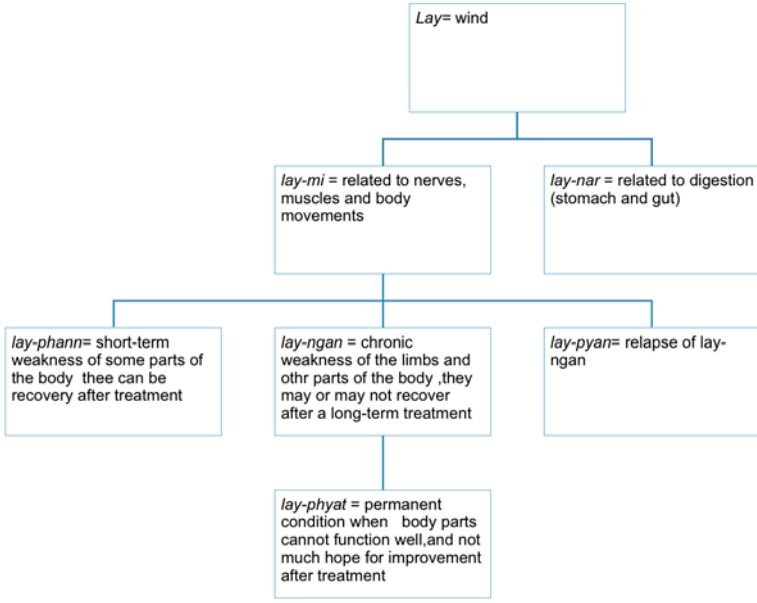
1. Before the illness (*lay-ngan-yaw-gar)*
2. Experiences at the onset of illness
3. Aftermath of illness and seeking health
4. Impact of illness on social life.

Burmese Definitions of Types of Stroke

Before going on to discuss these major themes, I would like to clarify some local terms relating to to *lay-ngan-yaw-gar. Lay* in the commonly understood as similar to the "wind". In Myanmar, the term "*lay*" has two related meanings one is linked to the nerves, muscles, bones and body movement, while another meaning is related to digestion, stomach and gut. Here in this study, I will

focus on the first meaning of *lay* which is related to nervous system. The taxonomy of local terms is summarized in figure 12.

Figure 12 Local terminologies for *lay-ngan-yaw-gar*



The term "*lay-ngan*" is neither a chronic one like "*lay-phyat*", nor a short-term condition like "*lay-phann*". In fact, it is classified as an in- between these two conditions. It is also known as "*Thwat-char-par-da*" in Pali. If the illness condition is progressive, *lay-ngan* transforms into *lay-phyat*. For people who experiences a recurring *lay-mi* a second or a third time, it is termed "*lay-pyan*". The word "*pyan*" mean "coming back to you". Informants explained that "*lay-pyan*" is a very bad sign, and if someone experiences "*lay*" for a second time, it is risky and may be fatal.

After understanding local terms, it is good to explain individual definition and classification of *lay-ngan-yaw-gar*. Diverse definitions and classification were noticed during the interviews with cases, family members and health care providers. Some of definitions provided are based on their belief system (biomedical or traditional medicine), and some definitions are not clear for the cases.

For example, one of the interviewees revealed:

> I didn't know what *lay* was previously, but now I suffer *lay-ngan*, the difficulty of any movement. My condition is called lay-ngan/phyat as I have not been able to move my limbs for many years. Previously I considered my condition was only *lay-phann* (a short duration of weakness of body and then able to recover soon). *Lay-ngan* is more severe than *lay-phann*.

Case Study Patients at a Glance

Patient A

Figure 13 Patient A

- 31-year-old married man with *lay-ngan-yaw-gar* for 1.5 years from Shanywargyi village
- At the onset of illness he could no longer move all four limbs.
- First he went to seek treatment at a government hospital in Bago
- After treatment of tuberculosis, he could walk a little but the left side of his body was still affected with stroke

Interview with Patient A took about 2 hours and I interviewed he patient, his wife and his mother at the same time.

> In early July 2013[1], I consumed alcoholic drinks continuously for 5 days. And I also ate pork and sticky rice which are cold foods[2] in nature. I think these unsuitable foods made me sick At that time, we had very heavy rain and the weather was also very cold in the paddy fields. The cooler the weather, the more I drank. After 5 days, I was in shock and lost consciousness. My family sent me to Bago General Hospital. I do not remember how long I was unconscious in hospital. After 1 week, I woke up and saw I was in bed.

Wife of Patient A

> I was in a desperate mood due to his illness, but we have no choice but to go to hospital, as we have no doctor in the village. Although I was afraid to go to a government hospital, but I knew the hospital had the facilities to save his life. According to doctors, he had two disease conditions at the same time; tuberculosis of the brain and stroke. He was in hospital for a month and received anti-TB medication and physiotherapy for stroke.

Mother of Patient A

> You know in the case of an emergency situation like the case of my son, we rely on western medicine. But we do not give up our traditional belief in spirits and astrology. I went to the village astrologer and calculated his fortune and stars. The astrologer said he was suffering bad luck for a few months, and he would not

1. The patient explained in lunar month of Myanmar Calendar and I converted the dates into English Calendar.
2. In Myanmar traditional belief: foods are classified into different varieties as cold food, hot food, wind food etc.

be have a quick recovery. To speed up his recovery I carried out some charms with flowers, waters and candles and made a donation to Buddha. I donated 31 flowers, water cups and candles, so that he would soon get relief. But the spiritual medium said that he had been punished by the spirit due to heavy drinking. This may be true as he drank so much, and ate pork, despite the fact that we are supposed to avoid pork[3].

Patient B

Figure 14 Patient B's necklace is made of thread and the charms were developed by a spiritual medium to protect from the threat of her past life as member of *oat-ta-sount* family.

She is a single lady, 41 years old, living in Shanywargyi village. She contracted right-side *lay-ngan* one year ago. This case is quite interesting because the patient has a mental illness, and the traditional beliefs concerning the connection between past life, mental illness and *lay-ngan* is significant. As the patient could not communicate well with me, I interviewed her sister. The following quotes are drawn from the first interview which lasted an hour and a half.

3. In Myanmar, pork is considered as forbidden meat for those people who believe in spirits. People think about the negative impacts of social economic life are associated with pork eating behavior.

As she is mentally sick, we did not want to treat her in hospital, so she received treatment from *Sayargyi*[4] in the village. *Sayargyi* is the only suitable person to treat her, he knows every detail of her life and illness. We also feel confident about his treatment and assessment.

When she was 9, she suffered a head injury, falling off a ladder. As a result of that injury, she experienced repeated fits. Her memory is abnormal and unstable. Sometimes, she speaks alone loudly and cries in the middle of night. My parents believed that she was an *Oat-ta-sount*[5] in a previous life. According to spiritual medium, she was the youngest sister of five in a *Oat-ta-sont* family at the pagoda near our ward.

Despite her mental illness, before the *lay-ngan* she helped our family a lot, especially in the kitchen. But now she cannot help and we even have to arrange an extra person to take care of her. Now she has become a burden.

4. *Sayargyi* is used for someone who is respected in Myanmar, commonly used for teachers, doctors and senior officers. The *Sayargyi* here refers to the village "quack" doctor.
5. *Oat-ta-sount* is an angel-like being in the Buddhist belief system. They take care of sacred objects in pagodas and monasteries, safeguarding jewelry and gold inside the pagoda or buried underneath the monastery.

Patient C

Figure 15 Patient C with the implements he uses to cope with *lay-ngan:* a used rubber bicycle inner tube to stand up and for stretching exercises; bamboo stick to assist walking; a slipper with plastic string to adapt to foot-drop

- 50 years old carpenter with five children
- Suffering left sided *lay-ngan-yaw-gar* for 1.5 years
- First time treatment at government hospital
- Currently can walk with a bamboo stick for a short distance

I spent the whole morning interviewing Patient C. The first interview took about 3 hours, chatting about his case and talking with his wife, neighbors and children.

The social background implications of *lay-ngan-yaw-gar* were significantly seen in his case.

He is a carpenter working around Kayin state with a contractor team. He was very competent in building houses and schools. He has worked in Kayin State, particularly in *Pha-an* , the capital of Kayin State, for 2 years.

Last year during the rainy season around September there was a lot of rain and extremely cold in *Pha-an*. His apartment was not warm enough. He thinks that the cold weather condition caused his *lay-ngan*. Two days before he got stroke, he suffered numbness and a tingling sensation in the whole body, which he attributed to

the cold weather. Then, he suffered a stroke.His left arm and legs were not able to move. In addition he could no longer eat normally, as one half of his face was paralysed by *lay-ngan*.

His colleagues sent him to hospital and it was discovered that the stroke was due to high blood pressure. He was in the hospital for 2 weeks and then went back to his native village**.**

Subsequently he consulted with 12 different health care providers during the course of a year. He had initially expected to recover very soon. However when I interviewed him, he was suffering deep depression. He even requested me to provide treatment for him as well. "Sayar, please save my life. I don't want to live with this condition (*lay-ngan*). I want to work for my family. Right now all my kids are suffering because of my illness."

There are six members in his family, the patient, his wife and 4 kids. The eldest one was 23 and he is a monk. The Two daughters are working in a garment factory nearby Bago, and the youngest one is in primary school. As he did not have any income,his eldest son left the monkhood and went to work in a restaurant as a waiter. The two daughters are also working, and his wife is employed in the tobacco industry. He said

> Sometimes I cry alone because I am useless to my family now, and my condition does not show any improvement. Although I have consulted with various health professionals, I go walking and do physical exercises everyday hoping to recover, but I fail to get any better. Then I cry and get depressed.

Patient D

Patient D is 40 years old, gay man with left sided *lay-ngan*. He is a health assistant at village rural health center in Kamarnut village. He got *lay-ngan* a year and half ago while visiting to Yangon. His partner is lying beside him in the photo.

Figure 16 (clockwise from left) Patient D and his partner; the hat, a steel handle and foot-ware for walking; a package of betel nuts and multiple spikes for cleaning teeth

In October 2013 he imbibed alcoholic drinks for 3 continuous days during the farewell party of his partner going to work in Korea. Then he got a headache. He thought that it was hypertension, and took medicine to reduce blood pressure. He also had sleepless nights during that period. He went to visit Yangon for the day. While he was trying to use the zebra crossing at the traffic junction, he felt very weak and shouted for help. Then he collapsed on the road side, and his friends took him to the nearest private clinic. There it was found that he was in a state of shock with very low blood pressure. The clinic doctor advised that he as he was in a critical condition, should be admitted to the government hospital.

> I was in the government hospital for 2 days without treatment because I was admitted on the Saturday and I had to wait until Monday, when specialists came to the

> hospital and then I received an injection. After one week, I changed my mind and decided to transfer to a private hospital and get treatment from a neuro-physician. I received several injections to stimulate the nerves, and it helped me to recover well, but it was too expensive in a private hospital. I could not walk at first but I tried to do regular exercises with the help of a physiotherapist, and I tried to walk with the help of steel structure. I did regular physiotherapy exercise every day for 2-3 months.

The negative social-economic impacts of *lay-ngan* is very significant in the case of this community health assistant

> Being affected with stroke (lay-ngan), I could not practice medicine, and I lost my income. Many patients lacked confidence in my capacity to provide treatment. Furthermore my supervisor forced me to resign with a medical pension. It was really bad luck for me to be a *lay-ngan* patient.

Being a health assistant working for a western medical practice, he had no belief in traditional medical practices and the folk-lore sector.

> I took Neurogeon[6] and other drugs prescribed by a physician. I don't believe in traditional medicine. However, my mom went to an astrologer and also met with a village monk to predict my future prospects, but I have no faith in them.

Although he placed no value in traditional medicine, he agreed to try out a traditional massage as suggested by many of his relatives.

> Now I am going to the traditional masseur in Htauk-kyunt (a small town near Yangon) because my relatives urged me to go there and get a massage. They said that the masseur is very famous and provides very good treatment. I am not so sure but for the first time I agreed to try it.

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6. A medicine for brain and nerve diseases

Background of Three Main Cases Selected for Analysis

Here in my report, I will put particular emphasis on three selected cases to illustrate what these people experienced with the health system, and how they have struggled in terms of social, cultural and psychological sphere in seeking treatment in the case of *lay-ngan-yaw-gar*.

Case 1

Case 1 is Patient D from the earlier profiles. A 40-year-old single man from Kamarnut village and a government assigned health assistant in the rural health center in the village. He was affected with *lay-ngan-yaw-gar* on left arm and legs for two years. First he sought health with biomedical doctors at the hospital and private clinics for one and half years. Then he consulted a traditional masseur while he was taking biomedicines. The reason for selecting this case is to highlight the change in perceptions of people in the course of seeking health care, when they experience improvement during their treatment.

Case 2

She is 15 years old, a dependent teenager living alone with her father and aunt in Kamarnut, when her mother passed away a year ago. She has *lay-ngan-yaw-gar* on right side of the body and face for six years, and consulted with both biomedical, traditional massager and spiritual medium. This case is particularly interesting because of her youth. Normally *lay-ngan-yaw-gar* is considered a chronic illness that is commonly seen in older people, who are above 40 years. It is very rare for stoke to afflict people young people and no one expected this girl to have *lay-ngan-yaw-gar* at such a young age.

Case 3

This is a street vendor from Saiti village. She is 38 years old, married and with four kids. She was aged 32 when she got *lay-ngan-yaw-gar* on right arms and legs. Both biomedical and traditional ways of treatment were taken throughout the course of

illness. Case 3 is presented to demonstrate the diverse social impacts and interaction in seeking health care within a family

It was established that Case 3 had no previous personal definition of *lay-ngan-yaw-gar* as she has no clear understanding what is *lay*. But now after her experience, she has come to know about *lay* and understands the different types of *lay-ngan-yaw-gar*.

The interview with a spiritual medium[7] defined *lay-ngan-yaw-gar* from her professional stand points as follows:

> If you cannot move your body, it is called *lay-ngan*. For me I have only two classifications: Ordinary *lay-ngan* and evil-related *lay-ngan*. If the patient recovers within 21 days of my treatment, it is evil-related *lay-ngan*. If it is ordinary lay-ngan, it will take longer and then I refer the patient to either biomedical or traditional practitioners. For me evil-related evil is considered severe, ordinary *lay-ngan* is curable by doctors and traditional practitioners. Evil-related *lay-ngan* has sub categories; it may be either due to under influence of a magician or witch, or disturbance of people from previous life, or people behaving in a bad way to the spirits. For such types, I called upon powerful spirits and make appropriate rituals and treatments.

Her definition is quite professional and smart with a clear differentiation between two types of *lay-ngan-yaw-gar*. For evil-related type, she already has some treatment options. Her practice of referring some patients to other health care providers is a responsible approach.

The personal definition of *lay-ngan-yaw-gar* by health assistant Case 1 also reflects his professional view:

> Stroke is a condition when your body cannot move as a result of a blockage or a rupture of a blood vessel to

7. The spiritual medium is famous in the community and my parents also began to believe in her when I was hospitalized at the age of 8. She is famous for evil-related conditions and witch and ghost related rituals.

> the brain. Therefore stroke may be a schemic stroke or a hemorrhagic one. The hemorrhagic one is more severe, and can lead to sudden death.

The patient in Case 1 used the term "stroke" as he was trained in a biomedical school as a health assistant. When I asked about his definition, he smiled and said that he took the definition of stroke from medical texts that he used for his study for a medical exams. It seems he operationalized his definition of *lay-ngan-yaw-gar* with biomedical concepts.

The traditional medical practitioner holds a different view about the definition of *lay-ngan-yaw-gar*. His point of view is quite different from others and is rarely heard in our day to day discourse:

> In my view, *lay* does not directly apply to wind. It is just a physical nature/concept of body element. For example, the function of *lay* in our body is to support or facilitate the body in every movement and posture. You will not find *lay* inside the body.

The definition of the traditional medical practitioner on *lay* stimulates me to think about the meaning of *lay* in traditional medicin, as compared to a biomedical perspective of how doctors define 'nerves' and 'movements' in our body. MacDonald (MacDonald, 1879) studied about Burmese medicine in the colonial period. She mentioned four elements (*Dats*) including *War-yaw*. However her explanation could not provide clear view of what does *War-yar* mean in traditional medical perspectives.

The biomedical perspective considers nerves function as stimuli for the movement of muscles and bones. Oxygen reaches all parts of the body s via the blood stream. However the traditional medical practitioner has a far more complicated explained of *lay.* This healer explained that the traditional way is called *Abhidama-Taung-Thar*[8] which is partly linked with Ayurveda medicine (Nargathein, 1956).

8. *Abhidama* is the Buddhist way of analysis to find real truth. *Abhidama* is also a branch of traditional medicine in Myanmar with a long history. Taung-Thar is the city in Myanmar where the pioneer practitioner was born.

He continued to mention six types of *lay* which is called *War-yaw* in Pali, Buddhist scriptures. Six types of *war-yaw* are (1) *lay* that we breath-in and breath-out, (2) *lay* that is outside the gut of belly, (3) *lay* that is present inside the gut, (4) *lay* that reached to distant organs like head, hand and foot, (5) *lay* that ascends to upper part of body parts above the stomach and (6) *lay* that descends downward toward lower body parts and genital organs. Based on the type of imbalance of different lay, the illness type is also different. This is the first time for me to learn that the Buddha had explained such different types of *lay* in his teachings.

Before Illness

Now, I would like to move to the major themes. The first one is about stages of life before the onset of the illness. All cases noticed some pre-warning symptoms before onset of *lay-ngan-yaw-gar,* while some of them explained that they had suffered from high blood pressure (*thway-toe*) and a neurological condition (*a-kyaw-tat*).

Pre-warning symptoms

"When she feels headache and shaking arms, we suspect she has *lay-ngan*." (Aunt of Case 2)

As Case 2 has experienced *lay-ngan-yaw-gar* three times, her family clearly remembers the pre-warning symptoms how they took care of her and told her to alert family members if she felt either headache or shaking arms.

Case 1 experienced pre-warning symptoms, but paid little attention, as he had consulted with an orthopedic surgeon who diagnosed another condition. He said

> Two weeks before the stroke (he used the term stroke as he is a health worker), I felt dizziness and numbness in my left arms. I consulted with Dr. YYY[9] and he

9. Dr. YYY is a local well-known biomedical doctor, a native of Kamarnut village and runs a clinic in the eastern part of Bago, 4km from Kamarnut

> warned me about a possible stroke. However, I did not think it was possible at my age. I changed my mind and went to see an orthopedic surgeon (bone and joint specialist) and he diagnosed a cervical spondylosis.[10] I underwent treatment but I ignored the evidence that indicated symptoms of stroke.

As he did not pay proper attention to the early symptoms, this resulted in time wasted when it might have been possible to prevent the development of *lay-ngan-yaw-gar.*

Existing health conditions

In both Cases 2 and 3, there was an pre-existing condition prior to the onset of *lay-ngan-yaw-gar*. For Case 2, it was a cold and flu. In the village people usually practice self-medication for flu by taking over the counter drugs like Paracetamol. However in Case 2, her father sent her to a nearby clinic hoping for a quick recovery, as they had a forthcoming wedding in the family. Her father described what happened.

> She was sick with flu and cold two days before she got *lay-ngan*. She was receiving medicine from a nearby doctor for flu. We sent her to the clinic as we had planned a wedding ceremony of her brother at this time.

For Case 3, she noticed that she had high blood pressure for a long time before *lay-ngan-yaw-gar*. However she did not take regular treatment as she was hard up and could not afford the medication.

She said, "once, a doctor told me that I have high blood pressure. But I did not take any treatment, because we are poor daily- wage laborers. We just focus on our daily income,rather than our health. I noticed high blood pressure *thway-toe*[11] and I also feeling *a-kyaw-*

10. Cervical Spondylosis is a disease of the back (neck vertebra) which has various symptoms including neurological conditions like numbness, dizziness and pain.
11. *Thway-toe* is local term for high blood pressure. Thway means blood and toe means increased with force.

tat[12] and headache."

Like Case 3, village people have high incidence of high blood pressure according to my experience in community clinics. However, people rarely seek advice or treatment because they cannot afford to pay for a medical consultation.

Moreover the government health services are giving priority to acute and infectious diseases like HIV, tuberculosis and malaria. Chronic diseases like hypertension and diabetes derives little funding support from the government side.

Rapid urbanization may be also exacerbating the problems. Far more artificial food commodities are now in circulation including seasonings, read-made foods, preserved foods and alcoholic drinks. This has resulted in major changes in dietary consumption, and have exacerbated the numbers of people suffering from chronic diseases.

Along with urbanization, the income opportunity for villagers has declined by comparison with earlier decades. People cannot afford to spend more on health care, and are increasingly dependent on free-of-charge clinics in the community. In Case 3, the street vendor was earning less than three dollars per day on average.She could not afford to pay more attention to her health, than her economic survival from her daily work and income.

Experience of Illness

This is the critical part during my interviews and in all the cases, family members are very excited to retell their stories and share their real life experiences.

My question of "How and when did it happen (*lay-ngan-yaw-gar*)" stimulated the informants to evoke their feelings and recall the day they got *lay-ngan*.

12. *A-kyaw-tat* is local term for neurological conditions like ache, stiffness and pain around the neck and shoulder. *A-kyaw* means nerve and *tat* means stiffness and uneasy condition. In some areas it is also called *zat-kyaw-htoe* which is pain and stiffness around the neck.

In some cases they expressed grief and sorrow during the interview. Some even cried when they recalled the event. It was also a good opportunity for me to observe how people experienced *lay-ngan* in different situations. In this gathering, my prime role was that of an attentive listener. Sometimes I clarified the information and asked the reason for their explanations, I was unclear about their narrative. This part of interview helped to build a strong relationship, rapport and trust between me and my informants.

Onset of *lay-yaw-gar* and initial decision to seek treatment

All cases explained that the onset of *lay-ngan* was sudden, abrupt and they had never encountered it before.This sudden onset of *lay-ngan* also causes psychological shock for individuals, families and the community as well. In all cases informants reported that they opted first to seek emergency care in biomedical sector, either in clinic or hospitals. The reason why they selected biomedical sector will be discussed later in health seeking section.

For Case 2, the family was completely unprepared when she got *lay-ngan-yaw-gar* as her father mentioned.

> She was sick during Tasaungmone[13] (around end of October and early November) when the season had changed from rainy season to winter. Although it was in winter, there was still a bit of rain. As we were busy with her brother's wedding ceremony, we could give her much attention. When she woke up next morning, she was in lay-ngan and her faced had changed. Her arms and legs became "dead" (she could not move). I urgently brought her to the doctor.She could not express anything apart from crying.

Case 3 got *lay-ngan-yaw-gar* during the rainy season while she was busy at the village. The lengthy story of Case 3 below reveals that although friends and neighbors tried their best in the event of a

13. *Tasungmone* is the 8th month in theMyanmar Calendar, between the end of October and early November.

sudden and unexpected condition, it may lead to harm rather than helping. Case 3 got injured at her shoulder joint (dislocated shoulder) as three men tried to lift her (three men lifted he unevenly) up to the horse cart and her arm completely dropped.

> I remember well the day I got *lay-ngan*. It was the next day of the full-moon day of Warso[14]. I helped in the monastery to clean the floor and kitchen in the morning and the afternoon. Then around 3:00pm, my friends informed me that there was going to be a cow slaughter in the village cemetery. I joined the event to get some meat to sell in the evening for my daily income. It was a very wet rainy day.
>
> The weather was very cold compared to other days. I sat on the wet floor (cement floor), and was waiting until my turn came to buy some beef. All of a sudden I felt my muscles tense and my legs became rigid. I became totally paralyzed. I suffered a terrible headache, but I could not speak out loud. With strange eyes and frozen limbs, my friends considered that I was possessed by *ma-kaung-so-war*[15] (evil spirits). We were sitting in the cemetery yard and they were thinking about *a-pa*[16] (evil spirits). Although I knew that I was not attacked by 'a-pa', I couldn't stop them lifting my body to the horse-cart. Three strong men lifted me, pushed me into the horse-cart but they did it in a rough way, and did not take care about my arms. My left shoulder was very painful as it was lifted and pushed me up into the cart. It was very painful. I was completely mute and unable to complain. Then, they called my husband and someone put some powderinto my mouth. (she

14. *Warso* is the 4th month of Myanmar calendar, around the middle of June to early July.
15. *Ma-kaung-so-war* is local term for evil spirits and ghost.
16. *A-pa* is another local term for evil spirits and ghost.

> didn't know what the powder was, but it was a traditional medicinal powder with a very bitter taste). As I could not stand the smell and taste of the powder, I felt sick and vomited. After vomiting I felt a little bit of relief. I remembered that while we were on the way to clinic, my husband chased us and we met at the clinic. There the doctor said my blood pressure was extremely high (240mm Hg of upper level) and gave me an injection (she thinks that was to reduce the blood pressure). Then the doctor urgently referred me to Bago general hospital, although I did not want to go there due to high cost of its medical care.

In Case 1, it is a completely different and astonishing story about how he experienced *lay-ngan*. He got *lay-ngan-yaw-gar* while he was crossing the road in the city. This is his account:

> It was October and I was in Yangon[17] with three of my friends. While we were at a zebra crossing by a traffic light, I was left alone on the pavement standing like a robot, and my friends were already on the opposite side of the road. I shouted for help. They thought that I was kidding them. I felt stiffness in my legs and I couldn't them at all. I noticed general weakness in my body and I almost fell down. Then I gained some support from an umbrella, and I stepped on the ground. Then one of my friends came to hold my body, to prevent me falling over. I also suffered very severe headache and my whole body was sweating, as if I was in a shower.

Perception of the Causes of *Lay-ngan-yaw-gar*

The explanation of different causes of *lay-ngan-yaw-gar in these cases* is quite different, and depends upon the social and cultural background. Some cases were explained in relation to high blood

17. Yangon is the former capital of Myanmar

pressure and the food consumed (biomedical concepts), while one case described the cause of *lay-ngan* as a result of imbalance of the four elements,cold and hot interaction (traditional concepts), and in some cases thought that *lay-ngan-yaw-gar* is due to loss of a good relationship between the person and the spirits (local spiritual concepts).

> I think she got *lay-ngan* mainly due to cold weather and cough and cold she suffered. Before she got illness, there was also some rain during the winter. (Father of Case 2)

One interesting finding is that even in the same family, the perception of the cause of *lay-ngan* is different. The different perceptions, among mmbers of the family also affected their attitude towards the type of treatment. For example in Case 1, the patient thought that *lay-ngan* was due to high blood pressure, while his sister thought that it was due to his life-style, such as drinking, eating pork and sleeping habits. He said, "I think it is due to high blood pressure, so I took medicine to reduce hypertension (*he used the English medical term 'hypertension'*)."

> For me I think his illness is related to the heavy drinking of beer. He was drinking for 3 or 4 days before the onset of *lay-ngan*, and he also likes pork[18] and oily foods, which would also be a contributory factor. He also had many sleepless nights during the spell of cold weather. (Sister of Case 1)

For case 3, both husband and wife adhere to a biomedical explanation as the cause of *lay-ngan*, but their belief on the causal agent or factor is different. Case 3's husband said,

> I think my wife got *lay-ngan* for three reasons. First she had high blood pressure and she did not take care

18. Pork is considered as forbidden food in the culture where people worship spirits in the villages.

> of it. Second she ate some *a-tat-sar*[19] (a food that aggravates high blood pressure) especially su-pote leaves and coconut noodles. Thirdly she was having menstruation during those days and touching the cold cement floor. Raw meat (beef) also causes high blood pressure. The combination of all three factors added to high blood pressure can trigger *lay-ngan*. I believe that there is a link between *lay-ngan* and *thway-toe* (high blood pressure).

Here in this conversation he mostly accepts the biomedical perspective but his explanation about "menstruation and wet floor and the raw meat' is based on local beliefs.

Figure 17 *Su-pote* leaves

Concepts and taboos about menstruation as a community health issue is worth exploring in future research. Although Case 3's husband pointed out a combination of factors, she provided an additional and different explanation for her *lay-ngan*:

> I took contraceptive injections for seven years. The doctor gave me some pamphlets about the side effects

19. *A-tat-sar* are foods that can cause or worsen high blood pressure. Some examples are coconut, noodles, seafood, tuna, *su-pote* leaves, etc.

> of contraceptives, but I had not read them. Then when I got *lay-ngan*, I found out that contraceptive use is related to *lay-ngan*. I think I got high blood pressure due to the use of contraceptives, and it also makes a contribution to developing *lay-ngan*.

The perception of others outside the family is sometimes different from what the individual thinks about the cause of *lay-ngan-yaw-gar*. For instance, Case 3 does not accept the "evil spirits" concept but her friends believe it: "My friends thought that I was possessed by *a-pa* (evil spirits) when I became paralyzed."

Similarly for Case 2, although the father thought that *lay-ngan* is due to cold weather and flu, neighbors proffered different opinions on the cause of *lay-ngan*. Case 2's father said, "My neighbors said that my daughter ate coconut noodle soup and this made her ill (*lay-ngan*)."

Here from this study, it is obvious that people hold their own opinion and have their own explanation, and this may affect the choice of health-care for *lay-ngan-yaw-gar.*

Food and *lay-ngan-yaw-gar*

In the interviews nearly all informants mentioned food as a causal agent to *lay-ngan-yaw-gar* and I asked them "why" and "what" was the connection between food and the onset of stroke.

The sister of Case 1 mentioned 'pork' as a clue for *lay-ngan-yaw-gar,* and she linked her reason with a spiritual concept: "You know we worship *nats* (spirits) and they don't approve of eating pork. As my brother likes pork the spirits put a curse on him."

In Case 2 there are references to problems with certain types of food including "coconut noodles," but they have not provided any detailed reasons or evidence of a link to *lay-ngan-yaw-gar*. In Case 3, the patient mentioned that she ate *su-poke* leaves, coconut noodles, and her husband mentioned eating raw meat.

From a biomedical perspective there is no specific food that is known to cause stroke. However there is strong evidence that stroke is related to high blood pressure. Biomedical texts have

mentioned some foods and drugs that may increase high blood pressure. The explanations of our informants may be the result of confusion over the link of certain foods with high blood pressure.

Then I tried to understand it from a traditional medical perspective.

The interview with a traditional medical practitioner revealed that foods are basically classified into two types; hot and cold. Table (3) shows a list of hot and cold food according to my informants.

The concept of a traditional practitioner is that either cold or hot foods account for *lay-ngan-yaw-gar*. As mentioned in previous discussion about the six types of *war-yaw*, he stated that foods also form part of the determinants and causes of disease according to a Buddhist understanding. "You know in Buddhist teaching, the cause of all events is explained in four ways: karma (*kan*), mind (*citta*), season (*u-tu*) and nutrition (*ahraharra*)."

Table 5 List of hot and cold foods

Hot food items	Cold food items
Alcohol?	Beer
Chicken	Pork
Mutton	Duck
Coconut	Cold drinks
Coconut oil	Ice-cream
Sticky rice	Cucumber
Su-poke leave	Watermelon
Durian	Mangosteen

Aftermath of Acute Illness and Health-seeking Patterns

Ppeople try to seek health based on their belief in what causes *lay-ngan-yaw-gar*. When I interviewed informants, I tried to understand the relation between the social background and the health seeking pattern. Here the classification of socio-economic condition is only based on how villagers perceived an individual family in relation to their properties, land, vehicles and housing status. Among the three cases Case 1 is considered as a well-off

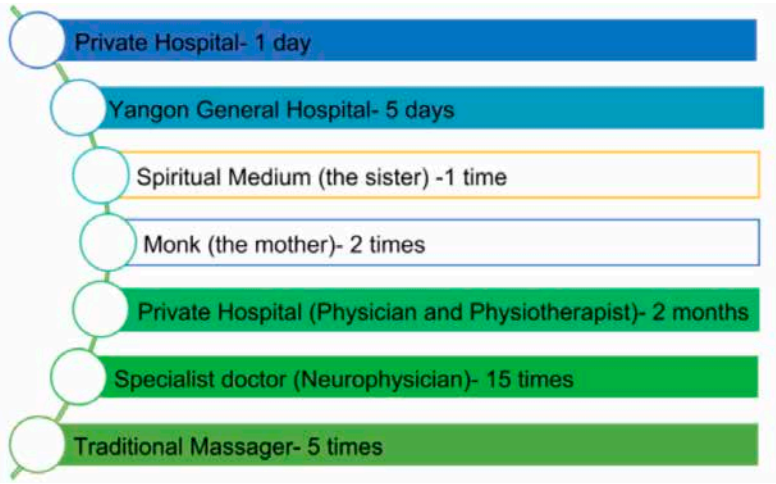
family in the local context, Case 2 as middle class, and Case 3 a poor family. As I mentioned earlier in the case of a sudden onset of illness, people seek health in the biomedical sector either at a clinic or a hospital.

Pattern of seeking health care

In looking at the health care seeking pattern, it was clear that the affluent family predominantly selected to seek care in the biomedical sector. But the fact that the patient was a biomedical practitioner was the major reason why he trusted in western medicine. Case 1 invested a lot of money to seek health in a private hospital and a locally renowned physician.

Figure 18 illustrates how Case 1 sought health with various providers throughout the course of his illness lasting 2 years. At the onset of his illness, he was admitted to a private hospital. Due to his state of shock the private hospital urgently referred him to Yangon general hospital (a government facility). As he was disappointed by the negligence of the doctors in the government hospital, he decided to go to a private hospital. He said, "as there is a good physician and physiotherapist, I made up my mind to go there." While he was in the hospital, his family members decided to seek health advice from other providers—a spiritual medium and a monk.

Figure 18 Health seeking pattern of Case 1



The consultation with spiritual medium and the monk were done by his family members while he was in hospital. His family members replied me that they do not consider consultation with a spiritual medium and the monk as health seeking, and they think this consultation is just checking or supporting his good fortune (karma). What his sister explained is as follows:

> We do not seek health advice from the spiritual medium and the monk. We just check his fortune (with the monk), and relationship of his illness to bad spirits (with spiritual medium).We asked the monk about(the birthday of provider) about treatment and if we should perform some rituals and make donations the corner of the Pagoda?

Although family members believe in the spiritual world and astrology, the patient in Case 1 does not subscribe to these ideas and maintains his biomedical view.

After a lack of improvement at the private hospital as well as his plus lack of financial means to stay in the hospital, he goes for a consultation with a different neuro-physician. This neuro-physician becomes his the main treatment provider.

My question is: why did this patient who believed in orthodox medical principles also opt to be treated by traditional massage.?

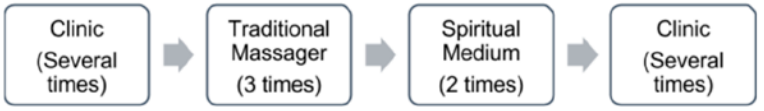
He replied that his relatives forced him to consult with the traditional masseur. (This I will call 'social pressure' in further discussion). He tried once to consult with the masseur and he felt a small improvement in his legs.Then after one month he visited him again. After four visits he said he could walk without the help of a stick. Now he accepted his need for regular massage treatment However Case 1 still retain his biomedical view, and continued to take pharmaceutical l drugs daily, as prescribed by the neuro-physician.

The middle-class family in Case 2, also consulted with a general practitioner (ordinary doctor) as their first preference but also sought additional help from a traditional masseur and spiritual medium as shown in figure 19. They normally seek treatment from a general practitioner for any illness in the family.But their

neighbours suggested they could also benefit from consulting with a traditional masseur.(this I define as social pressure.

The father of Case 2 personally does not like massage. He explained, "You know, it is nonsense to use a sling and splint for my daughter. She got *lay-ngan*, not a broken bone. Besides the treatment was very painful for her. As she has not improved significantly we switched to another person."

Figure 19 Health seeking pattern of Case 2



The spiritual medium is a good choice according to an aunt in Case 2. She explained as follows:

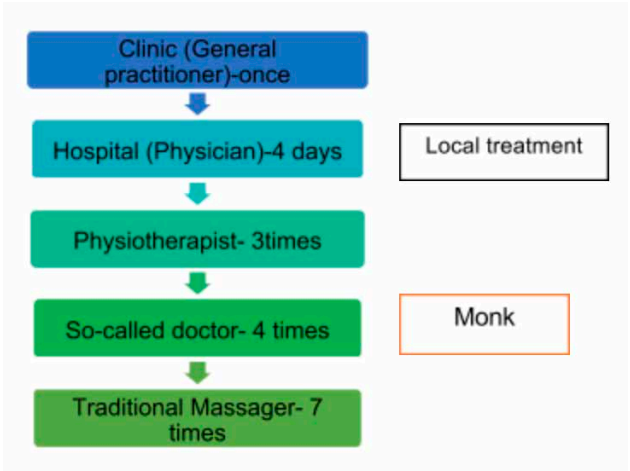
> We consulted with her (the spiritual medium) and she said that there is an evil spirit derived from when she was a child and fell down near the pond.She provided a ritual to perform, and she promised that after 4 or 5 days, the child will be able to speak about her improvement. So we performed some rituals; raw meat and rice were placed near the pond, and to our surprise the child can now speak normally after 4 days.

As the child gets better the family increases their trust in the spiritual medium.After the evil spirits have departed, the spiritual medium referred her to a doctor to continue the biomedical treatment.

Here the family of Case 2 witness the power of the spiritual medium, and they may contribute to increasing social pressure on other families dealing with *lay-ngan-yaw-gar*.

In case of a poor family, like Case 3, although they tried to get help from hospitals and clinics, they lacked the financial resources and were obliged to seek the majority of treatment from a traditional masseur and a so-called village doctor.

Figure 20 Health seeking Pattern of Case 3



On the day when Case 3 got *lay-ngan*, her friends send her to the nearby clinic. The clinic gave her one injection and immediately referred her to the Bago government hospital due to very high blood pressure. When she was in hospital, she could not move her limbs and her tongue. According to the husband, the medical staff provided various injections, but no explanations. (I will discuss more in 'settings'). After 4 days of hospitalization, the husband requested to see the consultant physician. They carried out a lumber puncture (to obtain some fluid from the spine for a lab test).

The husband observed the face was also affected by *lay-ngan* and he decided to apply to utilise local knowledge. In the village people used the bile of a big snake for the relief of *lay-ngan*. He requested the snake bile from a village monk, and applied it as a lotion on the face, and also placed it on his wife's tongue. He did this secretly as he knew that doctors would not approve of such traditional local remedies. The husband also checked Case 3's fortune with the village monk. As the condition of Case 3 did not improve, the husband decided to take her back home. On the advice of a relative, they went to visit a physiotherapist in Bago (another social pressure). The husband mentioned that the physiotherapist explained patiently how to do exercise, and offered to visit her frequently. However they could only afford a few visits. They also tried to get medical help from a so-called village doctor in their

village. Later she received treatment from a traditional masseur. The patient in Case 3 attributed her eventual recovery to the skillful treatment of the traditional masseur.

Settings: Clinic, Hospital, Traditional Masseur, Spiritual medium, and Monks

In my overview of the three cases, I would like to establish the different settings where the health provider and the patients meet, or where the patients interact with different sectors as Kleinman stated. The first setting is a clinic in Bago. Most of general practitioner clinics in Bago are located on the main road and are easily recognized by their red-cross sign.In front of the clinic the name is clearly visible on an advertising signboard. The name and degree qualification of the doctors is also proudly displayed on a plastic board together with the clinic's opening hours.

Inside the clinic there are two rooms. The first room is the waiting room and the second room is for examination and treatment. Patients can read many health education posters and different pamphlets about common health issues while they are waiting for their turn. By the time one patient has finished the consultation, the next patient will be called upon to enter to the examination room by the clinic assistant. Inside the examination room, the doctor may sit on a chair with a table Unlike western doctors, general practitioners do not wear a white coat, but they put a stethoscope over the shoulders in most cases.

Among different cases, Case 2 is very familiar with clinics and the aunt of Case 2 shared their experience at the clinic*:*

> When we go to clinic, we have to get a token. When doctor's assistant called our name we have to enter the examination room. After examination and getting treatment, we have to pay cash to the clinic assistant,but the doctor decides how much to pay for the consultation. On average, each consultation took about five to ten minutes and we spent about 3000 to 4000 kyat (2.5 to 3.5 dollars) in each visit. As we are

> familiar with the doctor, you can discuss and ask some questions after treatment.

In Case 1, he is familiar with private hospitals and specialist neurological physicians. For him it is not a strange experience to be in a private hospital and consulting with specialist, as he was accustomed with biomedical perspectives. His view on biomedical perspectives showed as a patient:

> When I became sick, I can understand the feeling of a patient. Mostly we (biomedical practitioners) have very poor communication with our patients. When I got this illness, I had many questions to ask to the specialist,but when I met him (specialist),he spent nearly all the time on prescribing a long list of drugsand I forgot to ask my questions. There was little conversation, and no explanation about the prescription. Nevertheless I followed this treatment as I believed him to be the best doctor.

For case 3, it was their first time to visit a government hospital and they shared their experience in Bago hospital. Government hospitals have different wards such as surgical, medical, and emergency departments. In the government hospital, the patient has to share a common room with 10-15 people. Individual patients will get a bed and a bench for their visitors. There is a shared toilet and bathroom .The main interaction between physicians, staff and patients is the 'ward round' during which all the members of the medical team check individual patients. The consultant physician in charge of the ward , instructs staff to take notes on medical treatment.Most of the time they use English medical terms, and it is hard for ordinary people to understand.

The husband of Case 3 shared his view on interaction at government hospital.

> When we were in hospital, nurses and doctors gave many injections to my unconscious wife. We did not know why these injections were provided, it was never explained. After 3 days and little change in her condition, I gathered my courage to meet with the

> consultant physician. It was my first time to speak with a senior doctor in an air-con room. When I requested, she (physician) instructed (in English) her staffs to do some treatment for my wife. I tried to apply the bile of a snake to face of my wife. I did it like as if I was committing a crime as nurses and doctors do not accept our local remedies.

Case 3 also seeks treatment with a traditional masseur and the setting is quite different. The patient in Case 3 shared,

> The masseur opens the main room in his home. he does not like to labelled as a masseur (*a-neik-thae*). He prefers that I should call him *sayar* (master). The massage usually takes about half an hour to forty-five minutes, Apart from massage, he sometimes uses some oils to apply in the affected body parts. Afterwards we pay on average around 3000 kyat (2.5 dollars) per visit.

As mentioned before most informants do not consider consultation with a spiritual medium or a monk as health-seeking behavior. But we should also include the setting.

At the spiritual medium's home, visitors can see many different spirits, their characteristics and worshiping methods. In order to consult with the spiritual medium, one has make an appointment one week in advance. The consultation time will last about forty-five minutes to one hour. The individual can ask diverse questions when the spiritual medium starts her service. Case 2's aunt explained their experience with a spiritual medium:

> We had two visits. On the first visit, she could not speak and the spiritual medium instructed us to make a ritual for bad-spirits. She also gave us holy water and some charms to protect her from evil-spirits. Then we made the ritual and to my surprise she started speaking – speaking with clarity.After the second visit the medium said it was time to consult with a professional doctor. Then we switched to the nearby clinic. For these consultations, we spent about 6000 kyat (5 dollars)

In our culture sitting and meeting with a monk has special rules for social interaction. There is a correct position for sitting down, and a special version of Burmese language for communic ating with the monkhood. Most consultations are free of charge. Case 3's husband shared his experience on consultation with a monk:

> I believed in the monk as he is the son of Buddha. He pointed out the conditions for bad and good luck He also told me to carry out some religious rituals for a faster recovery.

In these different settings the concept of 'powerful others' is also observed when a particular patient meets with a provider. In our society health care providers are considered as benefactors and paid a high level of respect They are not only seen as service providers as in Western culture.

It is rare for any health provider to ever be sued in our culture. In the above settings, it is clearly seen that each different setting has rules and customs to socialize patients, and patients themselves tried to adapt to the new setting, to follow the rules and customs described.

Although interacting with different settings, people with *lay-ngan-yaw-gar* do not make see any obstacles or boundaries to prevent them from readily switching from one provider to another. Hence we noticed frequent changes of provider in above cases. My next question is about their decision to change their provider. All informants were able to provide a reasoned reply for their choices.

Change of provider: social pressure

The decision to change provider is often related to social pressure. I define social pressure as advice from family members, siblings, relatives and friends (usually they have already suffered from a stroke or are familiar with *lay-ngan-yaw-gar cases*), to seek health with a particular provider. I call it 'pressure' because the people feel as if they are obliged to accept this advice according to Myanmar culture. Sometimes patients even feel guilty, if they have failed to follow particular advice from other people. The husband of Case 3 described the social pressure as follows:

> You know, I have many friends and relatives. They gave me hundreds of suggestions to improve the health condition of my wife. Although they gave me recommendations with good intentions, it is hard to follow each and every advice as money adds up for each treatment.

Change of provider: perceptions of health seeking

The change of provider is also related to the personal meaning of health seeking in different cases. Here I would like to share the quotation of a traditional medical practitioner; "For us (medical practitioners) it is important to understand the patient's point of view. For each illness, they (patients) come to me with an expectation and hope."

I like this quote a lot because it reflects the need for a good health provider-client relationship. Then I asked my cases about their meaning of health seeking, and almost all cases have common responses and I want to share the response of Case 3:

> My big objective is to recover as soon as possible. Whenever I hear about a famous health provider, I tried to go and see him. My search for a good provider is with the expectation of achieving better health whatever the cost. If I have invested a lot of money, I expect in return much improvement in my condition. Otherwise it makes no sense.

Change of provider: evaluation of treatment

The change of health provider is also related to how the patients and their family members evaluated their treatment.The informants' criteria for evaluation of the treatment includes several factors. As previously discussed the father in Case 2 pointed out that the use of splints in *lay-ngan-yaw-gar* was useless, and so they switched to another provider. This evaluation is based on *logical* considerations. In Case 3 she expressed her criteria as based on cost and outcome; "if I consulted with a doctor, but if no improvement then I think it is a waste of money".

When the provider could provide positive outcomes, then the patients would provide a better grade of satisfaction. eg family members in Case 2 deeply trusted in the spiritual medium as the childwas able to speak again after rituals were performed.

In Case 1 at first he just visited the masseur because of social pressure.However after six visits, he noticed some improvements, and he followed-up regularly to seek health with the masseur. This naturally changed his belief and he came to accept the benefits of traditional massage

Similarly, in Case 3, she got encouraged by her masseuse. "When I first visited him (traditional massager), he told me to visit him for a minimum of seven times.After six visits, I felt much improved. I was able to walk and stand without any problem and so I would refer other people to go to him."

From these explanations, I would say that trust and belief in a particular provider is the key to ending the search for a good health-provider.

Impacts and Drivers to Recovery

Informants explained their motive and the driving factors in their recovery. In Case 1, his main driver is his job and his family. As he was forced to resign from Ministry of Health, he is concerned about earning a living. He considered that his quick recovery would help to get his job back, and provide more income for his family, especially for his mother who is 82 years old. He said, "as the whole family relies on me for their livelihood, I needed a quick recovery. Therefore I tried to consult with traditional masseur." With hope for recovery, he tried to seek health care with a traditional masseur to perform regular exercise, and take care of his diet.

The motivation for a fast recovery in Case 2 is based on learning and earning. As she had been absent from school for a year, she wanted to continue her study and get a job soon to help her bfamily. In Case 3, it is a bit different from others. Her comments showed a significant insight for me:

> As I have four kids, I always try to get treatment whenever the provider is well-known and popular to treat lay-ngan. You know, if I cannot work and became a burden, my husband will get another wife and then my kids will not feel good l with a step-mother. I will never let it happen. Therefore, I do exercise daily and hope to have a normal health again.

Impact of illness on social life

We established from this study, that *lay-ngan-yaw-gar* is not merely a stage of physical ill-health, but it also affects the social life of individuals and families living with *lay-ngan-yaw-gar.* Informants mostly talked about the negative social consequences of the illness, and in some cases also pointed out some positive changes in the family, as a silver lining with the black cloud.

Negative social and economic consequences

In all cases family function and social harmony was distorted after a family member has suffered *lay-ngan-yaw-gar.* People with *lay-ngan-yaw-gar* are not socially engaged. Feeling loneliness and cut off from society, they sometimes tried to reach out beyond their normal social circle.

In Case 1, the patient had been the breadwinner for the family but after the stroke he was unable to work and provide health services to his clients. People had less trust in him to get an injection. as his fingers and hands were weakened by his condition.He had to find an assistant to help in the rural health center. Even worse these problems led to dismissal from the Ministry of Health. He said, "as I cannot participate in some public health activities, my supervisor forced me to resign. I had no choice."

In addition his marriage plan had also been rejected by his girlfriend. Previously they planned to get married in 2015 but when he got *lay-ngan*, the girl broke off their relationship and left him.

In Case 2 being much younger she suffered fewer social consequences from *lay-ngan*. She was most concerned about her lack of access to education, social participation and her confinement. She cannot move her limbs, she could not go to any school, and she dropped

out at grade 3. She also was upset that she could not play with her friends and enjoy sports. As a teenager, her father worried about her future. He said, "If she continued like this (*lay-ngan-yaw-gar*), no one will marry her." In our society, *lay-ngan* is sometimes negatively considered as a form of disability, and if people have a negative mind-set towards her then she will never get married.

In Case 3, the patient was a house wife. She mentioned that her house became a mess when she became ill. She could not fulfill the duties and responsibilities as a mother in taking care of her kids and her husband. She said,

> During meal times I was in always in tears because I was not able to cook, and so my kids had poor food. Their clothes became dim and dirty, as they had to wash themselves. My kitchen became very dirty and messy. And I could not clean my compound.

Although her husband took over household chores she felt unhappy. She also thought about the problems of family harmony in the future. Worried about her marriage, she tried to increase her her amount of exercise, and took a variety of quick-fit remedies and medicines in order to speed up her recovery. She was also concerned that if she did not quckly recover, her husband might abandon her.

The economic pressure is also a theme that everyone mentioned. The nature of a chronic illness and the uncertainty about the recovery, results of a major financial expenditure for *lay-ngan-yaw-gar* treatment. Unlike other countries, the Myanmar health system has no insurance and no social protection scheme. Individuals and families have to invest a lot and shoulder all the financial risk incurred by illness and disease including loss of property, land and business.

Unexpected positive side effects

Although most people considered *lay-ngan-yaw-gar* as an unwanted illness, it brings a few positive contributions to individual and family in their daily social life. The actions of family members looking after their patient on a daily basis had improved their relationships and understanding. The husband of Case 3 mentioned,

> I changed my behavior due to her illness; previously I was a gambler and a social drinker. When she got ill, I had to take care of our kids and I have to work twice as hard. This was my turn to be a good husband as previously she had been the leader in taking care of the family. Now we have a better marital relationship and more understanding of married life.

In Myanmar culture, cooking, cleaning and washing are considered as 'women jobs' and therefore, the husband did not help prior to her illness. Case 3's husband mentioned with a smile about his gender position as below:

> You know, at first I was very upset and felt very shy to do household work like a lady. But I had no choice. Unless I do these jobs, my kids will not have good food and clean clothes. Therefore I decided to do it and I decided to ignore comments by my friends. I even helped my wife in going to the toilet and taking a bath as she was in disabled. I have to be a good husband by taking good care of her

Living with *lay-ngan-yaw-gar* also creates new space for community learning. People with *lay-ngan-yaw-gar* can help to motivate neighbors to take better care of their health, eg people with high blood pressure. It can also encrouage people to advoid unhealthy behavior like drinking alcohol and eating food that increases high blood pressure. It also serves as a reminder to some people to carry out more religious and spiritual rituals to prevent such illness. People with *lay-ngan-yaw-gar*, and their experience with different health care providers, can also provide a useful case history and a guidance to others in the community in dealing with the same illness.

Lay-ngan-yaw-gar also increases the social arena of individuals and the family. As people seek health with various health care providers in biomedical, traditional or spiritual sphere, it widens the social boundary and people collected new experiences on how to deal or interact with different health sectors. For rural villagers lacking good road access to the nearest towns, they rarely visited hospitals. The husband of Case 3 shared his view :

> I have never been to government hospitals. What is more I have never been inside an air-conditioned room to meet with a senior doctor (specialist physician). It was a big step for me to talk and discuss with the doctor about my wife's illness.

Coping strategies

As *lay-ngan-yaw-gar* has negative social implication for the individual and families, my questions led to how they deal with this situation, and how they gather courage in case their hope of recovery cannot be fulfilled.

Case 1 has suffered many painful experiences, losing his job and also his fiancé. I wondered how he could cope with his plight. He also mentioned about his lack of social participation in social events like weddings and donation ceremonies after getting *lay-ngan-yaw-gar*.

He replied that he follows the Buddha's teaching, "everything is unstable, everything is associated with suffering and everything is uncontrolled."

First, all the cases are Buddhists, and interviews with cases and family members revealed that the Buddha's teaching was an important part of coping. As Buddhism is rooted in their thinking, explanations often reflect upon the "karma" perspective which means "you will harvest what you have sown." Karma explains that every event is as a result (an effect) of an action done (cause) that may be either in the past, or at present life. Based on this belief system people carry out more religious activities when they are suffering ill-health.

For instance, the sister of Case 1 mentioned that her mother had donated some flowers and water to the pagoda so that all the bad karma would be washed away and her son would feel better.

In Case 3, she mentioned that her *lay-ngan-yar-gar* was a kind of

wut-nar-kan-nar[20] (an illness due to bad karma) and she prayed to the Buddha for a good recovery.

Jocelyn Cornwell (1984) studied about lay belief in health and illness discussed a three-part classification of the cause of illness:

> 1) the cause of illness could be either internal or external; 2) the illness could be either avoidable or unavoidable and 3) the person was either to blame or not to blame for getting ill (Roger, 1991).

Here in this study all informants replied that the illness is internal, unavoidable and the person with *lay-ngan-yaw-gar* is not to be blamed. When asked questions about patients being a burden to families, they all dismissed this notion despite the fact they were faced with many social and economic problems coping with *lay-ngan-yaw-gar.*

20. *Wut-nar-kan-nar* is a kind of belief that the disease or illness is due to "Bad Karma" or "Bad Luck" and even treatments are provided, it is hard to get recovery. However, when the bad Karma has gone, it may recover automatically without treatment. Cancer, Leprosy, HIV and chronic diseases like Stroke and Diabetics are considered as *Wut-nar-kan-nar* in the community.

4

CONCLUSIONS

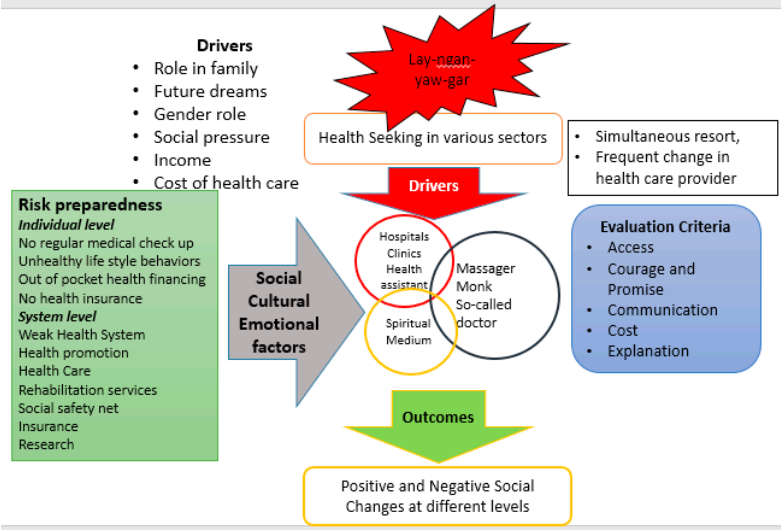
This study has explored the definition, meaning, classification and the severity of lay-ngan-yaw-gar from ordinary people's perspectives. It is obvious that based on individual belief about what causes lay-ngan-yaw-gar, people seek health care with a variety of providers. It was found that health seeking options are also related to socio-economic background, as well as the religious beliefs of a family.

In seeking health care with a particular provider, factors such as communication, trust, competency of the provider, matching expectations and socio-economic conditions are taken into account.

This study also explained about a new conceptual approach of health seeking behavior, in addition to Klinman's model (Kleinman, 1980). The major contribution of this study to the existing knowledge is that health- seeking is not merely a communication between the patient and the provider.

It also has other dimensions: social, cultural, religious, spiritual and psychological aspects that are interwoven with the world view of individuals and families. Social pressure and drivers to recovery are also explained by these different cases. The study also highlighted the social consequences and impact of lay-ngan-yawgar upon individuals and families. The coping strategies of people with lay-ngan-yaw-gar, also presented a positive contribution of illness towards the social life of individual and family.

Figure 21 Health-seeking patterns of people with *lay-ngan-yaw-gar* who simultaneously use more than one health provider



One major contribution of my study to the field of medical anthropology concerns religious belief and health seeking. Most of the explanations about the illness in this study were based on the Buddhist way of thinking, and the concepts of Abhidhamma. People do not consider consultations with a spiritual medium or astrologer, as a form of seeking health care. They mentioned it as checking up on their luck or fortune, and they also cited the four determinants of Buddhism.

It is clear that the chronic illness like lay-ngan-yaw-gar also contributes both negative and positive consequences for the social life of individual, family and community. In other words, it creates is a new reality for the patient with lay-ngan-yaw-gar and for all the relatives and friends affected by the illness,

In the given socio, cultural and emotional context, people with lay-ngan-yaw-gar identified some evaluation criteria for providers. Informants considered access, quality of treatment, communication skills as criteria for the evaluation a particular provider taking into account cost of treatment and overall satisfaction.

Although this short study is about the health seeking behavior, our view should be wider than Klienman's conceptual model. In other

words, we have to think about preconditions before the onset of illness, as well as the new reality (human experience) of people with lay-ngan-yaw-gar for their on-going survival and meanings of life under various settings.

Contribution of this Study to Existing Knowledge

This section is about why I would like to build on this study. I view the summaries of the case studies s (Figure 10) as the basis of a new conceptual map. From the summaries of the case studies in Figure 10, it is clear that health seeking is not simply a matter of consulting with a particular provider as Klienman has claimed. In reality there is a much wider range of factors that affects the selection of health providers.

In Kleinman's model, he has classified the health care sector as popular, folk and biomedical. However, in my study, there is clearly much overlap between biomedical, traditional and spiritual approaches. As Klienman stated, people with lay-ngan-yaw-gar have no boundaries in seeking different providers, and their health seeking patterns are not static. This means they might seek health simultaneously from more than one provider or frequently change the provider. Moreover they enter and exit different health sectors readily adapting with the protocol and mores of different treatment settings.

This study also puts emphasis on emotional factors and psychological factors, before the onset of lay-ngan-yaw-gar. The basic assumption of all the patients (not only the patients, but also just about the entire population of Myanmar) is the belief that "everything will be fine". This reflects an "under-estimation of health risk. People have a dream what they want to achieve, indivual or family goals but the people are not well prepared for the kind of setback in their life caused by a chronic disease.

Their emotional responses to finding out about having suffered a stroke varied: fear, anxiety, grief and helplessness. They searched for a health provider in their locality and primarily from the biomedical sector.

Here I raise the question what is happening? Their aim is to obtain recovery as quickly as possible, regardless of the kind of provider, health sector or the therapy. This urgency is driven by social factors. This study highlighted drivers for recovery, such as their role in the family, future dreams, gender role, social pressure, income and the cost of health care. Once the illness becomes stable, patients then make an evaluation of different treatment options. They consider their medical state along with their financial capacity of the family to pay (income). This is how people in a rural area adjust their socio-cultural life in the absence of any health insurance and health-risk preparedness.

A couple of themes are also highlighted in this study about social pressure and drivers for recovery. As mentioned earlier people have future dreams before the onset of illness and the experience of lay-ngan-yaw-gar makes them feel helpless and a sense of despair. However, there are drivers that propel the sick person to seek recovery.

Informants feel no boundaries or obstacles between seeking different providers. Their health- seeking patterns are not static, which means they might seek health simultaneously or frequently change the provider. They readily adapt to any particular health sector and setting.

Despite the fact that people are not well-prepared for dealing with the risk of lay-ngan-yaw-gar, their experiences tell us how they cope with lay-ngan-yaw-gar, how they have survived and inform us about their engagement with various health care settings.Their experience as people who suffered lay-ngan-yaw-gar ,strongly influenced by Buddhist teachings, sheds light on the this problem within an Asian perspective.

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About the Author

Aung Zaw Moe is a development practitioner with a background in public health. He was born in 1983 in Kamarnut village, Bago, Myanmar. He finished his medical degree in 2007 from University of Medicine, Magway, Myanmar, and graduated from James P Grant School of Public Health, BRAC University, Bangladesh with A Masters in Public Health 2011.

Since 2008 Aung Zaw Moe has worked in both NGOs and private sector as a freelance development consultant. He has experience with various development projects: Youth Development, Disaster Risk Reduction, Emergency Medical Response, Gender Equality, HIV/AIDS prevention treatment, Drugs Abuse reduction, Adolescent Reproductive Health, Workplace HIV prevention, Malaria Control, Political Leadership, Education Reform and Psycho-social Counseling. He also contributed his knowledge and skills in the field of Corporate Social Responsibility and Human Resource Development.

In his native village he founded *Kyan-Dyne-Aung* community based organization in 2008. He is the director of and provides community development services through 4 different projects: Non-formal Education for marginalized children, Youth Empowerment through soft-skill training, empowering local women with microfinance support and improved access to health care services via the community clinic.

He has attended further courses in social work and international and community development in Yangon, Switzerland, and the USA. Aung Zaw Moe is interested in social, political and developmental issues and is looking for opportunities to collaborate and learn from diverse professionals and institutions.

UNDERSTANDING THE HEALTH-SEEKING BEHAVIOR OF PEOPLE WITH *LAY-NGAN-YAW-GAR* (STROKE)

In Bago Township, Myanmar

Although *lay-ngan-yaw-gar* (stroke) is a common public health issue in Myanmar, the majority of studies to date have focused solely on the medical and physiological aspects of stroke, viewing the subject mainly from a Western medical perspective.

This study fills a knowledge gap and tries to understand how people with *lay-ngan-yaw-gar* in rural villages seek medical attention and treatment based on diverse influences derived from their community and leading to interaction with health care providers. Health care seeking behavior involves not just communication between the patient and the provider, but also has a multitude of social, cultural, religious, spiritual and psychological aspects.

The case studies in this volume give us a real life glimpse into the experiences of people with *lay-ngan-yaw-gar* and how they seek out health-care, their decisions and understanding of their illness, and evaluation of the treatment of different health care providers, both in the folk sector and biomedical sector.

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