

Caring for patients with drug use disorders in Yangon region, Myanmar:  
Socioeconomic and psychological burden and coping strategies



A Thesis Submitted in Partial Fulfillment of the Requirements  
for the Degree of Master of Science in Health Economics and Health Care Management

Common Course

Faculty of Economics

Chulalongkorn University

Academic Year 2018

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การดูแลผู้ป่วยที่มีความผิดปกติจากการใช้ยาเสพติดในเมืองย่างกุ้ง ประเทศเมียนมาร์:  
ภาวะทางเศรษฐกิจสังคม และจิตวิทยา และรูปแบบการรับมือ



วิทยานิพนธ์นี้เป็นส่วนหนึ่งของการศึกษาตามหลักสูตรปริญญาวิทยาศาสตรมหาบัณฑิต  
สาขาวิชาเศรษฐศาสตร์สาธารณสุขและการจัดการบริการสุขภาพ ไม่สังกัดภาควิชา/เทียบเท่า

คณะเศรษฐศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย

ปีการศึกษา 2561

ลิขสิทธิ์ของจุฬาลงกรณ์มหาวิทยาลัย

Thesis Title	Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies
By	Miss Khin Zar Khaing Thein
Field of Study	Health Economics and Health Care Management
Thesis Advisor	Assistant Professor Chantal Herberholz, Ph.D.

---

Accepted by the Faculty of Economics, Chulalongkorn University in Partial Fulfillment of the Requirement for the Master of Science

..... Dean of the Faculty of Economics  
(Professor WORAWET SUWANRADA, Ph.D.)

THESIS COMMITTEE

..... Chairman  
(Professor SIRIPEN SUPAKANKUNTI, Ph.D.)

..... Thesis Advisor  
(Assistant Professor Chantal Herberholz, Ph.D.)

..... Examiner  
(Assistant Professor NOPPHOL WITVORAPONG, Ph.D.)

..... External Examiner  
(Associate Professor Nathorn Chaiyakunapruk, Ph.D.)

คีน ซา ไค้ง เตน : การดูแลผู้ป่วยที่มีความผิดปกติจากการใช้ยาเสพติดในเมืองย่างกุ้ง ประเทศเมียนมาร์: ภาวะทางเศรษฐกิจสังคม และจิตวิทยา และรูปแบบการรับมือ. ( Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies)  
 อ.ที่ปรึกษาหลัก : ผศ. ดร. ชันทาล แฮร์เบอร์โฮลส์

ความผิดปกติจากการใช้ยาเสพติดนับเป็นโรคเรื้อรังประการหนึ่งเหมือนกับความผิดปกติทางจิตประเภทอื่นๆ ผู้ดูแลผู้ใช้ยาเสพติดได้รับผลกระทบในหลายมิติของชีวิต อย่างไรก็ตามงานวิจัยที่เกี่ยวข้องกับประสบการณ์ของผู้ดูแลผู้ใช้ยาเสพติดในประเทศเมียนมาร์ยังมีไม่มากนัก การศึกษาในครั้งนี้ใช้ระเบียบวิธีวิจัยแบบผสม โดยมุ่งหวังที่จะศึกษาภาวะทางเศรษฐกิจสังคมและจิตวิทยาของผู้ดูแลรูปแบบการรับมือกับภาวะดังกล่าวและสิ่งกีดกันไม่ให้ผู้ดูแลสามารถรับมือกับภาวะดังกล่าวได้ ผลการศึกษาชี้ให้เห็นว่า ภาวะทางเศรษฐกิจและสังคมที่สำคัญของผู้ดูแลได้แก่ ความสูญเสียทางเศรษฐกิจ ความสูญเสียผลผลิตภาพ ข้อจำกัดทางสังคมและผลกระทบทางลบต่อสมาชิกในครอบครัว ส่วนภาวะทางจิตวิทยาได้แก่ ความเศร้า ความโกรธ ความกังวล ความกลัว และความรู้สึกผิด ทั้งนี้ระดับความเครียดของผู้ดูแลและระดับการเสพติดของผู้ป่วยมีความสัมพันธ์กันในเชิงบวก ผู้ดูแลมักจะรับมือกับภาวะของตนด้วยวิธีการทางศาสนา การหาแหล่งทุนเพื่อจุนเจือครอบครัวเพิ่มเติม การยอมรับปัญหา และการวางแผนในอนาคต อย่างไรก็ตามผู้ดูแลพบว่ายังมีสิ่งกีดกันไม่ทำให้สามารถรับมือกับภาวะได้อย่างเต็มที่ ได้แก่ การถูกดูแคลนจากสังคมและการไม่ได้รับความช่วยเหลือจากรัฐหรือองค์กรอื่นๆเลย การศึกษานี้แสดงให้เห็นว่าความผิดปกติจากการใช้ยาเสพติดมีผลเชิงลบต่อผู้ดูแลและครอบครัวของผู้ป่วยอย่างมากรัฐบาลจึงควรให้ความสำคัญกับการปฏิรูปนโยบายและกระบวนการรักษาผู้ป่วยที่เกี่ยวข้องกับยาเสพติด

จุฬาลงกรณ์มหาวิทยาลัย  
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สาขาวิชา เศรษฐศาสตร์สาธารณสุขและก ปลายมือชื่อนิสิต .....  
 ารจัดการบริการสุขภาพ  
 ปีการศึกษา 2561 ปลายมือชื่อ อ.ที่ปรึกษาหลัก .....

# # 6185560929 : MAJOR HEALTH ECONOMICS AND HEALTH CARE MANAGEMENT

KEYWORD: caregivers, drug use disorders, burden, coping strategies

Khin Zar Khaing Thein : Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies. Advisor: Asst. Prof. Chantal Herberholz, Ph.D.

Drug use disorders are considered chronic illnesses, like other severe mental disorders, and caregivers of drug users face a large impact on various aspects of their life. However, there is shortage of research in Myanmar about caregivers' experiences with caring for patients with drug use disorders. This mixed method study, therefore, aims at exploring the socioeconomic and psychological burden caregivers carry, the coping strategies they employ, as well as the barriers to coping they face. The results of the framework analysis revealed that financial loss, productivity loss, social limitation and negative impact on family members are important dimensions of socioeconomic burden. Sadness, anger, worry, fear and guilt were main psychological distress factors encountered by caregivers of patients with drug use disorders. The strong positive correlation between caregiver stress level and the addiction severity of patients reinforced the qualitative findings. Religious coping, financial coping, acceptance and planning were commonly used coping strategies by the caregivers. Moreover, perceived stigma towards patients and caregivers was very high and the caregivers received hardly any social and financial support from the government or any other organization in Myanmar. The results of this study show that caring for patients with drug use disorders has devastating effects on caregivers and their families. Therefore, reforming existing drug policy, and strengthening drug abuse prevention and treatment programs and campaigns should be considered a priority.

Field of Study: Health Economics and Health Care Management Student's Signature .....

Academic Year: 2018 Advisor's Signature .....

## ACKNOWLEDGEMENTS

I would like to use this opportunity to send deep gratitude to my thesis advisor, Asst. Prof. Chantal Herberholz, Ph.D. for providing her precious guidance, valuable suggestions and support to complete my thesis successfully. I also thanks to my committee members, Prof. Siripen Supakankunti, Ph.D.; Asst. Prof. Nopphol Witvorapong, Ph.D. and Assoc. Prof. Nathorn Chaiyakunapruk, Ph.D. for their help and expert comments. I would like to appreciate all Ajarns from the Faculty of Economics, Chulalongkorn University who teach and share valuable knowledge throughout the whole year.

Furthermore, I contribute my heartfelt thanks to my local advisor, Dr. Win Pa Sandar (Assistant lecturer from University of Public Health, Yangon) for her technical support and advice in this study.

For data collection, I would like to give honorable thanks to Senior Medical Superintendent of the Mental Health Hospital (Yangon), Dr. Tin Tin Wynn for letting me to do this research. Moreover, I highly appreciate Dr. Myo Kyaw Thu from Unit III department of Mental Health Hospital (Yangon) for his help and support during data collection and I also thanks all the respondents who participated in this study for their time.

In addition, I express my sincere appreciation to ASEAN scholarship program for giving me the chance to study in Chulalongkorn University. Last but not the least, I am very thankful my family and friends for their love and moral support to complete my study.

Khin Zar Khaing Thein

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## LIST OF ABBREVIATIONS

ASEAN	Association of South-East Asian Nations
ATS	Amphetamine type stimulants
ASI	Addiction severity index
CSS	Caregiver stress scale
DTCs	Drug treatment centers
FBIS	Family burden interview schedule
FGD	Focus group discussion
GBD	Global burden of disease
GDP	Gross domestic product
GGHE	General government health expenditure
freq	Frequency
HIV	Human immunodeficiency virus
ICD	International Classification of Disease
IDUs	Injected drug users
IMR	Infant mortality rate
MANA	Myanmar Anti-Narcotic Association
MMR	Maternal mortality ratio
MMT	Methadone maintenance treatment
MOH	Ministry of Health

NGOs	Non-Government organizations
SARA	Substance Abuse Research Association
SMI	Severe mental illness
SUDs	Substance use disorders
THE	Total health expenditure
U5MR	Under-five mortality rate
UHC	Universal health coverage
WHO	World Health Organization



# CHAPTER I

## INTRODUCTION

### 1.1 Problem and Significance

In this global age, mental health becomes a pivotal part of human beings since it is strongly related with physical health and social well-being. A person never lives with full quality of life without mental health. Mental disorders commonly occur in vulnerable population such as people who used drug, prisoners, older people, poor people, lesbian, gay and so on. Individuals with mental disorders can lead to suicide and according to the World Health Organization (WHO), the second most common cause of death globally is suicide (WHO, 2013). According to the International Classification of Disease (ICD-10), drug use disorder is one of the mental disorders caused by using of psychoactive substances (WHO, 1993). Drug use became major public health problem to be handled in people of all age and the burden of drug use disorders has tremendous negative consequences on persons who used drug, caregivers, family members, society well-being and the country as a whole (WHO, 2003). According to world drug report 2017, approximately 5% of adult abused drugs (mainly cannabinoids, followed by opioid, cocaine and amphetamine) at least once in 2015 and 0.6 % of them suffered from drug use disorders globally which means that people use drugs up to the harmful level where they need treatment (WHO & UNODC, 2018).

Drug use disorders is defined as the use of psychoactive and narcotic drugs in the form of contributing significant physical and psychological impairment to individual's health which in turn lead detrimental effects to society (WHO, 2015). Since drug use disorders is long term health problem which also related with legal issues, taking care of drug users causes caregivers to endure unlimited burden physically and psychologically and to develop mental disorders as well since they have to survive difficultly under vulnerable conditions (Kronenberg, Goossens, van Busschbach, van Achterberg, & van den Brink, 2016). Caregivers take part not only for taking care of substance using individuals but to improve treatment by communicating with health professionals and by trying to improve their own



knowledge. They also have to balance between finance and patients' needs to reduce family financial burden (Kronenberg et al., 2016). Moreover, patients are being supported morally to protect from relapse and caregivers devote most of their time by doing personal tasks for patients (Orr, Barbour, & Elliott, 2013; Shamsaei, Cheraghi, & Esmaeilli, 2015). That why patient well-being is directly related with the one who provide care for them.

In Myanmar, although alcohol use disorder is significant, drug use disorder is likely to contribute more burdensome problems since it is illegal and more sensitive issue. There is no exact statistic about how many people are using drug at the certain year but according to the drug policy advocacy group, even the estimated number of people who injected drug in 2014 was more than 80,000. Moreover, because of the effect of destroying opium poppy fields during 1995 to 2006 by the Government, opium became expensive and trend of drug use has changed to more dangerous condition: smoking to injection. People started to inject heroin since it can contribute strong effect by injecting small dose into the vein (Jensema & Kham, 2016). In 2012, among 9000 suspected candidates, 6,414 drug cases were arrested (DPAG, 2017). So, it can be highlight that the drug use problem is likely to be very challenging in Myanmar nowadays than alcohol use disorders.

Since drug use disorders is chronic illness like other severe mental disorders such as schizophrenia and bipolar disorders, most of the caregivers in Choudhary (2016) study which was conducted in India revealed that drug use disorders had large negative impact upon the welfare of their life. These negative impact included socioeconomic burden such as financial losses, social limitation, family disruption and psychological burden such as grief, helplessness, anger, fear and guilt and are supported by several studies (Choate, 2011; Ishler, Katz, & Johnson, 2007; Sibeko et al., 2016; Usher, Jackson, & O'Brien, 2007). If the emotional feeling became worse, caregivers themselves had to face with mental disorders, commonly anxiety and depression (Orr et al., 2013; Shamsaei et al., 2015). In Myanmar, there is one study which qualitatively examined the emotional distress of drug users who had the experience of prisoning and harsh punishment (Jensema & Kham, 2016). However, there is no publication about caregiver burden of drug use disorders in Myanmar and

this study will fill the gap by exploring caregivers' socioeconomic and psychological burden of patients with drug use disorders.

Furthermore, common methods of coping of caregivers while caring for drug users were asking help from god which means that caregivers believed in religious support to relief from the suffering psychological burden, go to spirit and praying more than before (Doku, Asante, & Owusu-Agyei, 2015; Iselelo, Kajula, & Yahya-Malima, 2016). Planning and withdrawing from being a caregiver because of the feeling of hopelessness were other forms of coping (Choate, 2011; Usher et al., 2007). Moreover, in previous studies, although most of the caregivers needed health education and support from health profession to know more about their patient condition, they found out that health professionals usually had negative attitude and judgment with their patients and them (Shamsaei et al., 2015; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). On the other hand, Ishler et al (2007) mentioned that caregivers in their study rated that receiving less help from the community and high stigma from their friends gave more burden to them. Therefore, it can be considered, however, that stigma from surrounding and lack of support in terms of financial and social seems to be barriers to cope with socioeconomic burden and psychological burden. Again, In Myanmar, the coping mechanism of caregiver of drug use disorders is still unclear even though one systematic review described that religious such as meditation, acceptance and finding social and emotional support are the common coping strategies used by Myanmar refugees in Thai-Burmese border to cope with financial difficulties and human right loss (Cohen & Asgary, 2016). Since there is shortage of research about coping mechanism of caregivers of drug use disorders, it is very important to highlight that how caregivers cope with various difficulties in Myanmar and which are contextual factors that influence on caregivers' coping strategies.

Health expenditure in Myanmar is one of the contextual factors which proved that why drug use disorders' burden are shifted totally towards family members. Only 0.3 % of total health expenditure (THE) is used for mental health and people out of pocket health expenditure was about 35% even in public mental hospitals in 2013. The rest are subsidized by the government, external agent and social security

scheme. (Myint & Swe, 2016; WHO & MOH, 2006). However, not like in other developed countries, in Myanmar, there is only 1% of population who is covered by social security scheme since insurance system hasn't well-improved yet (Sein et al., 2014). This is one of the contextual factors in Myanmar why drug use disorders let to increase financial burden of the households.

Although the drug use problem is strongly significant in Myanmar, this burden has not been efficiently measured because drug use is illegal in Myanmar. Therefore, caregivers' burden is also ignored since family members don't want to open up their feeling. It becomes undefined and hidden burden in order that caregivers were being afraid of blame from surrounding and they cut off relationship with friends and relatives to protect themselves from receiving stigma (Choudhary, 2016; Usher et al., 2007). Even though stigma associated with all forms of mental disorders is strong, it is likely to be more substantial with drug using individuals in Myanmar. Individuals with drug use disorders have to survive under vulnerable conditions and they lost human rights such as attending school, working with colleagues, reproductive rights and so on (WHO, 2003). These burden cannot stop at the level patients with drug use disorders and continually affect to caregivers and family members intensively. Therefore, it can be clearly seen that it is major health issue and policy makers should focus on drug use disorder to improve public health with better quality of life in Myanmar.



## 1.2 Research Questions

According to the above information discussed in problems and significance, it is essential to examine the socioeconomic burden, psychological burden and coping strategies of caregivers and to find out which are barriers of coping in Myanmar. The following are the related research questions with this study.

- What is the socioeconomic burden on caregivers of patients with drug use disorders in Yangon region, Myanmar?
- What is the psychological burden on caregivers of patients with drug use disorders in Yangon region, Myanmar?

- How do caregivers cope with socioeconomic and psychological burden occurring while taking care of drug users in Yangon region, Myanmar?
- What are the barriers to coping for caregivers of drug use disorders in Yangon region, Myanmar?

### 1.3 Research Objectives

The followings are the research objectives relevant with the research questions.

#### 1.3.1 General Objective

- To determine the burden on caregivers of patients with drug use disorders in Yangon region, Myanmar

#### 1.3.2 Specific Objectives

1. To better understand caregiver and patient characteristics
2. To examine socioeconomic and psychological burden on caregivers of patients with drug use disorders in Yangon region, Myanmar
3. To explore coping strategies of caregivers to tackle socioeconomic and psychological burden of drug use disorders in Yangon region, Myanmar
4. To identify the barriers to coping strategies for caregivers of drug use disorders in Yangon region, Myanmar

### 1.4 Scope of the study

This is a cross-sectional descriptive study using mixed methods. The study includes both quantitative and qualitative approaches to analyze caregiver and patient socio-demographic characteristics, to explore caregivers' socioeconomic burden, psychological burden, coping methods in caring for patients with drug use disorders and their barriers to coping. The study includes 30 caregivers. Only primary informal caregivers, which means caregivers who are family members of drug using patients and also spend most time for caregiving activities, are included in this study.

The primary data were collected from caregivers between May 2019 and June 2019. Caregivers were approached in the Mental Health Hospital (Yangon), Myanmar.

### **1.5 Potential benefits and policy implications**

There is no published study in Myanmar which analyze caregivers' burden of drug use disorders even though it is very challenging problem and the coping mechanism of caregivers are also unclear. This study aims to analyze socioeconomic and psychological burden of caregivers who have the individuals suffering from drug use problems. It will also explore the coping mechanism used by caregivers to tackle a diversity of problems concerning drug use disorders that they encountered and also the barriers of coping. Drug use disorders have negative impact not only on patients but also on family members, societies well-being and countries wellness. Caregivers' burden cannot be mitigated without exactly knowing what they are actually suffering from, how they solve their problems and cope with it. It is clear that getting effective treatment of patients with drug use disorders is one of the important ways to reduce caregivers' burden and this study will provide evidence to increase government's health expenditures for mental health to reduce the burden and to strengthen health education to increase public awareness of drugs. Furthermore, reducing stigma is strongly related with reducing burden of families and this study can imply policy makers to set drug use disorders as priority health program, to increase financial and social support, to promote prevention and promotion plan for drug use disorders, to develop campaign to reduce stigma, to implement rehabilitation centers in all States and regions, to increase the number of mental hospitals across the country, to strengthen methadone treatment programs and to create better occupational chances for young population.

## CHAPTER II

### BACKGROUND INFORMATION

#### 2.1 General Background on Myanmar

##### 2.1.1 Location

The Republic of the Union of Myanmar which is situated in South-East Asia, is surrounded by China to the north and east, Laos and Thailand to the east, India and Bangladesh to the west and coastal line of 1760 miles is bounded by Bay of Bengal on the west and Andaman Sea on the south of the country. Total area of 676,578 kilometers square is possessed by Myanmar and the boundaries are enveloped in the form of a diamond shape with a kilometer of 800 from east to west and 1300 km from north to south (Sein et al., 2014).

##### 2.1.2 Geography and Demography

Naturally, Myanmar is divided into three parts namely the western hills, the central belt and the Shan plateau on the east while the parallel series of mountain ranges from north to south divide the country into three river systems, the Ayeyarwady, Sittaung and Thanlwin. Myanmar is basically composed of seven regions (Ayeyawady, Bago, Magway, Mandalay, Sagaing, Taninthayi and Yangon), seven states (Chin, Kachin, Kayah, Kayin, Mon, Shan and Rakhine) and Union Territory called Nay Pyi Taw which is the capital city of Myanmar. These 14 regions and states are subdivided into 70 districts and 330 townships, 84 sub townships, 398 towns, 3063 wards, 13 618 village tracts and 64 134 villages. Opium poppy fields cultivation are commonly abundant in Upper Myanmar and number of drug users are also higher in Kachin and Northern Shan States (DPAG, 2017).

Figure 1 illustrates the population pyramid of Myanmar and in 2014, total population of Myanmar was 51,486,253 persons with an annual population growth rate of 0.89% which was lower to compare with neighboring countries (1.61% in Malaysia, 1.75% in Cambodia, 1.24% in India and 1.19 % in Bangladesh respectively). Of these, 24,824,586 were males and 26,661,667 were females and there were more older females than males according to the figure 1 (MOIP, 2015). In Myanmar, misuse

of substances such as tobacco, alcohol and other illegal drugs is prominent health problem among youth (MOHS, 2017). Amphetamine is the popular drug among adolescent and students (Jensema & Kham, 2016). In 2003, according to United Nations Office on Drugs and Crime (UNODC), 25 to 53 % of people who registered in methadone treatment programs were aged between 25 and 29, indicating that the younger population is more prone to drug used.

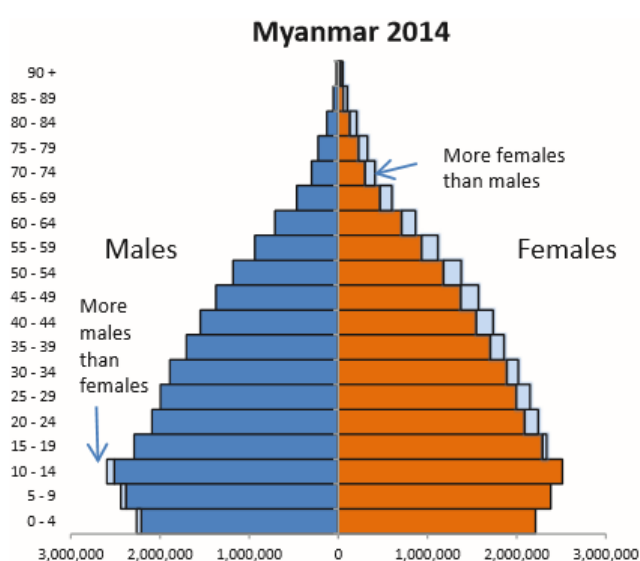


Figure 1: Population pyramid of Myanmar, 2014.

Reprinted from (MOIP, 2015)

### 2.1.3 Economic Context

Myanmar is the lower middle income country. The estimated Gross Domestic Product (GDP) of Myanmar was 67 billion dollars in 2017 with an annual growth rate of 6.8%. In 2017, 23% of Myanmar's economy was contributed from agriculture, 36% from industry and over 40% came from services (The World Bank, 2018). 64.4 % of the population who were aged between 15 and 64 were employed while unemployment rate within the country differ depending on the regions and state and it was the highest in Rakhine and Kayin State while it was low in Shan State, Kayah State and in Nay Pyi Taw (MOIP, 2015). In 2017, approximately 300,000 household in mountainous area were growing the opium poppy since they were poor and they

had to depend on this cultivation as their main source of income (DPAG, 2017). Opium is refined into heroin for local market and also trafficked to ASEAN countries especially China (Jensema & Kham, 2016)

#### **2.1.4 Current situation of illicit crops cultivation in Myanmar**

Myanmar is the second largest producer of illicit crops in the world after Afghanistan. Most of the illicit opium fields are occurred in upper part of Myanmar especially in Shan mountains and Kachin state. Only a small amount of opium can be useful for pharmaceutical drug production but the bulk of it is heroin for local and international market. Moreover, Myanmar also became the main source of producing amphetamine-type stimulants. In Myanmar, drugs can be available easily and number of drug users are increasing in many states and regions even though Myanmar Government destroyed opium poppy crops field and forced the arrests of drug sellers and abusers during the past few years. Most of the prisoners in Kachin state were drug users and 5,740 drug users lived in prison in the year 2012 (DPAG, 2017). In 2014, according to the statistics from the Yangon Police Headquarters, there were 1,300 people who had been arrested with drug cases (Jensema & Kham, 2016).

#### **2.1.5 Various types of illicit drug commonly abused in Myanmar**

There is no exact data about how many people are using drug in a certain year in Myanmar but according to the official statistics, it can be noted that methamphetamines, heroin, opium and cannabis are the common drug used by the people. Because of the effect of destroying opium poppy fields during 1995 to 2006 by the Government, drug became expensive and trend of drug use has changed to more dangerous condition. Heroin injection is one of the popular drug use since it is more cost effective than opium smoking in order that small amount can contribute strong effect for drug users. The other popular trend of drug among youth, sex workers, truck drivers and blue collar workers is amphetamine (Jensema & Kham, 2016). In previous years, it could get only in Yangon and Mandalay but nowadays it can get easily and cheaply even in countryside. It is also called Yaba or Ah-thee in local terms and main route of transmission is smoking via water pipe. On the other



hand, poly drug use which means use of more than one drugs by the drug user became another popular trend since psychoactive substance has different interaction effect and second usage of drug can exaggerate the first action. Poly drug users sometimes mix heroin and diazepam or heroin and amphetamine together (Jensema & Kham, 2016).

## 2.2 Health Status

The health status of the Myanmar population is not very good to compare with other nearby countries and according to Table 1, life expectancy at birth in 2014 is 66.8 years which was the lowest among ASEAN countries. The maternal mortality ratio (MMR) is 282 deaths per 100,000 live births and it was also the second steepest among ASEAN countries. More than 2000 women die during pregnancy and birth yearly. The under-five mortality rate (U5MR) is 72 deaths per 1,000 live births but it is 29 in Cambodia and only 12 in Thailand (MOHS, 2016). Moreover, infant mortality rate (IMR) is 62 per 1000 live births and that figure varies across the regions and states especially higher in rural areas (68) than in urban areas (41). It is clear that Magway has the highest IMR with 89 followed by Ayeyawady with 87 deaths per 1,000 live births (MOIP, 2015).

Both prevalence and incidence rate of Human Immunodeficiency Virus (HIV) and tuberculosis (TB) in Myanmar are rising more substantially than other ASEAN countries and according to the global burden of disease (GBD) profile 2010, TB, diarrhea and HIV/AIDS were the most common leading causes of death in Myanmar among infectious diseases while respiratory tract infection, stroke and heart diseases increased the death rate in terms of non-communicable diseases (GBD profile Myanmar, 2010). Since there is strong relationship between unsafe injection and transmission of HIV and other infectious diseases such as viral hepatitis, 37.5% of drug injecting individuals suffered from burden of HIV and it was ranged from 54% in Myitkyina (upper Myanmar) to 19% in Yangon, 79.2 % were HCV positive and 9.1 % were living with hepatitis B (WHO, 2010).

Table 1: Life expectancy and adult mortality indicators, 1990–2014

Health status indicators	1990	2000	2010	2014
Life expectancy at birth, total (years)	57.3	61.9	64.7	66.8
Life expectancy at birth, male (years)	55.9	60.5	63.0	63.9
Life expectancy at birth, female (years)	59.7	63.3	66.4	69.9
Infant mortality rate (per 1000 live births)	-	75.3	50.76	62
Under-5 mortality rate (per 1000 live births)	107.4	83.5	64.5	72

Source: (MOIP, 2015; Sein et al., 2014)

## 2.3 Mental Health System Overview

### 2.3.1 Mental Health Expenditure

In Myanmar, only 0.3 % of THE is used for mental health and of these, 87% directly went to mental hospitals and the rest 13 % accounted for other mental health expenditure (WHO & MOH, 2006). Nevertheless, mental health expenditure was very small compared with physical health spending and it was about 15,036 million Kyat for Mental Health Hospitals in 2012. People out of pocket health expenditure was about 35% even in public hospitals in 2013 (Myint & Swe, 2016). In Cambodia, <1% of health expenditure share to mental health and it is about 0.5% in Indonesia. There is no separate mental health spending in Laos since total health budget is limited (ASEAN, 2016). It implies that like in other developing countries, Myanmar has not considered mental health yet as a priority issue and government spending was still very low.

### 2.3.2 Facilities available for mental health in Myanmar

The following table (Table 3) indicates the total facilities available for mental health in Myanmar which include outpatient and inpatient services. There are 33 outpatient facilities in general hospitals and 3 non-hospital attached outpatient services. In case of inpatient facilities, there are 22 psychiatric units which are

integrated to general hospitals and only one forensic inpatient unit. There are only two Mental Health Hospitals in Myanmar: Mental Health Hospital (Yangon) and Mental Health Hospital (Mandalay).

Yangon Mental Health Hospital which is also called Ywar Thar Gyi Psychiatric Hospital in the past is Tertiary care teaching Hospital in Myanmar which is affiliated with University of Medicine (1). It is composed of 1200 bedded and largest Mental Hospital in Myanmar which intends mainly for curative treatment and also performs as a referral and specialist hospital with an outpatient department, general psychiatry units, mood disorder units, schizophrenia units, alcohol de-addiction and research unit, drug dependency treatment and research unit, forensic unit, long-stay and rehabilitation unit, and community mental health unit. Patients with mild psychological disorders are treated as outpatient and it was about 18,922 while patients with severe psychiatric disorders are admitted in the hospital which was 11,289 in 2013.

Another one is Mandalay Mental Health Hospital which is situated in Mandalay region. This is also Tertiary care Teaching hospital with 200 beds, 100 beds intend for general psychiatric unit and the rest 100 beds stand for drug dependency treatment unit. Since it is small size hospital to compare with Yangon Mental Health Hospital, the hospital was not too crowded. According to the admission data in 2013, there were only 2,379 patients who admitted to the hospital and 6,959 patients attended at the outpatient Department (Myint & Swe, 2016).

Although mental health services in terms of inpatient and outpatient have been integrated to some general hospitals since 1992, mental health treatment gap is still very broad in Myanmar because of many reasons such as higher stigma, lack of health education and unavailability of psychiatric drugs in primary care level and lack of chance to access treatment since psychiatrists are posted in a few regions and state around the country because of shortage of workforce (Sein et al., 2014).

Table 2: Total facilities for mental health in Myanmar

Total Facilities	Total number available
Outpatient facilities <ul style="list-style-type: none"> <li>• outpatient facilities attached to a hospital</li> <li>• "Community-based / non-hospital" mental health outpatient facility</li> <li>• Outpatient facility specifically for children and adolescents</li> </ul>	33 3 2
Inpatient facilities <ul style="list-style-type: none"> <li>• Psychiatric units in general hospitals</li> <li>• Forensic inpatient units</li> </ul>	22 1
Mental Health Hospitals	2

Source: (WHO, 2017)

### 2.3.3 Facilities available for drug use control in Myanmar

For drug use control, there are a total of 26 major drug treatment centres (DTCs), 40 minor DTCs and 3 youth correction centres all over the country to arrange treatment and care for drug using individuals and to hang over health education to all levels of the population concerning substance use disorders. Furthermore, case follow up and management are done regularly, training of health personnel to deal with drug users as a part of the program and research are performed to reduce detrimental effects on substance use patients (Sein et al., 2014). There was also an implementation of health and harm reduction centres by Non-Government Organizations (NGOs) such as the Burnet Institute<sup>1</sup> in the states and regions where drug use problems and prevalence of HIV is significant. The services offered are “needle and syringe exchange programs, HIV testing and treatment, opioid substitution therapy and drug overdose prevention and management” (DPAG, 2017). Additionally, other NGOs such as the Substance Abuse Research Association (SARA) and Myanmar Anti-Narcotic Association (MANA) conduct educational programs regarding drug use control in primary and high school (MOHS, 2017).

<sup>1</sup> The Burnet Institute is the Australia based non-profit organization which established drop-in centers in Mandalay, Sagaing and Pyin Oo Lwin to provide disposable needles for injected drug users (IDUs) and other service to reduce the transmission of infectious diseases among IDUs (Paing, 2017).

In addition, in 2017, there are 46 methadone centres across the country provided by Government: 15 in Kachin State, 14 in Shan State, 12 in Sagaing, 3 in Mandalay and 2 in Yangon which provide methadone freely as a substitution for the withdrawal drug users (Kanato, Choomwattana, Sarasiri, & Leyatikul, 2018). Drug users have to register in methadone maintenance treatment (MMT) program at least six weeks to access services such as health education and other socially supportive services. There are 6 rehabilitation centers in Yangon, Mandalay, Lashio, Kyaing Tong and Tachileik which support drug users to enter again into social community. It also encourages drug users to get treatment in DTCs and while they are treating, their caregivers and dependence can get necessary support including physical and mental rehabilitation(Kanato et al., 2018).

#### **2.3.4 Mental health workforce**

Psychiatrists and psychiatric nurses were available in all states and regional levels and some were sent to certain districts of the country whilst clinical psychologists, psychiatric social workers, occupational therapists were assigned duty only in the two Mental Health Hospitals (Myint & Swe, 2016). According to the Table 4, it can be clearly seen that Myanmar still has the problem of shortage of mental health professionals since there was only 140 psychiatrics per 2.3 million population in 2013. Among them, only 90 psychiatrics worked for public sector while 50 are in private facilities. That's why, it is one of the reason why mental health treatment gap is high in Myanmar. Again, there were only 156 nurses for 2.6 million population in 2013.

Table 3: Mental health workforce in Myanmar in 2013

Category of Workforce	Number	Per Million Population
Psychiatrists	140	2.3
Public	90	
Private	50	
Postgraduate trainees of doctors for Mental Health	50	
Psychiatric Nurses	156	2.6
Clinical Psychologists	3	0.05
Psychiatric Social Worker	5	0.08
Occupational Therapist trained for mental health	2	0.03
Specialists for Psychosocial Rehabilitation	-	-

Source: (Myint & Swe, 2016)

It is clear that Myanmar mental health workforce is nearly the lowest among ASEAN countries which contributed only 0.04 psychiatrists per 100,000 population and 0.01 nurses per 100,000 population (see Figure 2).

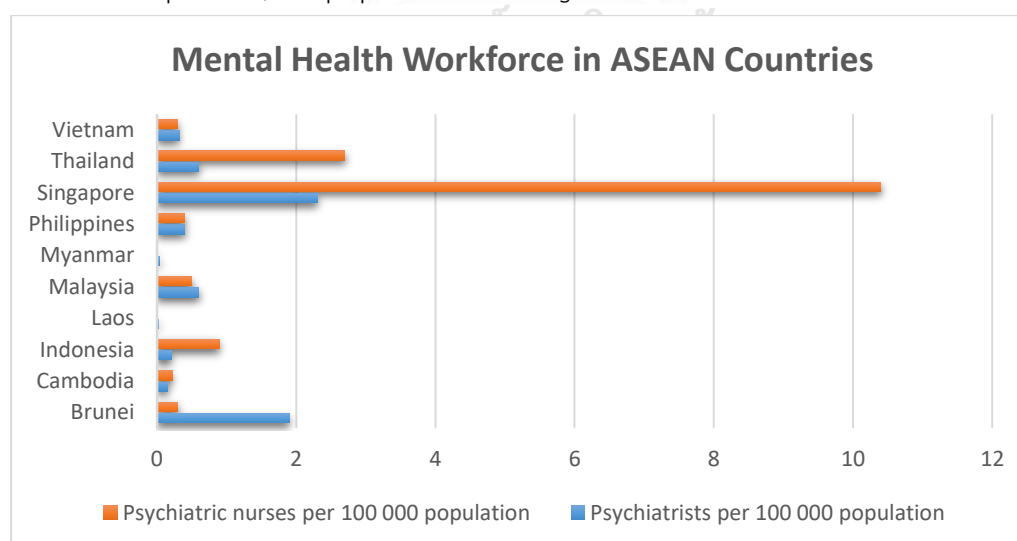


Figure 2: Mental health workforce in ASEAN countries

Source: (Maramis, Tuan, & Minas, 2011)

### 2.3.5 Utilization of Mental Health Hospitals by substance use individuals

Figure 3 illustrates the utilization of Mental Health Hospitals by substance use individuals in Myanmar during 2006 and the amount (34%) was considerably higher to compare with other types of mental disorders such as mood disorders, neurotic disorders and schizophrenia (WHO & MOH, 2006) . Since drug use disorder is the major subset of substance use disorders, it also shows that drug use disorders became major challenging public health problem in Myanmar. Although there were DTCs and methadone centers around the country, some of them are not operational in some townships, some with limited services and some with poor quality (Jensema & Kham, 2016).

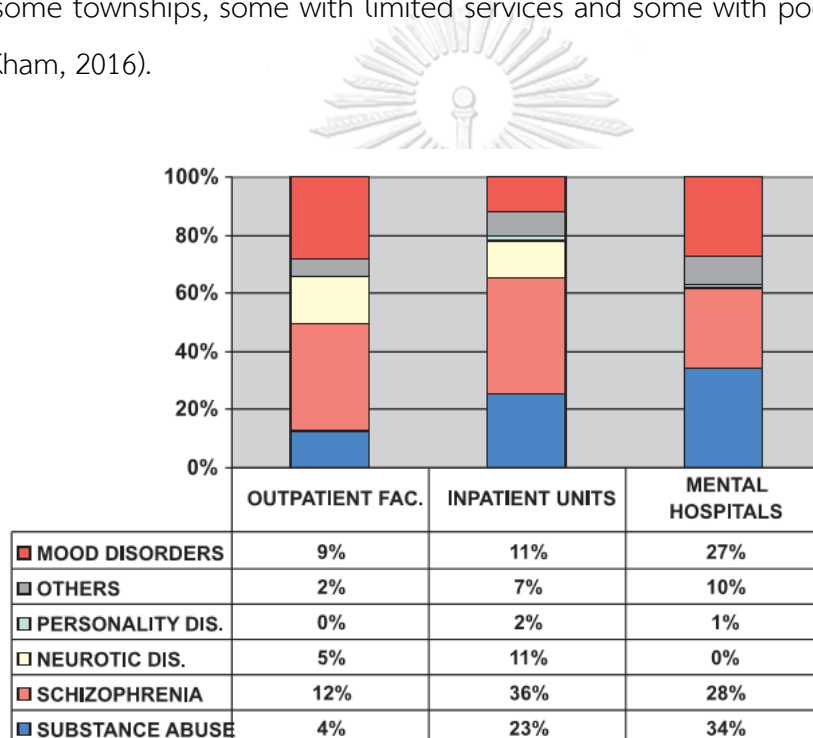


Figure 3: Patients treated in mental health facilities by diagnosis.

Reprinted from (WHO & MOH, 2006)

### 2.4 Policy related to drug use in Myanmar

Myanmar is the country which drug policies are based on the assumption that fear of severe punishment and arrest could reduce drug use and opium poppy cultivation. There are several drug related policies in Myanmar's legal framework and the most common ones are "The 1917 Burma Excise Act, The 1993 Narcotic Drugs and Psychotropic Substances Law and The 1995 Rules relating to Narcotic Drugs and

Psychotropic Substances”. According to the section 33 of The 1917 Excise Act, the possession and distribution of syringe without license is prohibited and most of the drug users have been prisoned for many years with the possession of syringe. At the end of 2015, the Myanmar government abandoned the section 33 of this Act. However, belonging syringe is still used as the evidence by the police to arrest the drug users in reality. Because of that strict policy, premature death of drug users are still increasing due to exposure of infectious disease and prisons are overcrowded with drug users (Jensema & Kham, 2016). In the Irrawaddy journal, it was stated that 49,072 people were arrested for drug related offences in the year between 2011 and 2016 (Paing, 2017).

The current 1993 Narcotic Drugs and Psychotropic Substances Law is still so tough and one of the harshest drug policies around the world as it just emphasize on punishment compared health problems suffered by drug users (DPAG, 2017). If the person is found with even small amount of illegal drug, they are being sentenced for at least five to ten years. Beside then, they were being physically abused by the police in the prisons. So, fear of family to this harsh punishment drove caregivers and family members away to seek care at hospital and harm reduction centers to their addicted patients. In 2015, Kofi Annan, former Secretary General of the United Nations said that “I believe that drugs have destroyed many lives, but wrong government policies have destroyed many more.” Like this speech, lack of supply and lack of responsibilities by the previous military Government increased the socioeconomic and psychological burden of the households with drug users (DPAG, 2017). Since 1999, the government tried to make the Myanmar as the country free from drug in 2014 but the target had postponed to 2019 because of the abundance of amphetamine and the upsurge opium cultivation (Jelsma et al., 2015). However, in 2016, Myanmar tried to develop “National drug control policy” with the help of the United Nations Office on Drugs and Crime Regional Office for Southeast Asia and the Pacific and Country Office for Myanmar and it was completed in February 2018. The main principle of this policy is “to shift Myanmar towards an evidence based and health-focused approach in developing drug legislation, and creating practical



strategies to reduce the negative effects of drug use”(Central Committee for Drug Abuse Control, 2018).

Fortunately, some successful interventions are already established for drug users like rehabilitation units where encourages caregivers and give support including physical and mental rehabilitation (Kanato et al., 2018). The Government also tried to expand MMT programs across the country for drug users and it can access freely but the quality is still needed to improve, quantity is still limited and most centers are not operated at all (Jensema & Kham, 2016). However, Myanmar Government should collaborate with local and international organizations to provide more help for the vulnerable drug users and family members by extending the number of rehabilitation centers throughout the country to get community level support in all states and regions.



## CHAPTER III

### LITERATURE REVIEW

#### 3.1 Introduction

Among the mental disorders, substance use disorders is also major health problem especially in young population since complementary use of alcohol and drugs become popular. This is because psychoactive substance has interaction effect on each other. For example, a second usage of substance can exaggerate the first action or the combination of the two substances may be experienced as a different effect (WHO, 2018). Moreover, drug use is very sensitive and legal issue rather than alcohol in every country. It has large negative consequences on caregivers of drug users since drug use disorders is long term health problem. Caregivers can also suffer from uncontrolled burden such as financial loss, productivity loss, psychological burden and diminishing quality of life, physical and social limitations, loneliness because of stigma and discrimination, depression and grief by seeing ill beloved one and exclusion from social networks (WHO, 2003).

In this study, both qualitative and quantitative study which analyzed caregiver burden of substance use disorders were mainly reviewed to be clearly seen both psychological and socioeconomic burden of caregivers from different point of views since drug use is major subset of substance use disorders. Additionally, as it is undeniable that drug use is very popular in young population, this review included some studies which accessed the caregiver burden of adolescents' substance use problems. Moreover, caregiver burden of severe mental disorders was also part of the literature review because drug use is considered to be one of the severe mental disorders. The literature was divided into eight main subsections: operational definition of caregivers, classification of drug users, socioeconomic burden of caregivers, psychological burden of caregivers, factors affecting caregiver's burden, coping mechanism and the barriers to coping.

### 3.2 Caregivers

Basically, there are two types of caregivers namely formal and informal who provide help and care to the patients with drug use disorders. 'Informal caregiver' was simply defined as the one who is not professional in service providing for the patient such as psychiatrists, psychologists and nurses but provide effective care for the ill person and they are also very essential person in ill patient's life. Informal caregivers can be parents, spouses, siblings and other family members who has the strong relationship with patients (Goossens, Van Wijngaarden, Knoppert-Van Der Klein, & Van Achterberg, 2008). Moreover, there is also another term called primary caregivers who are aged 18 years and above and who considered him or herself as the primary caretaker to be responsible for the substance use disorders patients' physical, mental and social wellbeing by providing significant support (Orr et al., 2013).

Most of the reviewed literatures emphasized on primary informal caregivers who were family members because they had strong relationship with problematic drug used clients and understood more about them (Choudhary, 2016; Clark & E. Drake, 1994; Doku et al., 2015; Malik, Kumar, Sidhu, Sharma, & Gulia, 2012; Orr et al., 2013; Shamsaei et al., 2015). Moreover, 2 out of 8 qualitative studies analyzed the parental experience of having addicted clients (Choate, 2011; Usher et al., 2007). In this study, the term caregivers referred to the primary informal caregivers. Health care professionals who provide mental health services for drug users which is also called formal caregivers are excluded since the study emphasize only on informal caregiver burden of drug use disorders.

### 3.3 Classification of drug users

Drug use disorders is defined as the use of psychoactive and narcotic drugs in the form of contributing significant physical and psychological impairment to individual's health which in turn lead detrimental effects to society (WHO, 2015). This paper was mainly emphasized on the drug use disorders caused by the use of illicit drugs in Myanmar such as heroin, amphetamine and cannabis because it is the most commonly used illicit drugs by Myanmar people even though there is no exact

statistics source (Jensema & Kham, 2016). However, according to the ASEAN drug report 2017, over 72 million of amphetamine type stimulant (ATS), 570.62 kg of heroin and 198.8 kg of marijuana were seized during 2017 and it was proved that these are top illicit drugs abused by Myanmar people (Kanato et al., 2018). Psychoactive drug has different actions and so the severity of disorders depends on many factors such as types of drug and its properties, mode of administration, degree of addiction, physical harm like accidents, interpersonal problems due to effects of drug, giving up social activities, difficulties in withdrawal, time devotion to get or use drug and tolerance (NAMI, 2015).

Amphetamine called Yaba or Ah-thee locally has the chemical name of alpha- methylphenethylamine which is mainly in the form of white crystal powder, capsule and tablet and main route of administration is swallowing in usual case but it can also be injected and smoked in case of addicted use. If a person is amphetamine dependent, he or she may have some physical and psychological symptoms such as “reduced appetite, decreased fatigue, euphoria, isolation, hallucination, problems with law/police, failure to meet responsibilities at school or work and also sleep disorders”. Withdrawal symptoms include anxiety, depression, psychosis, and also suicidal thoughts (UNHCR & AMI, 2009).

Heroin mainly called No (4) in Myanmar is also white crystalline powder extracted from opium poppy plant. Its chemical name is diacetylmorphine since it can convert to morphine when it reaches to the human brain. It can be injected, snorted, smoked and heroin dependence symptoms are “droopy appearance, alternately wakeful and drowsy, signs of injection on back, knee etc., constricted pupils, runny nose, change in character, withdrawal from usual friends, poor self-image etc.” If a person don't use heroin within 6-24 hours, withdrawal symptom start to appear like sweating, anxiety, some abnormalities in genital organ, yawning, sneezing, severe pain in bone and muscle and so on (UNHCR & AMI, 2009).

Cannabis is a plant type stimulant which is commonly called marijuana or weed and 0.6 % of world's adult population abused cannabis daily. Main route of administration is smoking by adding into cigarettes and there are also various devices for vaporization. Hallucination, suspicious thoughts, reddening eyes, high blood

pressure, etc. are symptoms of cannabis dependence and it can cause increase heart rate and myocardial intoxication when it reacts with ATS and other agents (UNHCR & AMI, 2009).

### **3.4 Socioeconomic burden of caregivers**

#### **3.4.1 Financial losses**

Substance use disorders can contribute substantial financial strains to caregivers and family members as providing care for mentally ill person requires many resources, especially since mental disorders are usually not included in national health insurance packages (Shamsaei et al., 2015). Both direct medical cost and direct non-medical cost incurred by the caregivers led to the financial loss. Direct medical cost is any out of pocket costs incurred by the people during seeking care for certain diseases and direct non-medical cost is defined as the cost incurred by the illness such as travel and food cost which are not directly related with purchasing medical services (Sherman et al., 2001). According to one study from Tanzania, hospitalization fees, medication fees were direct medical cost and transportation cost to reach to hospital were direct non-medical cost of caregivers of patients with severe mental disorders (Iseselo et al., 2016).

Matoo et al (2013) study which was conducted at the Drug De-addiction and Treatment Centre in India with 120 caregivers used family burden interview schedule (FBIS) to measure financial loss and other domains using 3-point Likert scale. Descriptive statistics has shown that more than 80% of caregivers reported moderate financial burden while the rest reported higher financial burden. In one qualitative study which analyzed primary caregiver experience on caregiving of patients with severe mental disorders by using both in-depth and focus group discussion (FGD) with 75 caregivers in Ghana, caregivers mentioned that the economic burden was very high since most of them became unemployed after taking care of patients and some of them were poor farmers. One female caregiver in FGD said that she had to find money from somewhere to continue other siblings' education and it was very difficult to work and to take care of mentally ill person simultaneously (Doku et al., 2015).

However, financial losses due to direct medical and non-medical cost was considerably higher in families with only one breadwinner. In one qualitative study in India with 27 caregivers, one caregiver said that the patient used to ask for a lot of money since the time he became addicted. Money was also spent for his treatment process and it was very difficult for the caregiver to handle this situation since there was only earner in the family. Other caregivers also mentioned that it was impossible to balance between health expenditure for addicted patients and other household expenditure when there was only one bread winner (Choudhary, 2016). Moreover, one qualitative study conducted in South Africa showed that households suffer from financial burden since they did not have enough money to buy food for drug using patients as they ate a lot because of the strong effects of medicine and also to pay for hospitalization fees (Sibeko et al., 2016).

#### **3.4.2 Productivity losses**

Productivity loss is the other forceful burden encountered by caregivers which directed towards financial losses. This was also known as indirect cost because indirect costs included income loss and job limitation of caregivers or patients due to the effect of illness (Sherman et al., 2001). In Doku et al (2015), caregivers could not be able to work or lost their job because of taking care of person with mental disorders and sometimes they worked as blue-collar workers to survive themselves. The longer the number of contact hours between patient and caregiver, the higher the productivity loss since caregivers had to take responsibility for all the personal tasks of patients including cooking, bathing, accompanying to the health facility and it could also promote psychological burden of caregivers. Moreover, they had to sell their possessions including both income generating and non-income generating assets to cope with financial burden and these were also indirect cost of the family members.

Moreover, according to the findings of one study, productivity loss was significantly higher in caregivers who lived together with substance use individuals at home since they had to spend more than ten hours in daily activities for the patients

while caregivers needed less hours of care for hospitalized patients (Clark & E. Drake, 1994).

### **3.4.3 Social limitation**

Since caregivers are the main persons within the family who have to take full responsibility for drug use individuals' well-being and daily life activities, as a result, they have to give up a lot of social activities and steadily they are excluded from participating in the general social network. Doku et al (2015) described that caregivers faced with social limitation as they couldn't spend their time to deal with their colleagues. They had to devote most of their time for patients in helping daily activities and sometimes this was more serious when the patients lived together with caregivers rather than long term hospitalization (Clark & E. Drake, 1994; Doku et al., 2015).

The other reasons why they became socially isolated was that caregivers cut off visiting to neighborhoods and relatives as they worried about receiving stigma from surrounding to their drug used clients and themselves (Choudhary, 2016). On the other hand, the chaotic environment created by substance use individuals was the other main factors that contribute social limitation to caregivers (Sibeko et al., 2016). One qualitative study in rural Ghana which interviewed 75 caregivers described that caregivers even suffered from feeling of worried when patients got abrasive and rude to their friends and neighbors especially at the time friends came and visited to their home (Doku et al., 2015).

### **3.4.4 Negative impact on family structure**

Caregiver burden is strongly and positively associated with having a bad relationship between drug use patients and other family members within the family. As far as families are the major source of supporters for patients financially or socially, the association between family members and patients are essential to be healthy (Ishler et al., 2007). Sometimes drug use individuals created conflicts even within the family by doing physical, verbal abuse and rude behavior such as stealing things that cannot be accepted by culturally to get drug. That can lead to

disorganization of family system and once the relationship is broken, it was very difficult to build up again.

Additionally, as the caregivers devoted most of their time to ill one and there was some misunderstanding between family members such as neglecting the other child because of taking care of substance used adolescents (Choate, 2011). Therefore, family dysfunction become another tremendous social burden to caregivers that cannot be solved and manipulated easily. The other serious problem of substance use disorders on children was that the development of psychiatric disorders. Children who had to survive together with substance use parents had the higher chance of causing mental disorders such as depression, anxiety and trauma since they used to face with aggressive behavior of their parents since they were very young. There was also evidence that some children became weak and less active and it could have detrimental effects on their education since parents paid any attention to help with their home works and so on (Lander, Howsare, & Byrne, 2013).

What is more, mother substance abuse has large negative impact on fetal development and in severe case, it could lead to fetal death (Lander et al., 2013). In one qualitative study which explored about the burden of adolescents' substance use problems on parents in Australia, parents said that the burden was unlimited and sometimes they ended up by taking care of their grandchild who also suffered from some abnormalities because of maternal substance abuse during pregnancy (Usher et al., 2007).

The study which was performed on prisoners with substance abuse problems at mid-Atlantic proved that children who lived with substance use individuals in their childhood had greater probability of being drug users themselves in the future and also they had more chance of suffering from physical abuse, emotional abuse and sexual abuse in their adulthood from surrounding (Sheridan, 1995).

### **3.5 Psychological burden on caregivers**

Psychological burden is sometimes called emotional burden or subjective burden which can receive easily by caregivers and it is the most challenging burden. It is not very easy to tackle this burden since it can reduce quality of life of



caregivers. Most of the negative feelings experienced by caregivers of drug use individuals are sadness, anger, stress and guilt (Choudhary, 2016). They felt unhappy whenever they saw their ill beloved one with burden of illness and all of their dreams for their patients' well-being and success became scattered and deteriorated (Choudhary, 2016; Usher et al., 2007). In Ishler et al (2007), the authors analyzed the predictors of both socioeconomic and psychological burden. However, the result shown that caregivers suffered moderate to severe psychological burden while they faced low socioeconomic challenges. So, it allows to say psychological burden seems to be higher in caregivers than socioeconomic burden.

Patients' violence, rude manner and aggressive behaviors are major cause to develop the anger in caregivers (Choudhary, 2016; Iselelo et al., 2016). Guilty is another bad experience encountered by the caregivers. For instance, whenever parents became irritated with their adolescents' substance use problems, they said their child to go away. But when their child became disappeared actually, they became regret and guilty for their cruel words and they started to worry something bad happened to their child (Usher et al., 2007). On the other hand, parents blame themselves for their children's substance use. They tried to hide his or her drug use because of the fear of legal problems and they also did not want to see their child in the prison. to hide from legal problems. Nevertheless, it seemed to encourage substance use individuals to go ahead without any fear (Lander et al., 2013).

Moreover, caregivers reported shameful feeling when they asked help in terms of finance from their relatives and friends (Choudhary, 2016). Caregivers stressed and depressed because of taking care of patients and the unpredictable behaviors of their patients. This led to develop both physical and mental illness (Ishler et al., 2007). Lack of sleep, resentment, depression and anxiety are the main mental disorders suffered by caregivers and in severe case, development of suicidal thoughts by caregivers was another problem (Choudhary, 2016).

Even though caregiver role is of vital importance in caring ill patients with all types of disability, it is clearly that caregivers of mentally ill patients faced larger burden than caregivers of physically ill patients since they need to provide physical support, emotional support and time support substantially (Orr et al., 2013). In

Kronenberg et al (2016), the amount of time contact within caregiver and patient was directly related to a higher psychological burden and it was the reason to develop psychiatric problems in caregivers themselves. Besides then, one study in India which analyzed the burden on caregivers of substance use disorders by using binomial logistic regression analysis shown that caregivers in rural area who had low income reported severe psychological burden (Mattoo, Nebhinani, Kumar, Basu, & Kulhara, 2013).

Caregivers are worried for their patients to live without any hardship in the future and they wanted their patients to survive normally by attending school or by getting job like the other normal person (Haskell, Graham, Bernards, Flynn, & Wells, 2016). In qualitative study which accessed parental experience upon adolescents' substance use, parents reported that withdrawing the drug use children from school was not the right way to solve the problems and it could exaggerate their abuse because of the inability to control them at home. Additionally, parents were frightened when their child left home since they always thought that their child was going to run away from home, involving in illegal affairs, using drug overdose, committing suicide and damaging themselves (Choate, 2011). It can be noted that caregivers who have female substance use individuals had endured more psychological burden since they worried about sexual disturbance to their patients (Brannan, 2006).

Having a tense relationship between family members and patient can extend caregivers' emotional burden (Iseselo et al., 2016). Female caregivers are the ones who sustain the emotional burden most especially mother and wife as they felt they lift all the obstacles, duties and difficulties on their shoulder (Doku et al., 2015). Caring for persons with mental disorder is a kind of challenging problem since it can affect both physical and mental health of caregivers. In one qualitative study conducted in Iran in 2015, one caregiver mentioned that even though she was alive, she was dead inside with blunt minded and she did not want to take psychiatric drugs anymore for her mental health. Some participants in this study believed that patient's mental health problem was jeopardizing not only their mental health but

also physical health such as suffering from hypertension, chest pain and migraine most of which were stress related health problems (Shamsaei et al., 2015).

### **3.6 Evidence on the determinants of caregiver burden**

Among the 15 main literatures, most of them are qualitative study which use purposive data collection method to access both psychological and socioeconomic burden while 7 studies are cross sectional descriptive study which quantify the burden by using statistical analysis.

There was two studies which analyze the burden of primary caregivers of substance dependent individuals in India by using FBIS. FBIS was semi structured questionnaires which focused on financial crisis, disturbance to family harmony and activities, effect on physical and mental health. It was 24 item scale with 3 point scale (mild, moderate and severe) (Malik et al., 2012; Mattoo et al., 2013). Malik et al (2012) analyzed the data by using descriptive statistics in terms of mean and SD to measure high burden and it was found that higher burden was seen in caretaker of illiterate patients, lower socioeconomic status, having multiple and longer substance and times of relapse. In Mattoo et al (2013), the study used many variables in simple binomial logistic regression analysis but only the residence of caregivers is statistically significant as rural subjects reported higher emotional burden than urban residence. Chi-square test statistics was used to compare between financial burden score and demographic variables and higher financial loss was seen in unemployed caregivers ( $P < 0.05$ ).

Moreover, the quantitative study which was performed in Ohio to predict the burden of caregivers who have the women substance abusers within family used Behavioral Problems Scale to measure the patient's aggressive behavior (Ishler et al., 2007). It was composed of 58 items with 5 point scale to access client's behavior such as creating monetary problems, aggressive with neighbors and did shameful things towards caregivers. The study used predictor variables including patient factors such as age, education, dual disorder, behavioral problems, extent of drug/alcohol problem, extent of emotional problems, caregiver's gender, less help form family and less help from friends to measure subjective burden (worry, stigma, displeasure)

and objective burden (impact). It was clearly seen that only the patients behavioral problems is significant factors affecting positively on both outcomes ( $p < .01$ ) while lack of family support ( $p < .05$ ) predicted a greater objective burden after controlling all other factors in the regression analysis (Ishler et al., 2007).

There is another study which examined differences in caregiver burden and expressed emotion between caregivers of patients with substance use disorders (SUDs) and co-occurring disorders such as attention deficit hyperactivity disorders or autism spectrum disorders and caregivers of patients with only SUDs. The study used one way ANOVA to find the significant difference in burden score between three groups of patients: one group with only SUDs and other groups with SUDs together with dual disorders. The result proved that only the number of contact hours between patients and caregivers increased the caregivers' burden substantially no matter patients had co-occurring disorders or not. In multivariate analysis, number of contact hours between caregivers and patients was significant indicator that promote psychological burden (Kronenberg et al, 2016).

There was also one study which used two secondary data sets to measure the differences in caregiver burden between youth with SUDs and youth with other mental disorders. The result was shown that caregivers of patients with SUD reported more conflict with neighbors, community and legal problems and also felt more grief and worry. Being a biological parent, poor psychosocial functions of patients with surrounding were two indicators of caregivers' psychological distress in multiple regression analysis (Brannan, 2006).

Most of the qualitative studies used in depth interview to access caregiver burden and coping methods of caregivers (Choate, 2011; Choudhary, 2016; Templeton, Patel, Copello, & Velleman, 2007; Usher et al., 2007). Among 8 studies, most of the studies used thematic analysis (Choudhary, 2016; Doku et al., 2015; Iseleso et al., 2016; Orr et al., 2013; Templeton et al., 2007). Others used grounded theory and phenomenological analysis (Haskell et al., 2016; Shamsaei et al., 2015; Usher et al., 2007) for data analysis.

### 3.7 Coping mechanism

Coping mechanism is defined as “the behavior that protects people from being psychologically harmed by problematic social experiences” (Pearlin & Schooler, 1978). So, the more important the caregiver’s role in the family, the higher the burden and the greater the stress from caregiving. To measure the coping mechanism quantitatively, Brief COPE is a commonly used self-rated scale. It is a shorter version of 60 item COPE scale and it has divided to 14 coping strategies including self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame (Carver, 1997).

Although, there is no study which analyzed caregiver burden of drug use disorders by using Brief COPE, it can be seen in other studies like caregiver burden of schizophrenia. Since drug use disorder is also severe mental disorder like schizophrenia, some findings can imply to this study. There was one literature which analyzed the coping methods of 200 caregivers of schizophrenic patients by using cross-sectional descriptive study. In this study, 28 item Brief COPE self-rated scale was used. Pearson’s correlation was used to analyze the relationship between Brief COPE with psychological distress and it was found out that psychological distress had a positive correlation with the avoidant coping strategies such as substance use, behavioral disengagement, venting, and self-blame and these are also predictors of stress in multiple regression analysis. But Coping strategies such as substance use and behavioral disengagement were seldom adopted coping methods among caregivers of schizophrenia while positive reframing, acceptance and religion are the most common methods of coping (Ong, Ibrahim, & Wahab, 2016).

Another study also used Brief Cope to measure coping mechanism among caregivers of women with breast cancer. In this study, coping was mainly divided into two main parts, active coping and avoidant coping strategies. Active coping is also known as favorable and problem focused coping where individual accept the current situation and try to deal with difficulties actively while avoidant is maladaptive coping where individuals refuse the situation they faced. Active coping included acceptance, seeking emotional support, planning, religion and positive reframing

while avoidant coping were substance use, behavior disengagement, humor and denial (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004). In this study, descriptive statistics indicated that acceptance was the most frequently used coping strategy reported by both patients and caregivers. Moreover, Pearson correlation coefficients were calculated to assess the relationship between coping strategies and demographic variables and found that less educated caregiver used avoidant coping more. Moreover, multiple regression analysis was run to find the effect of coping strategies on quality of life and it was found out that caregivers who used avoidant coping strategies had lower mental quality life scores ( $\beta = -0.34$ ,  $p < 0.01$ ) (Kershaw et al., 2004).

There was one systematic review about the coping mechanism of caregivers of clients with severe mental illness (SMI) by reviewing 14 papers to analyze the most applicable coping strategies in caregivers. Qualitative (43%), quantitative (21%) and mixed method studies (36%) were included and studies were from different countries such as United States, Taiwan, Korea, Australia and Wales. All the caregivers in the articles are family members of mentally ill person such as parents, siblings, spouses, son and daughter. Caregivers reported receiving health education could help them to cope well with mentally ill person and sometimes, lack of information and loose communication between service providers and them made them to survive more difficultly with patients. Accept the real condition of person with SMI was common coping and it could relief stress and tension of the caregivers in their life and could reduce misunderstanding between caregivers and ill loved ones. Performing religious activities to be resilient with psychological burden was recommended coping strategies for the caregivers according to this synthesis paper. Last but not the least, having plans for future in caregivers was found out as good coping strategies to have peaceful life (Cotton, 2015).

According to the qualitative studies, the most common method of coping of the caregivers with severe mental disorders was religion such as asking help from god which means that caregivers believed in religious support to relief from the suffering burden, go to spirit and pray more than usual (Doku et al., 2015; Iseselo et al., 2016). Withdrawing from being a caregiver because of the feeling of hopelessness is the

other way of coping of caregivers of drug use disorders (Choate, 2011; Usher et al., 2007). In Iseselo et al., 2016, caregivers said that they cut off some expenditures to purchase medicine for mentally ill person which cannot be provided by public hospital. Giving a positive response to the current situation, accepting, finding social support from surrounding and trying to know more about patients' health condition were the other strategies of coping to cope with emotional crisis (Bhowmick, Tripathi, Jhingan, & Pandey, 2001; Doku et al., 2015; Iseselo et al., 2016). Hope can also be seen in two qualitative studies Doku et al (2015) and Iseselo et al (2016), according to which hope for miracle, hope for new treatment process and hope for support from self-help group were discussed as coping.

There was one qualitative study which examined the caregiver perception upon their substance use patients, their opinions on health intervention and changes of ways of coping after getting intervention in England. In this study, before interviewing to caretakers, they have been given psycho social intervention which last about 12 weeks. In semi-structured interview, most of them reported that these intervention could affect them positively to change their coping style to better way but some still mentioned that the interventions are not much effective to be relieved from problems they suffer. Moreover, some of the caregiver reported that accepting the real condition like saying out loud their emotional burden to good listener (health professional) reduced their burden and felt strong since they knew that there was someone who cared their problems. Controlling their feelings of worry for patients and reducing stress were the other domain of coping called acceptance. Finally, caregivers said that being optimistic towards the problems and stop shouting, blaming and saying cruel things at patients could alleviate patients' agony and change their behavior (Templeton et al., 2007).

It is also found that planning was one of the coping strategies of parents with drug using adolescents such as being a friend of drug using son or daughter to influence their behavior instead of over-controlling or blaming, try to cooperate with police to frightened addicted person (Usher et al., 2007). To overcome the lack of information, some caregiver planned to read books to understand more about patient illness. Some said that they never got health education from health

professionals except interviews and so they felt that they left too much behind in treatment process of patients (Shamsaei et al., 2015).

So, it can be clearly seen that religious coping to cope with emotional crisis was the common coping strategies used by caregivers of patient with drug use disorders and severe mental disorders (Doku et al., 2015; Iseselo et al., 2016). Planning and getting rid of being a caregiver were the common coping mechanisms of substance abused adolescents' parents (Choate, 2011; Usher et al., 2007). In the studies which applied Brief Coping, avoidant coping strategies such as substance use and behavioral disengagement were seldom adopted coping methods among caregivers of schizophrenia while positive reframing, acceptance and religion are the most common methods of coping especially to control emotional feelings such as disappointment and un satisfaction (Ong et al., 2016). Sometimes caregivers cut other expenditures to cope with financial loss even though it was not discussed directly as financial coping in the literatures (Doku et al., 2015; Iseselo et al., 2016). It was also found out that acceptance was the common coping adopted by both patients with breast cancer and their caregivers (Kershaw et al., 2004).

### **3.8 Barriers to coping**

In this study, stigma and lack of support is considered to be main boundaries to active coping since there is an evidence in the literature that receiving less stigma and much social support can alleviate both socioeconomic and psychological burden suffered by caregivers.

#### **3.8.1 Stigma**

Stigma is regarded a significant barrier to get support and help for mentally ill persons and their family members from the surroundings, and also a large hindrance to seeking care and recovering (Hanafiah & Van Bortel, 2015). It is important to note, however, that stigma was strong with all forms of mental disorders but worse with drug use disorders and this contributed detrimental effects to caregivers and family members of drug use individuals. Stigma was the significant barrier to get financial support to cope with socioeconomic burden and it was also the main barrier to seek



emotional and social support to cope with psychological burden (Choudhary, 2016; Doku et al., 2015; Usher et al., 2007)

### 3.8.1.1 Stigma on patient

Drug using individuals suffered stigma not only from surrounding but also from health care professionals (Haskell et al., 2016). As a matter of fact, caregivers could also feel sad, powerless and they had less desire to seek care for their alcohol or drug users and it became main barrier to get access by patients.

Health professionals usually had negative attitude and judgment with individuals who were suffering from substance use disorders especially with drug users. For example, nurses described that they had no desire to take care of drug using individuals since they thought it was unsafe for them and they used to be less prompt to give care to them. This negative opinion could diminish quality of life of patients (van Boekel et al., 2013). In one qualitative study which analyzed the perception of patients and family members on services for mental health, drug users mentioned that it was very painful for them when health professionals called them “fool or stupid”. Another drug using individual mentioned that they did not get enough services from doctors because of the reason of being addicted. For example, if they were in the ER with comorbidities of drug use disorders like seizure, doctors did not try to stop their problems by giving medicine in time. So, to escape from that kind of negative judgment, they tried to conceal their problems without saying true medical history such as concealing the history of trying to attempt suicide (Haskell et al., 2016).

There was one study conducted the perception of health professionals including psychiatrists, psychologists and counsellors on stigma of mental disorders in Malaysia by using in depth interview. They reported that stigma push sufferers to live silently in the agony and the negative consequences of stigma has considerably large impact on caregivers and also on societies. Main reason that exaggerate the stigma in public were lack of education and the media showing inappropriate image of mentally ill person. Meanwhile, participants in this study mentioned that patients or

family members who received that sort of discrimination became less self-worth, lost confidence and mental within society (Hanafiah & Van Bortel, 2015).

### 3.8.1.2 Stigma on caregivers

In Ishler et al (2007), 82 family members of women substance used individuals were chosen purposively and stigma scale was applied to measure the level of perceived stigma. It was nine item self-rated scale and higher score intended to have greater stigma. In regression analysis, it was found out that receiving less help from friends was the main predictor which contributed higher stigma on caregivers after controlling all other factors. Moreover, in Choudhary (2016), caregivers tended to mask their patients' substance use problem as they were afraid of accepting stigma from their friends and surroundings. Thus, stigma became the barrier to get emotional support for the caregivers of patients with drug use disorder to cope with psychological distress.

Moreover, caregivers in Tanzania from qualitative study reported that no neighbor came and visited to their household with drug users and they did not allow patients to deal with them (Iseselo et al., 2016). In one qualitative study which performed both in depth interview and FGD to explore the experience of caregivers of clients lived with severe mental disorders, caregivers mentioned that they suffered social isolation because of taking care of client which in turn lead to suffer stigma from surrounding since they were being withdrawn from society. Some caregivers were afraid of their clients being hostile to new friends or respected person when they visited to their home (Doku et al., 2015). In Iseselo et al (2016), some caregivers suggested that stigma upon mentally ill patients seemed to be obvious as their behaviors was unacceptable by surrounding but blaming was stronger upon them for letting patient into this condition. However, caregivers' emotional distress was more significant when they received discriminated words and manners from relatives and close ones.

This type of social stigma was more significant in parents especially mother of adolescents with drug use disorders. Parents have been accused by the environment that they had to have some problems within their household such as children

imitated drug using behavior from their parents or sometime people criticized that parents did sexual or physical abuse to their child. That kind of strong negative judgments from surrounding created shame and forced parents to be withdrawn from society (Usher et al., 2007). Therefore, it can be clearly seen that both sufferers and caregivers endured different forms of stigma at everywhere at any time and these are the barriers to seek care, to seek emotional and social support by the caregivers.

### **3.8.2 Lack of support**

According to Ishler et al (2007), receiving help from society in terms of financially, socially including education, information and morally can be regarded as social support. There is evidence that getting sufficient social support can alleviate both socioeconomic and emotional burden of caregivers. In one qualitative study which was analyzed about the burden of caregivers of severe mental disorders in rural Ghana, caregivers described that there was no financial and social support from community in such a way that resources were limited, people were already being poor and had any money to subsidize them, there was no sympathy and also has high stigma. Thus, in this study, author suggested that government should implement the policies to provide cash loans in order to improve work opportunities and should plan residences for family members to reduce financial burden substantially (Doku et al., 2015). Even though that study focused on all types of severe mental disorders, it can be noted that the society has same or even more negative perception upon caregivers of drug using patients.

Furthermore, caretakers also opened up that they needed educational support from health providers to better understand their patients' conditions and sometimes they became depressed because of lack of information. If they received educational support, they said that they can manage how to cope with the patients' behaviors and symptoms and they could plan for patient' future. Furthermore, they reported that mental health professionals should not exclude them form treatment process as they could help more if they knew what was wrong with their patients.

Therefore, lack of support in terms of education and information became the barrier to cope with positive ways (Haskell et al., 2016; Shamsaei et al., 2015).

In one qualitative study which was explored about caregivers' involvement in providing services for drug and alcohol users in North-east Scotland, only 5 out of 20 caregivers reported that they received support through counselling and social network team. Nevertheless, most of the caretakers in this study experienced feeling of helplessness since service providers were never regarded them as caregivers and not interested their feelings at all. They were seldom called up to discuss with them and if so, the meeting was full of their schemes and plans without focusing on caregivers' needs. Because of this, caregivers coped alone and sometimes they chose to withdraw from caregiving since they had no choice (Orr et al., 2013).

Moreover, in one study which was concerned about the burden of caregivers with women substance use patients in Ohio, among 82 caregivers, nearly 50% of them had no connection with health professionals (Ishler et al., 2007). This was because caregivers preferred health professionals who cooperated with them to improve patient's treatment, who treated their drug using patient as a family member, who provided knowledge concerning their patient's mental health prognosis and treatment to them and who did not exclude them from treatment course (Choate, 2011).

Therefore, it can conclude that both stigma and lack of support at different levels were the barriers for the caregivers to get financial support to cope with economic burden, emotional support to relieve from psychological burden and to access health education and information to plan for patient's future.

### **3.9 Summary and gap**

In conclusion, caregivers have to be responsible for a large share of direct medical and non-medical cost which lead to financial burden especially in developing countries like India and South Africa and caregivers' financial problems were discussed in the literature, both qualitatively and quantitatively (Doku et al., 2015; Mattoo et al., 2013; Sibeko et al., 2016). Selling belongings until exhausted, job limitation and time loss are the most common occurring indirect cost of

caregivers(Clark & E. Drake, 1994; Iseselo et al., 2016). It was found that social limitation and family interruption are other forceful dimensions of burden that incurred by caregivers of drug using patients(Choate, 2011; Choudhary, 2016). Sadness, anger, stress, guilt, shame and worry are the main subthemes of psychological burden found from the literature (Choudhary, 2016; Haskell et al., 2016; Ishler et al., 2007; Usher et al., 2007). It can also be noted that caregivers who have female substance use individuals had to endure more psychological burden than other caregivers (Brannan, 2006). Furthermore, according to the synthesized literatures, religion, acceptance, withdrawal and planning are main forms of coping which was used by the caregivers of substance use individuals (Choate, 2011; Doku et al., 2015; Shamsaei et al., 2015; Templeton et al., 2007).

There is also a relationship between socioeconomic burden and psychological burden such as financial crisis, time devotion and patients' behavioral problems with surrounding which could exacerbate the caregivers' emotional crisis (Brannan, 2006; Kronenberg et al., 2016; Mattoo et al., 2013). In Ishler et al (2007), they analyzed the predictors of both socioeconomic and psychological burden. However, the result shown that caregivers suffered more psychological distress compared social and economic burden. So, it can be considered that psychological burden is more evident burden in caregivers of patients with drug use disorder.

There is only one study which analyzed socioeconomic burden, psychological burden, coping mechanism of caregivers of drug use disorders using qualitative methods(Choudhary, 2016). Another qualitative study from Tanzania was nearly the same with current study which interpret psychosocial problems of caregivers, coping and barrier to coping but it explored only on caregivers who caring patients with mental disorders (Iseselo et al., 2016). Therefore, it is clear that no research was extensively done on caregivers of drug use disorders by using four outcomes such as socioeconomic burden, psychological burden, coping strategies and barrier to coping by using mixed methods.

One of the important gap in the literature is that there is unclear about which are the strategic coping methods of all types of caregivers. Since most of the literatures are mainly intended to access the coping strategies of parents with

adolescents' substance use problems, it is very necessary to know how other caregivers (relatives, spouses, and friends) cope with diverse hindrances for drug use disorders (Choate, 2011; Usher et al., 2007).

In addition, in Myanmar, there is a shortage of research to drug use disorders compared with other mental disorders since it is a very sensitive issue. There is only one study which examined the experience of imprisoned drug users to know the difficulties that they encountered with current Myanmar drug policy (Jensema & Kham, 2016). So, it is essential to know that what the main driven factors of caregiver burden of drug use disorders are in terms of financially, socially, psychologically in Myanmar. Again, it is not very clear how caregivers cope with these burden in Myanmar since coping mechanism of Myanmar refugees was only accessed in one of the systematic review for mental health interventions (Nguyen, Lee.C, Schojan.M, & Bolton.P, 2018). Therefore, it is urgently to know the caregiver burden of drug use disorders, their coping strategies and barriers of coping in Myanmar.

## CHAPTER IV

### RESEARCH METHODOLOGY

#### 4.1 Conceptual framework

The idea of the conceptual framework came from literatures and it was constructed by using deductive approach. Even though drug use disorders contribute huge burden to the sufferer, family members, employer, and country as a whole, the study emphasized only the burden on caregivers. The framework was divided into four main parts: socioeconomic burden, psychological burden, coping strategies and barriers to coping according to the outcomes of the study. Furthermore, all the pre-identified themes under each outcome were consistent with the existing literatures.

In Mattoo et al (2013) study, it was found out that financial burden was commonly occurring burden and it was more prominent in unemployed caregivers. Moreover, in one qualitative study in Tanzania, all the respondents stated that financial crises including transport and medication cost during hospitalization was very high. Job limitation of caregivers due to taking care of patients with mental disorder was the main reason of income loss. Patient's uncontrollable aggressive behavior created problems inside and outside family. Social isolation was occurred because patients made conflicts with surrounding and also caregivers had to devote most of their time to them (Iseselo et al., 2016). In another qualitative study in Ghana, caregivers who took care of family members with severe mental disorders could not deal with their best friends as they had to emphasize on patients almost all the time (Doku et al., 2015). Therefore, financial losses, productivity losses, social limitation and negative impact on family were considered as sub themes under socioeconomic burden in the current study.

Psychological burden was mainly discussed by using qualitative methods in two literatures (Choudhary, 2016; Usher et al., 2007). In Choudhary (2016), sadness, anger, stress and guilt were subthemes under psychological burden. Usher et al (2007) analyzed the parents' psychological burden when they encountered their adolescents' drug used problems. Some of the studies analyzed the predictors of psychological burden in caregivers of patients with drug use disorders by using

different caregiver variables, family variables and patient variables. In one study which used parental stress scale to measure the level of stress in parents who had the children of age group between 3 and 10, high stress was found in parents with lower education levels, divorced and single parents, unemployed mothers and parents who had more children (Algarvio, Leal, & Maroco, 2018). In Malik et al (2012), FBIS was used to measure both socioeconomic and psychological burden and higher burden was seen in caregiver of patients with lower education level, low income, longer duration of substance use, younger age, multiple misuse and times of relapse. In Mattoo et al (2013), the study used many variables in simple binomial logistic regression analysis such as age, marital status, occupation, type of family of caregivers but only the residence of caregivers is statistically significant as rural subjects reported higher emotional burden than urban residence. Being a parent caregiver, number of contact hours, having female addicts were the main reason why emotional crisis was interrupted in caregivers (Brannan, 2006; Kronenberg et al., 2016). Therefore, in current study, twenty variables that consistent with literatures were chosen to find the differences in level of stress of caregivers according to caregiver, family and patient socio demographic characteristics. To find the association between patient's severity and patient's characteristics, eight patient variables were included. These variables were clearly stated in the following conceptual framework (See figure 4).

In terms of coping, to cope with psychological burden, positive coping such as doing religious activities, accepting patient's condition, planning for future and negative coping such as getting rid of being a caregiver were commonly used by the caregivers of patients with drug use disorders and severe mental disorders (Choate, 2011; Cotton, 2015; Iseselo et al., 2016; Usher et al., 2007). However, to cope with financial coping and to alleviate economic burden, cutting other expenditures were the common coping strategies used by caregivers (Doku et al., 2015; Iseselo et al., 2016).

Stigma and lack of support from the government and community were the significant barrier to get financial support to cope with socioeconomic burden, it was also the main barrier to seek emotional and social support to cope with



psychological burden and to access health education and information to plan for patient's future (Choate, 2011; Choudhary, 2016; Doku et al., 2015; Haskell et al., 2016; Usher et al., 2007)

Therefore, in the current study, financial burden, productivity loss, social limitation and negative impact on family structure were the sub themes of socioeconomic burden while sadness, anger, worry, fear and guilt were pre-defined as psychological burden. Moreover, religious coping, financial coping, acceptance and withdrawal were the most common method of coping of caregivers from literatures. Finally, stigma and lack of support was considered as the barriers to coping mechanism of caregivers. After data analysis, new themes came out from the interview organized again with pre-identified themes from the conceptual framework.



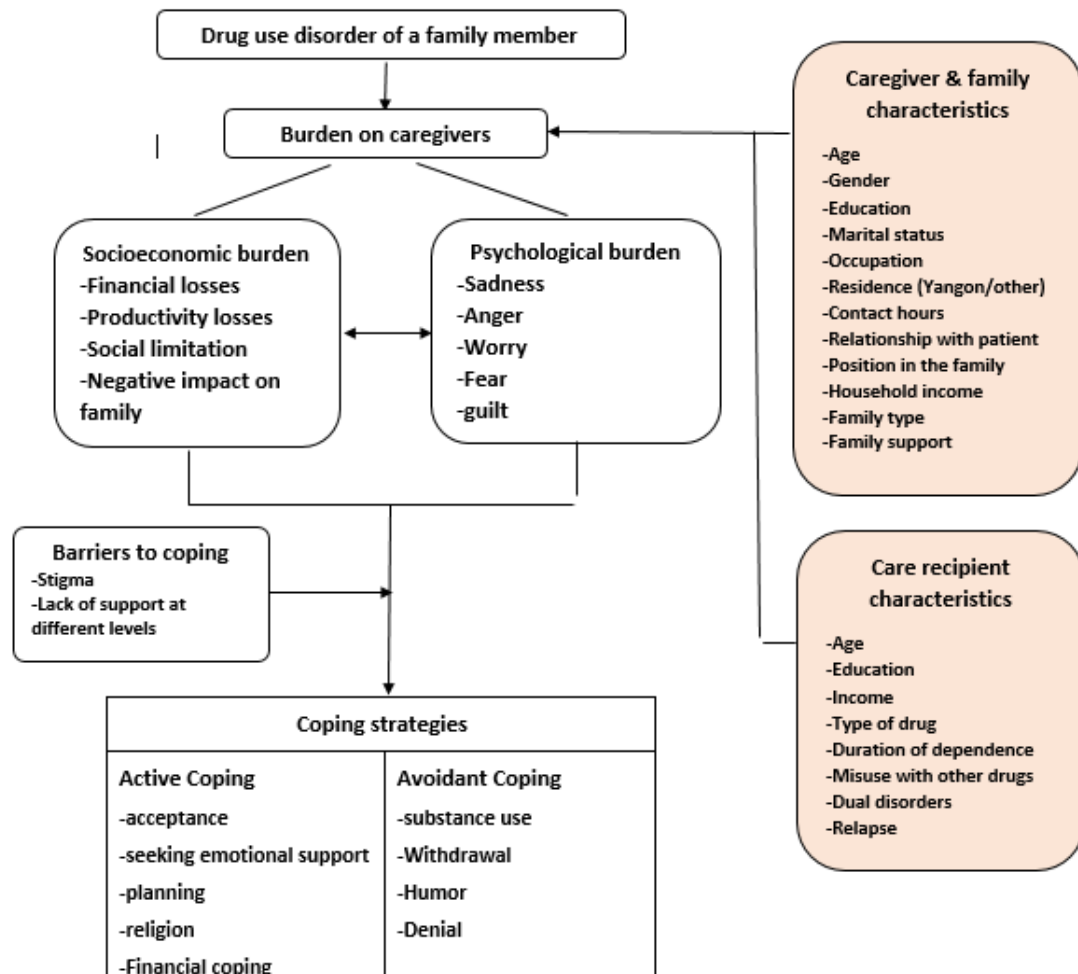


Figure 4: Conceptual framework

## 4.2 Study design

This was a hospital-based cross-sectional descriptive study using mixed method. This study was the combination of both quantitative and qualitative approach to capitalize on the strengths of each approach. The study was included only hospital-based population. Hospital-based in this study refers to the caregivers of drug use disorders who are seeking treatment recently in the Mental Health Hospital (Yangon). Those who do not access the hospital are excluded, which is a major limitation of this study. The mixed method approach was applied in all stages of this study, such as formulation of research questions, elaboration of the research design, data collection and data analysis procedures, and interpretation and discussion of the findings. Since the aim of the study intend to explore the hidden burden of vulnerable population, in depth interview was chosen to be more suitable to understand details of caregiver burden of patients with drug use disorders and to see their insight of how they feel psychologically, socially and economically. Moreover, in depth interview is the way of communication between interviewer and interviewee strongly and can explore their feelings, norms and contextual factors related to specific topic. It also allows the researcher to know sensitive and complex issue more clearly and precisely (Save the children, 2014). Most of the literatures explored the caregiver burden of drug use disorders by using qualitative approach with in-depth interview (Choate, 2011; Choudhary, 2016; Haskell et al., 2016; Templeton et al., 2007; Usher et al., 2007). However, in the current study, in order to achieve the research objectives and provide comprehensive data, both quantitative and qualitative data are collected and given equal emphasis, which allows the researcher to combine the strengths of each form of data.

## 4.3 Study period

The study was conducted from April 2019 to July 2019.

## 4.4 Study area

The study was conducted in Mental Health Hospital (Yangon), Myanmar. Although there are two mental hospitals in Myanmar, Yangon Mental Health Hospital

is chosen since it is the largest mental hospital in Myanmar composed of 1200 beds and also it is Tertiary care teaching hospital affiliated with University of Medicine (1). It intends mainly for curative treatment and also performs as a referral and specialist hospital with an outpatient department, general psychiatry units, mood disorder units, schizophrenia units, alcohol de-addiction and research unit, drug dependency treatment and research unit, forensic unit, long-stay and rehabilitation unit, and community mental health unit. This study was performed in drug dependency treatment and research unit and Unit III of mental hospital since the primary informal caregivers of drug use disorders were approached here.

#### 4.5 Study population

The study population was primary informal caregivers of patients with drug use disorders who had registered in the Mental Health hospital (Yangon) as inpatient. The study included inpatient because most of the heroin users were usually long term hospitalized patients. Even the amphetamine and other drug users were hospitalized since caregivers usually sought care for their patients at the hospital when their patients became aggressive, uncontrolled or occurred other severe symptoms with drug use.

##### 4.5.1 Inclusion criteria

Since the study cannot access all the caregivers of drug use disorders within limited time frame, it is very important to set inclusion criteria. Most of the inclusion criteria were in line with literatures and also contextual factors of Myanmar. The following were the inclusion criteria of this study.

- Caregivers who were 18 years and above.
- Caregivers with at least one year of caring experience.
- Caregivers who were family members of drug use patients and who lived in the same household with drug users.
- If there was more than one caregivers for one patient, primary caregiver who spent more time with patient was chosen.

#### 4.5.2 Exclusion criteria

This is also essential to set as it allows the study to be more homogenous within particular population and also to come out with more specific and reliable result. Since the drug using patients can have alcohol misuse, this study included informal caregivers of patients who also had alcohol misuse. The following are the exclusion criteria of this study.

- Caregivers who did not want to participate in the study.
- Caregivers of drug using patients who were under rehabilitation process.
- Caregivers of patients with other long term medical illness not associated with drug used.
- Paid caregivers and formal caregivers were excluded.

#### 4.6 Sampling procedure

Purposeful sampling method was used to achieve required sample size for both qualitative and quantitative analysis, at least 30. In order to emphasize on main problem in depth, it is of vital importance that the participants are rich with particular information related to research topic which means that it is better to choose participants who have experience with research title as researcher only know a little about this (Patton, 1990). In this study, primary informal caregivers of patients with drug use disorders were chosen since they keep in touch with social, financial and emotional burden of taking care of patients and also various strategies in coping to tackle with these burden. Moreover, in order to avoid the issue of bias and heterogeneity, only the primary informal caregivers of patients with drug use disorders who were under the treatment in the hospital as inpatient were selected.

Firstly, psychiatrics at drug dependency treatment unit and unit III who were currently giving treatment to drug users were approached to know the history of patients, diagnosis of patients and to get the information about the informal caregivers who accompanied with patients. Since psychiatrics used to talk with caregivers, they suggested the ones who were free from severe psychiatric illness, who were interested in interview about their patients and who had ability to sit in

the interview. Secondly, nurses were approached to know the day when caregivers came to meet with their patients. Registered book was checked to get the address and phone contact of the caregivers. Finally, caregivers were approached while they were waiting for the psychiatrics to know their patients' condition or while they came to the hospital to meet with hospitalized patients. Researcher explained the purpose of the study to the primary informal caregivers and if they were interested to participate, the informed consent form were given to them. After that, convenient date, time and place for them were asked.

#### **4.7 Data collection method**

Face-to-face in-depth interview was conducted by using structured and semi-structured questionnaires using native Myanmar language. Firstly, approval was requested from authorized people of the hospital and other related departments with drug care. Moreover, some relevant documents such as registration were checked to ensure the total year of addiction, address to contact with caregiver of the patients. Then, the participants were explained about the purpose of the study, risk, benefits and confidentiality according to informed consent (see Appendix 3) which provided to every participants and requested for participation in the study. If they allowed, the interview was initiated. The interview took about approximately 45 minutes to 1 hour.

The structured questions were used to access socio-demographic characteristics of caregivers, family and patients, addiction severity index (ASI) and caregiver stress scale (CSS). The qualitative study was carried out to explore the burden of caregivers, coping strategies and barriers to coping. A mixed method study answers both issues. The quantitative method addresses the stress level of caregivers and the qualitative method addresses and explores why these stresses were incurred.

To measure the severity of addiction of the patient throughout lifetime, ASI was used. Since the burden between different caregivers with different caregiving period could not be identical, ASI was included to know how each caregiver rated their patient's severity with their own knowledge. The scale was adapted from

(McLellan, Carise, H.Coyne, & Jackson, 1984). Since the scale was too long, it was adapted to fit in limited time according to context of the recent study and it consists of only 10 questions to assess severity. Actually, it is patient rated scale for their severity themselves. However, since patients were not included in this research, it was caregiver subjectively rated scale for their patient's severity such as 0 - Not at all, 1 - Slightly, 2 - Moderately, 3 - Considerably and 4 - Extremely. However, each patient's chart was cross-checked by the researcher to ensure the respondent's answer. The reliability of the short version was calculated after data collection and it was mentioned in the next chapter.

Furthermore, to measure the level of caregiver stress, CSS was used which was directly adopted from parental stress scale, 18 item self-report scale with 5 points such as strongly disagree, disagree, undecided, agree and strongly agree. The higher the score, the greater the caregiver stress. It was included in this study to be clearly seen how caregivers' psychological burden is higher to concern with their patients. The internal reliability of the scale showed the satisfactory level which is (.83). (Berry & Jones, 1995). These scales can be seen details in the Appendix (1).

Guided questions emphasized on socioeconomic burden, psychological burden that they incurred during taking care of drug using individuals, their coping methods and what were barriers to coping. Socioeconomic burden included probes such as financial problems, productivity losses, social limitation, negative impact on family structure because of drug users. Psychological burden contained emotional feeling and suffering of caregivers such as fear, anger, sadness, guilt, blame and stress. Coping mechanism intended mainly to know how caregivers solve a variety of problems that they encountered by drug users. Finally, it was included some questions which explored about the barriers to coping.

#### **4.8 Data management and analysis**

For the quantitative analysis, the descriptive statistics is used to interpret socio demographic variables of caregivers, family and patients. Categorical variables were described by using frequency and percentage while mean and standard deviation were used to show continuous variables. To find the association between

caregivers' stress level and severity level according to these variables, independent sample t-test for independent variables which have only 2 groups and one way ANOVA with post hoc test for the independent variables which have more than 2 groups were applied. For the comparison study, Pearson's correlations between the two dependent variables: caregiver stress and severity was assessed. Reliability of the scales was measured by the Cronbach's alpha.

Since Framework analysis is popular method of data analysis used in health related qualitative research, it was chosen for this study. Basically, framework analysis is usually inductive but it is well suited with the research which has already developed pre-determined interests with framework (a priori issue). It is very useful in the research mainly intends to implement policy implication for the specific case within short period and it allows to clearly see the every step of data analysis until the outcome and result come out. The framework analysis includes five steps as described below.

1. Familiarization
2. Identifying of the themes
3. Coding
4. Charting
5. Interpretation (Lacey & Luff, 2009)

All the interviewees in this study were Myanmar and native Myanmar language was used for the interviews. Firstly, data was transcribed from audio tape record using Myanmar language. Verbatim transcriptions were prepared after each interview and translated into the English language by the researcher. The transcripts are read many times to familiarize with data and to identify themes according to conceptual framework. Since the study already had pre-identified themes, new themes emerging from the in depth interview was extracted and organized again with the existing ones. Furthermore, coding was conducted by using Atlas.ti software. During the second step, the researcher developed codes. The developed codes were refined until there was no new code that emerged. The third step was searching for themes. A matrix table was used to list the codes, and all the codes were sorted and the related codes were listed into one theme. For example, hospitalization fees,



legal fees, religious fees, increasing expenditure, etc. were the codes under subtheme “Financial loss” which corresponds to the major theme “Socioeconomic burden”. This process was carefully performed on all the transcripts. The last two steps involved reviewing and refining the themes and report writing.

#### **4.9 Ethical Consideration**

Ethical approval of this study was obtained from Institutional Review Board, Defence Services Medical Research Centre, Directorate of Medical Services, Ministry of Defence, Republic of the Union of Myanmar. Ethical clearance has been approved on May 4, 2019 with reference number (IRB/2019/15). The ethical clearance form can be seen in Appendix (4).

##### **4.9.1 Description of the process used to obtain document informed consent**

The informed consent form which contains title, purpose of research, procedures, duration, risks, benefits and confidentiality was obtained from the Defence Services Medical Research Centre, Myanmar and it was provided to each and every participants. After that, they were requested to participate in this study. The signature of the interviewee was taken after he/she thoroughly read and understand the information given in the consent form. If he/she was illiterate, researcher explained and read all the information enclosed with consent form in front of the witness and signature of witness together with interviewee’s finger print was obtained at the same time. The confidentiality of the private information was maintained and can see details in section 4.9.3.

##### **4.9.2 Plans for publication of results while maintaining the privacy and confidentiality of the study subjects**

The findings is used only for the research purposes in writing academic journals, paper and oral presentation in conferences. Interviewee’s name and personal data are not described. After thesis, the results will be submitted to graduate school of Chulalongkorn University and also to Department of Medical

Research (Myanmar). The findings will be shared to the superintendent of the Mental Health Hospital (Yangon).

#### 4.9.3 Procedure for maintaining confidentiality

The participant's private information is kept confidential and it is not subject to an individual disclosure, but is included in the research report as part of the overall results. Before data collection, the researcher explained nature and purpose of the study and assure the confidentiality. No name is mentioned in this study and coding system is used in collecting the data. The results of the study is used only for health care and research purpose. All the written documents and recording of the participants' speech will be deleted one year after data analysis.



## CHAPTER V

### RESULTS AND DISCUSSION

The results of both qualitative and quantitative methods on caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies will be discussed in this section.

#### 5.1 Socio demographic characteristics of caregivers

A total of 30 caregivers participated in the study and most of them were from Yangon (83%). More than half of caregivers were aged between 45 and above (53.3%) and nearly two third were female (63.3%). 73.3 % of Bamar were included and majority of respondents were Buddhists (90%). Almost two third of the caregivers were parents of the drug using patients (60%) while the rest were sibling (20%), wife (13.3%), son (3.3%) and uncle (3.3%). As can be seen in contact hours per day between caregivers and their clients, nearly half the caregivers spent 6 to 10 hours (43.3%), others spent 1 to 5 hours (36.7) and a few devoted more than 10 hours per day for caring (6.7%). Two third of the caregivers lived in the same household with other family members who helped in caregiving activities: 43.3% lived with one helper, 10% with two helpers, other 10% with 3 helpers while one third of the caregivers had no helper in the family (36.7%). In the sample, 40 % of the household heads were caregivers. As in the education category, most of the caregivers were graduate and middle-school passed, 40% and 33.3% respectively. Majority of caregivers were married (80%) and the remainders were either single (10%), widowed (6.7%) or divorced (3.3%). Regarding to occupation status of caregivers, more than half ran their own business (63.3%). For income level, more than half of the caregivers had a monthly income of >250,000 MMK (>165 USD) (55.2%) while a few caregivers had no income (10.3%). The important findings expressed in Table 4 below and the complete table could be seen in Table 1 in Appendix (6).

Table 4. Socio demographic characteristics of caregivers

Variables	Frequency	Percent
<b>Age (Years)</b>		
≤30	4	13.3
31-44	10	33.3
≥45	16	53.3
<b>Marital status</b>		
Single	3	10.0
Married	24	80.0
Divorced	1	3.3
Widow	2	6.7
Separated	0	0.0
<b>Occupation</b>		
Unemployed	3	10.0
Own business	19	63.3
Government staff	3	10.0
Non-government staff	3	10.0
Others	2	6.7
<b>Position in the family</b>		
Household head	12	40.0
Housewife	14	46.7
Family member	4	13.3
<b>Relationship with patient</b>		
Parent	18	60.0
Son	1	3.3
Sibling	6	20.0
Wife	4	13.3
Uncle	1	3.3
<b>Contact hours per day</b>		
Unspecified	4	13.3
1-5	11	36.7
6-10	13	43.3
>10	2	6.7

## 5.2 Family characteristics

According to the respondents, nearly half of the household head were middle school passed (53.3%) and 56.7% ran own business. In some cases, 40% of the caregivers themselves were household head of the family. Half of the family were nuclear (50%) whilst the other half were extended family (50%). Nearly half of the caregivers had monthly family income between 300,000 and 700,000 MMK (200-450 USD) (43.3%). In terms of expenditure, approximately two third of the caregivers used 100,000 to 300,000 MMK (65-200 USD) per month for food (60.7%) while nearly half of the caregivers used less than 100,000 MMK (< 65 USD) per month for non-food such as health, education, clothes and others. The table can be seen in Table 1 in Appendix (6).

## 5.3 Socio demographic characteristics of patients

According to the caregivers' answer, majority of patients were young person (40 % of patients were aged between 19 and 24, 10% were  $\leq 18$ , 16.7 % were 25-29 age group). Most of them were male (96.7%). About 66.7% were single where as 7% were married and 3% were divorced. Similar with caregivers characteristics, most of the patients lived in Yangon (83.3%), majority were Bamar (76.7%) and 90% believed in Buddhism. In terms of education, more than half of the patients were middle school passed (63.3%) while some did not finish university (26.7%) and only a few were graduated (10%). Two third of the patients were unemployed (63.3%) and most of them had no income. Only 10% of patients were household head and most of them were just family members within family. In case of number of drug used per week by the patient, most of them (77.8%) used illicit drug more than 3 times per week while only 22.2 % used drug less than 3 times per week. More than half of the patients (56.7%) used drug from three, four, five and ten years while 43.3% used drug less than two years. Among 30, nearly half of the patients had the experience with relapse and more than 80% faced with relapse for 1 to 3 times while only 15 % had relapse more than 3 times and above. There was 21 patients who had dual disorders and most of them had psychiatric comorbidity with psychosis (66.6%) and mood

disorders (14.3%) while a few had physical comorbidity either HCV or HIV or both. The detail description of the table can be seen in Table 2 and 3 in Appendix (6).

Figure 5 reveals that the type of illicit drugs used by the patients with drug use disorder in Myanmar. Amphetamine (70%), heroin (16.7%) and cannabis which is also called marijuana (13.3 %) were included in the sample.

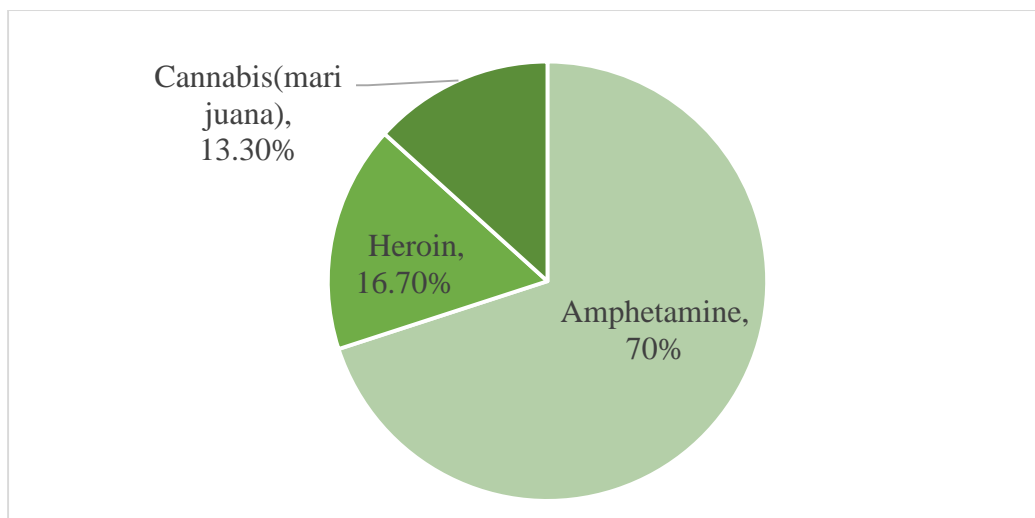


Figure 5: Types of drug use

For the misuse category, most of the care recipients used other types of psychoactive substances along with major dependence on drugs, tobacco (73.3%), alcohol (63.3%), betel (33.3%), amphetamine (16.7%) and marijuana (13.3%) (See figure 6). Even though amphetamine was the major illicit drug used by patients, in 16.7% of the patients, they had two drugs misuse (heroin or cannabis as a major drug and misused amphetamine). It was also same in the case of marijuana. 13.3% of the patient misused marijuana as the minor dependence with heroin or amphetamine.

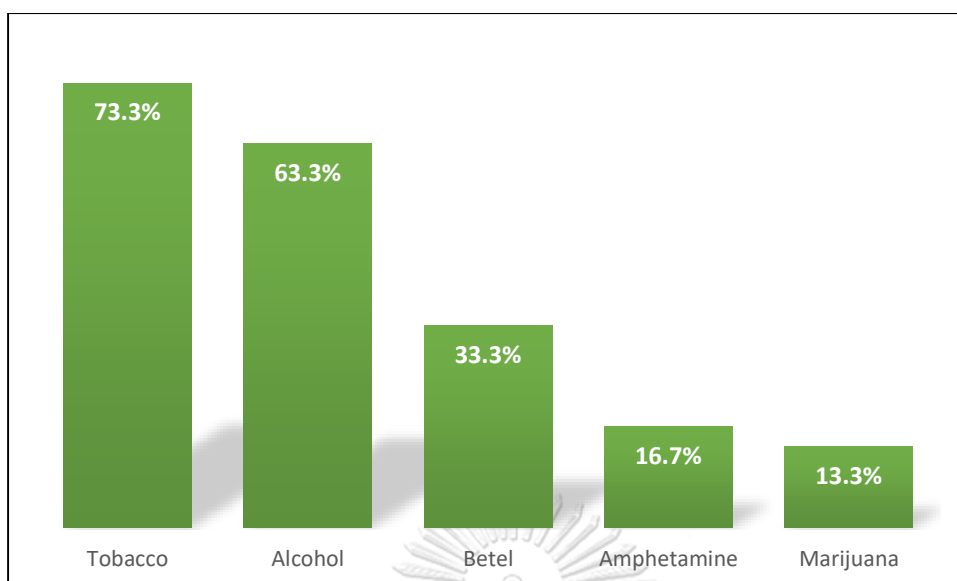


Figure 6: Other types of misuse (Multiple responses)

#### 5.4 Addiction severity index

This scale was used to measure the severity of addiction of the patient throughout lifetime. It was caregiver's subjectively rated scale for their patient's severity as patients were not included in this research. This scale was adapted from (McLellan et al., 1984). To establish of the reliability of the questionnaire, internal consistency of the rating scales was done by Cronbach's alpha coefficient. Overall Cronbach's alpha coefficient for addiction severity index showed the satisfactory level which was 0.72. It was composed of 10 questions and 90% of caregivers said patients had never experienced with drug overdose and legal problems while 83% of caregivers mentioned that their clients had no problems with understanding skills, no suicidal thoughts and no severe anxiety. On the other hand, regarding hallucination, 13.3 % of caregivers expressed as their patient condition was extremely severe. Only one caregiver (3.3%) stated that his/her patient has severe suicidal thought. In addition, 50% of the caregivers stated patient has idea to use drug all the time. Among them, 20% expressed this problem was moderately severe. The detailed description can be seen in Table 4 in Appendix (6).

Since the outcome was considered as continuous, independent sample t-test for independent variables which have only 2 groups and one-way ANOVA for the

independent variables which have more than 2 groups were used to find the association between patient's severity and patient variables (Daniel & Cross, 2013). The minimum score was 1 and the maximum score was 22. As can be seen in the following Table 5, two variables which were duration of dependence and patient's income showed the significant association with patient's severity. The result showed that severity was higher in the patient group who was dependent on drugs for less than two years compared with the group with more than 2 years of drug dependence ( $p = 0.05$ ) but it was contradictory. However, this could be the fact that ASI was rated by the caregivers. Another possible reason was the time dimension. If caregivers faced with their loved one's addiction for a long time, they might be adapted with this problem because they have already used the coping strategies and then it led to lower stress and less severity. Moreover, a one-way ANOVA was performed to determine the changes in patient's severity according to patient's income. There was statistically significant difference between different income groups ( $F(3, 26) = 5.13, p = 0.006$ ). A Tukey post-hoc test showed that severity was statistically higher in 100,001-250,000 MMK group compared to group with no income ( $p = 0.004$ ) and up to 100,000 MMK group ( $p = 0.01$ ). Therefore, it was clear that the higher the income level, the more severe the patient addiction since they had money to buy drugs for themselves without depending on other person's income.

Table 5: Association between severity level and patient characteristics

Variables	Addiction Score		p value
	Mean	SD	
<b>Patient characteristics</b>			
<b>Age (Years)</b>			
≤18	9.7	10.7	0.71
19-24	6.7	3.2	
25-29	7	6.6	
30-34	6	4.4	
≥35	4.7	3.8	



<b>Education</b>			
Middle school passed	7.1	5.5	0.61
Undergraduate	5.9	4.3	
Graduate	4.3	1.5	
<b>Income MMK/month</b>			
No income	6	3.9	0.006
≤100,000 MMK ( ≤ 65 USD)	3	0	
100,001-250,000 MMK (65 – 165 USD)	22	0	
>250,000 MMK (>165 USD)	6.2	4.6	
<b>Types of drug use</b>			
Amphetamine	6.5	4.2	0.34
Heroin	4.4	3.1	
Cannabis	9.3	8.9	
<b>Duration of drug use</b>			
≤2 years	8.5	1.7	0.05
>2 years	5	0.7	
<b>Relapse relate to duration of caregiving</b>			
Yes	6	1.3	0.68
No	6.8	1.2	
<b>Dual disorder</b>			
Yes	7.2	1.2	0.21
No	4.8	1.2	
<b>Misuse with other psychoactive substances</b>			
Yes	6.4	0.9	0.85
No	7	2.3	

### 5.5 Caregiver stress scale

To measure the level of caregiver stress, a caregiver stress scale was used which was directly adopted from the parental stress scale, 18 item self-reported scale with 5 response options (strongly disagree, disagree, undecided, agree and strongly agree) (Berry & Jones, 1995). After data collection, reliability of the scale was checked by Cronbach's alpha coefficient. The scale expressed the satisfactory levels of internal reliability which was 0.82. The scale has two components with positive (8 statements) and negative (10 statements). Among the positive statement, nearly half

of the respondents (43%) agreed with the statement such as “I am happy in my role as a caregiver” and more than one third agreed that they can fulfill their patients’ needs and wants. Although the majority of caregivers (93.3%) disagreed that they could have better future because of having an addicted patient, they agreed with the following statement: “My patient is an important source of affection for me”.

More than half of the caregivers agreed with negative statements such as caring patient required more energy, left little time in their life, could not balance between different responsibilities and exhausted of being primary caregivers. 40% agreed and another 40% strongly agreed that the patient is major source of stress in their life. Nearly 80% of caregivers agreed that patient contributes to the financial burden and that the patient causes embarrassment to them. Almost all of the caregivers (93.4%) agreed with the statement “If I had it to do over again, I might decide not to have a drug using patient”. The detailed description of this scale can be seen in Table 4 in Appendix (6).

Since the outcome was considered as continuous, independent sample t-test for independent variables which have only 2 groups and one-way ANOVA for the independent variables which have more than 2 groups were used to find the association between the stress level of caregivers and caregiver, patient and family level variables. The minimum stress score was 26 and the maximum was 74. Only one variable showed a significant association with caregiver’s stress level (See Table 6). Regarding the caregivers’ age, it was divided into three groups: caregivers with the age of below 30 ( $n = 4$ ), caregivers who were aged between 31 and 44 ( $n = 10$ ) and caregivers who were 45 years and above ( $n = 16$ ). In one-way ANOVA, there was a significant difference between caregiver age groups ( $F(2, 27) = 4.15, p = 0.02$ ). A Tukey post-hoc test revealed that caregivers’ stress level was significantly higher in the caregivers who were aged below 30 rather than caregivers who aged between 31 and 44 ( $p = 0.02$ ) and caregivers who were 45 years and above ( $p = 0.08$ ). Therefore, it can be concluded that stress was higher in younger caregivers. This was because they were sibling, son and wife of drug using individuals and they also had other responsibilities such as job. So, they seemed to be more stressful than older caregivers.

Table 6: Association between stress level of caregiver and characteristics of caregiver, family and patient

Variables	Stress Score		p value
	Mean	SD	
<b>Caregiver characteristics</b>			
<b>Residence</b>			
Yangon	58.7	9.7	0.36
Others	63	7.6	
<b>Age (Years)</b>			
≤30	70	3.2	0.02
31-44	55.5	12.9	
≥45	59.3	5.3	
<b>Gender</b>			
Male	59.8	1.9	0.87
Female	59.3	2.5	
<b>Marital status</b>			
Single	67.6	6.5	0.42
Married	58.2	9.8	
Divorced	63	0	
Widow	60.5	0.7	
<b>Education</b>			
Only read and write	64	0	0.52
Primary school passed	52.3	4.6	
Middle school passed	59.6	5.2	
High school passed	67	5.7	
Undergraduate	66	0	
Graduate	59.6	12.9	
<b>Occupation</b>			
Unemployed	61	7	0.67
Own business	60	7.4	
Government staff	51.7	22.5	
Non-government staff	62.3	10.7	
Others	59.5	4.9	
<b>Position in the family</b>			
Household head	59.3	5.5	0.98
Housewife	59.7	7.6	
Family members	58.7	22	

<b>Relationship with patient</b>			
Parent	59.4	4.9	0.56
Son	71	0	
Sibling	55.8	16.9	
Wife	63	11.9	
Uncle	56	0	
<b>Contact hours per day</b>			
1-5	60.6	6.7	0.74
6-10	60.6	6.4	
>10	56.5	14.8	
<b>Family support</b>			
Yes	58.1	2.3	0.32
No	61.7	2.1	
<b>Family characteristics</b>			
<b>Family Type</b>			
Nuclear	61.4	1.9	0.26
Extended	57.5	2.9	
<b>Income per month(Household)</b>			
≤300,000 MMK (≤200 USD)	59	4.8	0.59
300,001-700,000MMK(200-450 USD)	61.3	7.6	
>700,000 MMK (>450 USD)	57.3	13.4	
<b>Patient characteristics</b>			
<b>Age (Years)</b>			
≤18	54.7	2.1	0.62
19-24	61	5.3	
25-29	60.8	5.7	
30-34	63.7	9	
≥35	56	16.9	
<b>Education</b>			
Middle school passed	58.5	10.9	0.57
University	62.5	6.3	
Graduate	57.7	2	
<b>Income per month</b>			
No income	60.5	6.8	0.66
≤100,000 MMK ( ≤ 65 USD)	63	0	
100,001-250,000 MMK (65 – 165 USD)	57	0	
>250,000 MMK (>165 USD)	55.3	17	

<b>Types of drug use</b>			
Amphetamine	58.9	10.5	0.63
Heroin	63.2	6.1	
Cannabis	58	5.2	
<b>Duration of drug use</b>			
≤2 years	61.2	7.6	0.37
>2 years	58.1	10.5	
<b>Relapse relate to duration of caregiving</b>			
Yes	61	1.8	0.42
No	58.2	2.7	
<b>Dual disorder</b>			
Yes	60.7	1.5	0.25
No	56.4	4.4	
<b>Misuse with other psychoactive substances</b>			
Yes	59.4	1.9	0.91
No	60	3.8	

To analyze the strength and direction of the two continuous outcomes, Pearson's correlation coefficient was determined. Caregiver stress scale was positively correlated with the addiction severity index (See Table 7). There was a strong positive correlation between caregiver's stress level and patient's severity ( $r = 0.4$ ;  $p = 0.02$ ). Therefore, it allows to say that the greater the patient's severity, the higher the stress level of caregivers. However, it is important to bear in mind that the addiction severity questions were answered by caregivers and their responses may reflect their perceived stress.

*Table 7: Correlation between CSS and ASI*

Variables	r value	p value
CSS	0.4	0.02
ASI		

## 5.6 Qualitative findings

Since the conceptual framework for this study was constructed by using deductive approach, it has already composed of pre-identified themes. These pre-identified themes included socioeconomic burden, psychological burden, coping strategies and barriers to coping which were shown in the following thematic mapping with light blue color. Mediating factors of psychological burden were shown with green color and physical health affected by higher psychological distress was highlighted in purple color. However, there was the new themes which were not priori emerged from the data analysis. Caregivers emphasized during the interviews that it is important to discuss why their patients started to use drugs. Moreover, since the study was hospital-based, caregivers expressed about the reason why they took patient to hospital and their perception towards the Mental Health Hospital (Yangon). These were the important main themes emerged from data analysis which were shown in with bright blue colors in the mapping.

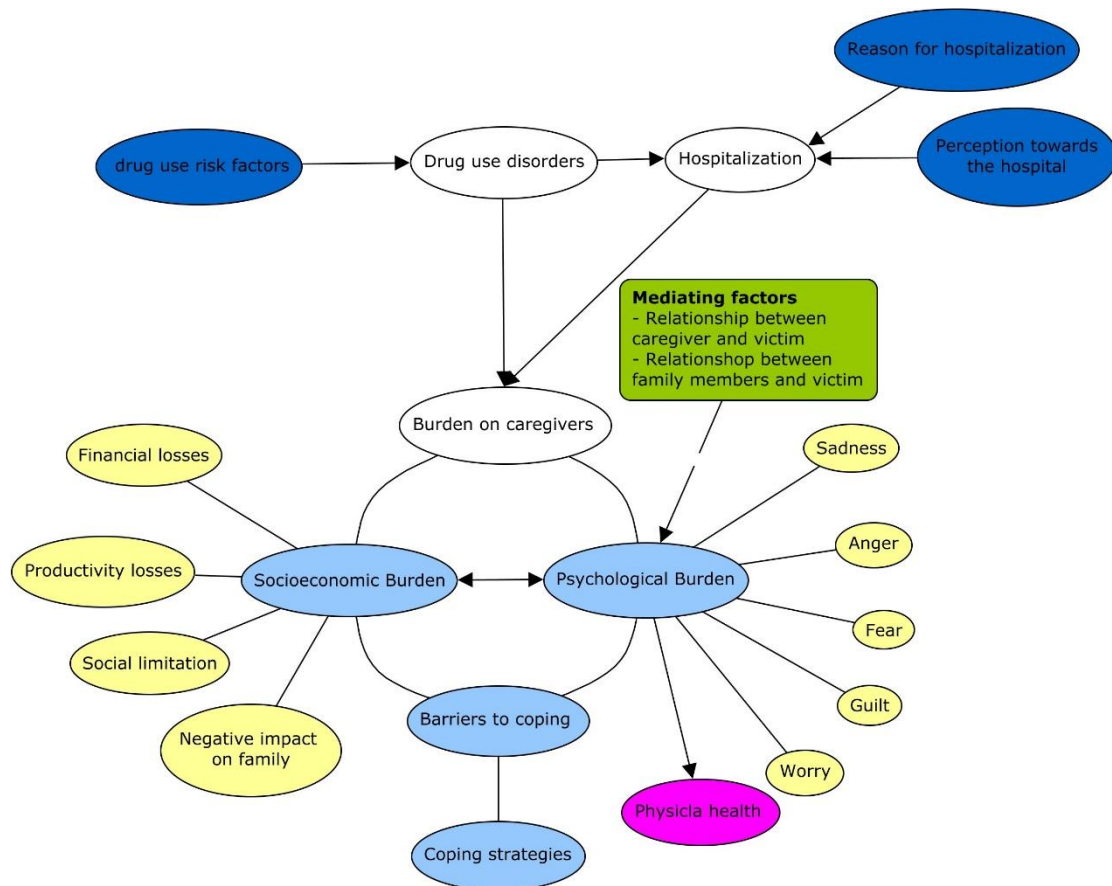


Figure 7: Thematic mapping of caregiver burden of drug use disorders in hospitalized patients

### 5.6.1 Factors initiating drug use

It was a main theme that emerged from the data analysis. Most of the respondents felt it is important to share their opinions of why their patients started using drugs and how they get drugs easily.

More than half the caregivers stated their opinion of why patients started to use illicit substances. Firstly, A few caregivers (Caregiver 7, 18, 24 and 25) said it was because of family problems such as growing up in a broken family, death of mother or not living together with parents. According to the Myanmar Demographic and Health Survey (2015-16), 60.2%, 3.3 % and 3.2 % of women aged between 15 and 49 years are married, divorced and widowed respectively. In case of men who were between 15 and 49 years, 62.4%, 2.1% and 0.7% are married, divorced and widowed respectively (MOHS & ICF, 2017). Sometimes patients did not live together with their

parents. They had to live in other relatives' homes since childhood as parents had to work and did not have time for them. One father caregiver explained as follows.

*“He became like this because of his mother’s death. Since I am a household head, I cannot stay beside him. I had to work and I sent him to his grandmother’s house. So, there is no one to control him. He started to hang out with many friends and did not go back home at night...”* (Caregiver 18)

Another reason that accelerates drug use problems is the abundance of drugs in the neighbourhoods and the easy access. Caregivers (Caregiver 4, 9, 11, 12, 14, 27 and 28) mentioned that there are many drug using individuals in the surrounding and that drugs are available very easily and cheaply. One caregiver expressed that her husband started using drugs during the time he was imprisoned. Another caregiver who used to live outside of Yangon thought that it was easier to get drugs in Yangon than in other regions. He said that he will send his son back to his native town after getting treatment from the hospital. One caregiver expressed the abundance of ATS in the surrounding as follows.

*“I don’t think he can withdraw from his addiction. At this age, it is very easy to use even though there is a little money. I am worried about the future. He will use drugs again, I have to send him to hospital again. And I want to ask how long I have to survive in this circle. Until he dies or until I die...”* (Caregiver 4)

Peer’s pressure was also identified as one of the factors that make patients go the wrong way. Some caregivers (Caregiver 1, 9, 10, 13, 24, 27 and 30) said that patients started to test the drug when they attended university since they met with many friends. In addition, one caregiver said that her care recipient has to work because of financial problems at home before the age of 18 (started working at the age of 14) instead of attending school. So, he could not decide which was right or



wrong and followed what his colleagues do and became addict. One caregiver of female drug user said her child became spoiled because of her partner.

*“She is a simple girl, with long hair. She started this when she eloped with her boyfriend. The wife of an alcoholic uses alcohol. Like this. She injected when she could not protect her husband from using it and she became addicted....”* (Caregiver 30)

So, it was inevitable that peer’s pressure, growing up in a broken family and abundance of drugs in the surrounding were the main factors that triggered drug use and test the drugs in patients. Financial hardship of the family can also indirectly lead to use drugs in patients.

#### **5.6.2 Reason for hospitalization**

More than half of the caregivers discussed the reason for hospitalization of their addicted patients. Some especially parents and siblings (Caregiver 4, 8, 9, 13, 23, 24 and 27) forced their patients to go to the hospital since they could not control the patient’s abnormal behavior and aggressiveness by themselves anymore. One mother caregiver took her son to the hospital when she saw her son was injecting heroin in the room. However, the majority of the caregivers (Caregiver 7, 16, 17, 20, 21, 22, 25, 26 and 28) claimed that it was the patient’s own desire to go to the hospital to get rid of drugs. Patients want to give up drugs for various reasons. For example, they intended to stop abusing substances as they could not afford to buy the drugs anymore, felt sorry for family members, regretted or feared imprisonment. One caregiver expressed that how she admired her brother’s decision to come to hospital as follows.

*“He is an addict. Alright. But he tried to get rid of drugs by himself and he can still be role model for accepting his mistake. We don’t know how to go to the hospital. He drove himself to the hospital....”* (Caregiver 7)

### 5.6.3 Perception of the hospital where treatment is received

Almost all of the caregivers had a positive opinion of the hospital, psychiatrists, nurses and even other staff such as security. During the hospitalization of drug users, caregivers were peaceful in mind since their patients were under the control of doctors. They said psychiatrists were very patient with their patients, explained the disadvantages of drugs well and provided counselling regularly to addicts. Some said they wanted to leave patients in the hospital more than two weeks since it is a safe place for them. Their patients gained weight, ate and slept well in the hospital. So, they had the idea to share information about the hospital when they saw other drug users in neighbourhood. One caregiver revealed that the hospital is very strict and tests all the things including food from outside to make sure patients are free from drugs and one caregiver described her positive feeling about the hospital as follows.

*“I appreciate all the service providers. Sometimes, even I am afraid of my son. But they have to deal daily with many drug users...”* (Caregiver 25)

*“I am pleased with this hospital and its services. All are very warm and treat patient like a family and support them physically and mentally. The hospital is clean and they also provide food. Sometimes nurses shout at patients but I understand that they threaten the patient with good intentions. I respect all.....”* (Caregiver 14)

Therefore, although caregivers reported hospitalization fees were high under the theme called financial losses, almost all of the caregivers were pleased with the services that offered by the psychiatrist, nurses and other staffs and they shared only their positive perception with the hospital.

### 5.6.4 Socioeconomic burden

According to the qualitative data analysis, socioeconomic burden was one of the major themes that emerged from the data and financial losses, productivity

losses, social limitation and negative impact on the whole family were the sub themes that followed. Caregivers suffered from financial losses not only due to the direct medical cost such as hospitalization-related fees during the time drug users were hospitalized but also due to direct non-medical cost such as religious fees, legal fees and compensation fees for losses and injuries caused by their patient etc. Income loss and job loss due to taking care of drug using individuals were considered as productivity loss and social limitation was a forceful burden that caregivers encountered as they devoted most of their time to ill individuals. Moreover, drug use disorders imposed a large negative impact on the whole family and it increased the caregiver burden. For example, some behavioral problems of patients such as stealing could increase the indirect financial loss of the family and caused a bad relationship between patient and family members, resulting in family disruption.

#### 5.6.4.1 Financial losses

Almost all of the respondents incurred both direct medical and non-medical cost when the patients were hospitalized in Mental Health Hospital (Yangon) to access treatment. Hospitalization-related expenses commonly encountered by caregivers include bed charges, expenses for food for patients during hospitalization and transportation charges to come to the hospital. Transportation is one of the major components of expenses. Even for the people who lived in Yangon, as the hospital is very far from the city centre, most of them used to take a taxi to take patients to the hospital and transportation was more difficult for those who lived outside Yangon. In this study, one-sixth of caregivers were from other states and regions and for those who were not from Yangon, accommodation expenses were also incurred.

*“I don’t need to pay too much for hospitalization fees but bed charges were 31,000 MMK per two weeks. Since I came from Yae, transportation charges were so high, 200,000 MMK for hiring a van and nearly 45,000 MMK for food. However, accommodation was just 1,000MMK per day” (Caregiver 2)*

One caregiver mentioned that money not only had to be paid at the time when the patient was hospitalized but also for legal affairs since the patients started conflicts with others in their surroundings and sometimes money had to be paid to the police. In some cases, caregivers had to compensate others who were attacked by their patients in order to solve the conflicts without having to go to court. There was also relationship between such financial losses and caregivers' emotional feeling. Some caregivers (Caregiver 5, 8, 14, 16, 24, 29 & 30) cried and said that financial crisis made them feel sad, depressed and worried about the future.

*“It’s nearly 2 years that I attended a court hearing and the case has not been settled yet. Over 1,000,000 MMK were gone for his legal case. And I had to pay money to the police whenever they arrested my son due to sitting in the dark at night in front of other peoples’ homes. I am very worried that I couldn’t afford the expenses for him further if I don’t have money .... ”* (Caregiver 5)

*“She worked and looked after the family before becoming addicted. After this case, the house has been sold and filled with debt. I sink in trouble since I have to spend extra money also for her partner who is also an addict...”* (Caregiver 30)

On the other hand, expenditures increased in the household because the drug addicted patient demanded money for different reasons such as asking money for health problems, money to repay lender or money to start business. One mother caregiver said heroin was very expensive and it cost nearly 300,000 MMK (nearly 200 USD) per week to get heroin.

*“At first, I thought she demanded money to repay to lenders. I had to pay 30,000 MMK, sometimes 15,000 MMK per day. Heroin is very expensive even for small amounts because they tried to get it stealthily from some connections....”* (Caregiver 30)

Having dual disorders in patients such as hepatitis C could exaggerate the direct medical cost. One mother caregiver said she had to spend nearly 20,000,000 MMK (about 13,000 USD) to treat Hepatitis C. Another caregiver explained how she lost money because her patient relapsed several times.

*“Whenever he became hostile, I sent him to the hospital. This is sixth time of his relapse. I used to send him to a private hospital and it cost 1,500,000 MMK just for 1 month of hospitalization. Millions of money were lost for his drug problem...”* (Caregiver 8)

Although the majority of respondents were Buddhists, only a few caregivers (Caregiver 1, 5 and 8) had extra cost for religious activities such as offering food to spirits or consulting fortune tellers how to reduce their patient’s drug use problem. Most of the respondents who believed only in Buddha, however, did not have any related religious expenses. It was found out that only two Islamic caregivers (Caregiver 8 and 9) participated in the sample and one described that the religious fees to relief patient problem was very high for her when she sent her husband abroad to worship.

*“Intending to get rid of drugs, I sent him to do the Hajj to perform religious rites in Saudi Arabia. However, he came back from Hajj, used the drug and the cycle started again. I remembered that nearly 6,000,000 MMK were gone for this activity...”* (Caregiver 8)

According to the findings discussed above, it is clear that most of the caregivers face direct financial losses such as bed charges, food expenses, transportation charges and accommodation charges for hospitalized patient while some encountered direct non-medical cost such as money for illicit drug, legal fees, religious fees and compensation fees which related to drug use disorders. Other reasons that increased expenditures included health care cost for dual disorders and treatment for relapse.

#### 5.6.4.2 Productivity loss

After exploring financial loss, one-third of the caregivers (Caregiver 1, 5, 13, 14, 16, 17, 19, 22, 24 and 26) continued the conversation by talking about income losses during hospitalization. It can also regard as the indirect cost of the caregivers. Caregivers had to accompany patients to the hospital when taking them to the hospital for the first time and whenever they went to the hospital again during the two weeks of hospitalization to consult with the psychiatrist or to do personal tasks for patients. So, income loss became inevitable since caregivers left their job and the income loss was more serious for caregivers who organized their own family business. One caregiver explained his income loss as follows.

*“I had to close my business, took him to the hospital and I stayed all day and night beside him. It is more tiring than working. Actually, I can get approximately 40,000 MMK per day if I work as much as I can. ...”* (Caregiver 24)

Other important finding was job limitation of the drug using patients. Nearly one fourth of the caregivers discussed about that and most of them (Caregiver 4, 8, 9, 10, 11 and 20) said their patients had no willingness to work since they were addicted and they just thought about how to get drugs and how to get money to buy drugs all the time without having any goal for the future. A few patients withdrew from their jobs because of drug used problem. However, one caregiver expressed that the patient had a desire to work and also tried to find a job, but learned that jobs were being limited for him.

*“He tried to find but he couldn’t because of his appearance. He is so thin and unclean like drug addicted street boy and also has tattoos on his body. You see! Which employer wants to give him a position? Before starting his drug use, he worked and gave me money back. So, nearly 100,000 MMK of his income were lost and it made me more difficult to survive...”* (Caregiver 16)

Selling the family's property and pawning were coded under productivity loss as caregivers described that they had to sell and pawn income-generating assets to come to the hospital, to solve social problems and sometimes patients sold the property to get money for drug.

*"I owned a house in the past and I opened a grocery store and my income was 300,000 MMK per month. Now, it has been sold and I get only 100,000 per month in the new place since there are only a few customers. I also pawned my jewelry...."* (Caregiver 5)

Therefore, it can be concluded that income loss was a major issue for caregivers when they accompanied their patients to the hospital and it was higher in caregivers who organized their own family business. Job limitation was the problem faced by a few patients. Selling the family's property and pawning were indirect financial loss of caregivers since they sold income generating assets to solve financial problems concerning drug users.

#### **5.6.4.3 Social limitation**

Caregivers did not say explicitly that they withdrew from their surroundings because of their patient's drug addiction, but some caregivers especially parents (Caregiver 2, 9, 10, 14 and 17) mentioned that they could not participate in social activities since most of their time was devoted to the patient's well-being such as cooking, accompanying the patient to the hospital, watching the patient all the time not to use drug stealthily and doing personal tasks for the patient. The other finding related to social isolation was patient's aggressive behavior and verbal abuse to neighbours. One mother caregiver sadly said that she even could not participate in religious events.

*"I cannot go to the monastery even in the Thingyan Holidays as I do care and cook for him. For a long time I could not go to wedding events and other social activities."* (Caregiver 2)

#### 5.6.4.4 Negative impact on family

Almost one third of the respondents (Caregiver 3, 4, 8, 13, 14, 15, 22, 24 and 26) agreed that their patients contributed negatively to family members and family cohesion. Stealing to get drugs was the common behavioral problem of patients faced by caregivers and other family members and it was unacceptable. Patients threatened family members when asking for money and sometimes they took the things and pawned them which exaggerated the indirect financial loss within the household and the family relationships were destroyed. One female caregiver described that her brother even tried to take the money she put aside for offering it to God and monks as follows.

*“If there are only 3 persons at home, the money did not disappear no matter where I placed it. But if he is at home, even the hidden money was lost. He stole the money which I intended to donate for monks and God. See! How he is stupid. One time, he asked for the earrings from my sister and my sister gave these to him since she was afraid of his hostile behavior...”*  
(Caregiver 4)

Parents’ drug use also has large negative impacts on children. Sometimes parents abused children physically when they got angry. The consequences of using drug included children being stigmatized by neighbours and facing educational disadvantages since patients even tried to take money meant for children’s tuition fees. One caregiver (wife) mentioned how her husband’s drug used problems affected their children.

*“He jeopardizes our child’s future, education and also business. He even tried to take money from his son’s tuition fees even though I said to him that this is for education. I am worried my adolescent (son) imitates his father. My son is in Grade 11 and he always goes to school and tuitions. He returns late at night and it is a dangerous condition for him of being wrongly accused under drug laws by the police...”* (Caregiver 8)



A few caregivers who were mothers (Caregiver 24 and 26) said they neglected other family members because of taking care of patients with drug use disorders.

*“I send my daughter to her grandmother. I felt sorry for not spending enough time with her. But I have to take care of my son and run a business as well. What can I do more?”* (Caregiver 24)

It can be noted that drug use disorders increased family disarray, decreased harmonization within family especially because of the poor behavioral functions of patients such as stealing and rude manner.

### **5.6.5 Psychological burden**

According to the findings, psychological disturbance of caregivers was divided into three sections: emotional crisis, relationship between caregiver and victim and relationship between family members and victim. It is the burden which is difficult to solve by the caregivers. They felt psychologically unwell since they were worried about drug users and family’s future, grief due to stress and hopelessness, fear, anger and guilt. Relationship between caregivers and victims was also important factors that influenced caregivers’ psychological burden. A few caregivers assumed that their physical health became worse because of the emotional crisis that they endured.

#### **5.6.5.1 Emotional crisis**

Almost all the participants expressed how they experienced a psychological trauma during the time taking care of their drug using patients and when coping with behavioral problems of addicts. The most common reported psychological burden was sadness, anger, fear, worry and guilt.

More than half of the caregivers especially mothers felt sad and hurt of seeing beloved one with drug use disorders. A few caregivers (Caregiver 23 and 30) never imagined that they would have to visit a mental hospital for their loved ones’ drug use problems. Parents also expressed feelings of hopelessness since they had high expectations of their children prior to them becoming drug addicts. They had

many plans for their children's future from various aspects and now all were torn down. Some wanted their children to grow up smart and educated and some wanted them to finish high school and to settle in a prestigious job. One caregiver with a heroin injecting daughter expressed her feeling of sadness as follows.

*“I have no tears left to cry. If I could, I would like to exchange her blood for new cells. She used to be afraid of syringes and she never did injections even she was ill. I cannot imagine how she injected heroin by herself. She is always asking for drugs....What can I do.....I....”* (Caregiver 30)

Feelings of helplessness occurred in a few caregivers (Caregiver 8, 16 and 24) because they said that they are the only breadwinner in the family, they shoulder all responsibilities and they have no way to escape from the trouble. One caregiver (wife) said that she is very tired of being responsible for all the mess.

*“I cannot speak out loud about these difficulties to my mom and others because it is an abnormal case. I wish I was mad. I have to run business by myself, take care of children and take care him as well. How can I handle all this by myself...?”* (Caregiver 8)

When exploring the psychological burden by using pre-set probes, almost all of the caregivers discussed how they are worried about their patients' wellbeing, family future and legal concerns. Moreover, in some cases, one caregiver (Caregiver 8) worried that patient problems had reflected on other family members such as family members being suspected in drug cases when ATS were found at home. Some (Caregiver 4, 19, 25 and 30) were worried that patients would abuse the drug again when they are discharged from the hospital, join with peers and return to the previous situation. One mother caregiver described that she even moved home and her intention was to reduce his son drug use but nothing was successful to handle this situation. Some (Caregiver 12, 17 and 22) stated having suicidal thoughts in

patient doubled their worry. The following statements underline that how caregivers were worried for their patients.

*“I tried to prohibit him from using drug. If he did not listen, I asked his friends not to give him drugs. I have no strength to see him in the prison. I am worried and watch him all the time so he is still outside. Most of his friends are now in the jail....”* (Caregiver 2)

*“I am so hurt and anxious for her whenever she goes out. It’s not just simple drug. It’s No (4). You know! Having an addicted daughter is like a thunder storm. I fainted when I heard about this for the first time....”* (Caregiver 30)

While discussing the worry, nearly two thirds of the respondents who were especially female caregivers unconsciously changed the topic to fear by expressing how much fear they carried because of living with drug users in the same household. It included fear of injuries to family members and others since patients were not in normal mood, legal fear and fear of negative judgment from surrounding.

*“I have heard in the news that a drug addicted person killed his family or the environment after overdose of drug and I am afraid of him causing danger to himself or to me or my family.....”* (Caregiver 4)

*“I am very afraid of seeing him in the prison. Whenever I hear legal news, I am worried that it’s my son...”* (Caregiver 3)

One sixth of the caregivers (Caregiver 2, 3, 5, 15, 29 and 30) felt angry when their patients were in obedient, aggressive to family members, stealing money and things, using verbal abuse to them. Some caregivers (parents) reported feeling of shame together with anger when their children became rude and physically abused to them. One female caregiver (wife) said that she was

very angry whenever her husband accused her of having an affair with other men. On the other hand, a few caregivers showed their feeling of anger upon drug sellers and large scale traffickers as they destroyed many lives of the youth.

*“It was very angry and also ashamed when he did not recognize me as his mother because of the strong effect of the drug. He pulled my hair hardly and I thought that it is better for him to die or for me to escape from this retribution.”* (Caregiver 5)

*“I cursed the drug sellers. However, I am not even satisfied should they die because I have to die every day. It’s feeling like blood is running outside from my heart. People feel sad even when the pet died but now the addicted one is my son, my blood, my life...so....”*(Caregiver 25)

Since drug use disorders are not similar to other physical illnesses, they cause large psychological trauma to all the family members. Patients’ behavioral problems let to develop anger and embarrassment in caregivers. One caregiver expressed how the whole family was stressed and worried because of drug using individuals as follows.

*“I have never seen drug users in my environment for 46 years. But I started to recognize my son was using drugs and he also admitted it. At that time, me, my husband, his grandmother had very large unwell feelings. How to say...we worried that these drugs spread to his brain or he is going to be mad. This feeling seems like an elephant pressed on our head. It’s too hard and we have no strength to go ahead...”* (Caregiver 22)

The other feeling they reported was guilt and one third of the caregivers (Caregiver 3, 11, 14, 16, 19, 22, 25 and 28) agreed with that. This type of psychological burden occurred especially in the parent caregivers. They thought their children fell into this vulnerable condition since they could not spend enough time

with them. They regretted letting their children run their own business, giving freedom, not suspecting drug use on time or neglecting children since they worked. They blamed themselves for not creating a perfect life for their child. If they knew earlier, their children would not have to survive under vulnerable conditions. One mother caregiver also expressed guilt for being pessimistic to her son and scolding too much as follows.

*“I was never optimistic to my son because he was abusing drug. I always scolded him and he may not want to live at home. He was happy outside and still used drug. I regretted that when seeing sa-yar-ma (psychiatrist) speaking to him kindly and guiding him patiently. I have never spoken to my son like this. I am guilty and I could not support enough for his education because of my low salary...”* (Caregiver 16)

It can be clearly seen that sadness, anger, fear, worry and guilt were commonly occurring emotional feelings of the caregivers of family members who suffering from drug use disorders. Parents expressed the feeling of guilt, sadness and hopelessness for their children and fear was the common psychological burden mainly encountered by female caregivers. Feeling of helplessness was more obvious in caregivers who were the main earner of the family.

#### **5.6.5.2 Negative impact on physical health**

A few caregivers (Caregiver 15 and 30) expressed that patient drug cases had negative effects on their physical health. They suffered from sleep disturbance since they were too worried about patients and had increased physical health problems such as hypertension, diabetes and heart diseases which were associated with stress. They said they could not take care of themselves enough as they took care their patients. One caregiver described that how she controlled herself not to sleep soundly at night since she worried about her husband.

*“I can’t sleep but I don’t take sleeping pills as I worry that he would go out. I sat and watched him. I reduced eating and seldom take vitamins because I have to wait for him to sleep....” (Caregiver 15)*

### 5.6.5.3 Relationship between caregiver and victim

This subtheme emerged from the interview and was not identified a priori. During the in-depth interviews, caregivers added that the relationship between them and the patients they have to take care of is important. It cannot be denied that having a bad relationship between caregivers and victims can exaggerate caregivers’ psychological burden. Among 30 respondents, one third shared their feelings regarding their patients. Half of the caregivers (Caregiver 1, 7, 17, 23 and 25) expressed their positive opinion upon the victim while the others (Caregiver 4, 9, 11, 18 and 29) reported the opposite.

*“He is clever and not similar to other children who abused drugs. He is understanding to me and never asks for too much money. Even though he saw a large amount of money, he never touched it. I don’t know how he gets the money for drugs ....”(Caregiver 25)*

*“He cannot live without drugs. He takes a large amount of trematol all day and night. I cannot control him and he hit the TV and other things at home. All assets have disappeared since he betted on football after using drugs....” (Caregiver 29)*

Moreover, some caregivers especially fathers said that there are misunderstandings between patients and them, which could increase emotional disturbance. When they sent patients to the mental health hospital, patients thought that they were abandoned by their caregivers in the ayuu-htaung (prison for the fool). Sometimes, patients misunderstood the caregivers when they were scolded too much. A few caregivers (Caregiver 18 and 19) reported they cannot give enough time for patients since they are the main earners of the family and they have to take

care of other family members. One father caregiver reported the misunderstanding between his son and him as follows.

*“Sometimes he said that living separately from his mom was my fault. He felt resentful for having to live in a broken family. I explained how I worked hard to meet his needs but.....”* (Caregiver 24)

*“I have many children and I could not spend too much time with him. And I believed him. I thought he would not be that stupid. I had to work for the family and his father was also late back home. No one can follow and watch him. But now I am feeling guilty for seeing him in this position...”* (Caregiver 19)

Therefore, having the negative opinion of caregivers on their victim could exaggerate the caregivers’ psychological burden and misunderstands was commonly seen between father caregivers and their drug using sons.

#### **5.6.5.4 Relationship between family members and victim**

Some behavioral problems of patients such as stealing and aggressive behavior created bad relationship between them and other family members. Since family members are typically the main source of support for the caregivers in taking care of patients, having a bad relationship between family members and patients could multiply the caregivers’ burden. According to caregiver 4, 14, 16 and 18, even siblings were found to neglect the patient because they thought it was shameful to have drug using person in the family and they were disgusted patient’s rude manner.

*“His brother does not even talk him (patient) or deal him because he said he is so ashamed of having that kind of unmoral sibling. And like I said, he (patient) did not listen to anyone and always full with complaints about his brother’s guidance....”* (Caregiver 18)

### 5.6.6 Coping strategies

After exploring caregiver's socioeconomic and psychological burden, caregivers were asked how they dealt with the variety of obstacles while taking care of patients with drug use disorders and how they coped with patient's behavioral challenges and financial difficulties. The main subthemes that came out from coding transcripts were active coping and avoidant coping. This classification was adopted from one literature which was about coping mechanism among caregivers of women with breast cancer (Kershaw et al., 2004). Most of the respondents used active coping whilst only a few revealed that they tried to avoid this uncomfortable situation.

#### 5.6.6.1 Active coping

Religion, acceptance, seeking emotional support, planning and financial coping are active coping strategies used by caregivers to tackle their difficult problems because of having drug using family members. In the sample, 90% of the caregivers were Buddhists. They said that they prayed, paid homage to Buddha, tried to be vegetarian and did other religious activities for patients and for the peacefulness of their mind. A few (Caregiver 16 and 27) encouraged their patients to chant an incantation (locally called than-bote-day) to be freed from evil. Only a few caregivers (Caregiver 1, 5 and 7) mentioned that they believe in spirits and made offerings to spirits to relieve patient's problems. Caregiver 7 and 13 went to fortune tellers and followed their advice to avert hindrances. One Christian caregiver said that he went to Church and prayed for his son every day to stop his drug use. 6.7 % of caregivers believe in Islam and one caregiver described that she sent her husband to Hajj to perform religious duty at Saudi Arabia and she also fasted once a week for her husband.

*“I spent nearly 100,000 MMK for spiritual offerings but he seems to be only a little bit improved after doing this ceremony.....” (Caregiver 5)*

*“Do you know how I can be resilient? If someone else was in my shoes, they would be mad. I have to take care of the whole family including him (drug*



*using brother). Sometimes I became angry with him and sometimes I wanted to die. But gradually, I tried to devote my mind to religious activities. Now I am more peaceful than before and can think that it's just fate that I can't change....” (Caregiver 23)*

Half of the caregivers agreed that they accepted the patient's problematic behaviors such as stealing, breaking things and some bear in mind that it was a retribution from the past. Caregivers mentioned that they could not turn back from this position so they tried to think of what they could do for patients to create the best future. Some parents (Caregiver 6, 17 and 25) tried to understand their children's aggressiveness and throwing rude words to them because they assumed their child was not in normal condition. One mother caregiver described as follows.

*“He broke the things but I consoled myself that he will not do this if he is in a normal health/mood. Sometimes I thought that life is too short to think unpleasant things too much. So, I try to be happy....” (Caregiver 6)*

Caregivers were full of plans for the future of their drug using patients such as sending the patient to a rehabilitation unit after leaving the hospital, encouraging patients to work or continue studying and spending more time with them. Plans such as shifting home, threatening patients by cooperating with the police emerged as common coping methods. Some (Caregiver 7, 13 and 23) mentioned that they watched news from the TV, radio and other social media to understand more about drug use disorders and to know how to deal with drug using patients conveniently.

*“Previously, I did not know what this drug addiction means. But, I watched educational programs for drug use disorders from TV and also read news from online. It allows me to improve knowledge about the disease. You cannot be too serious and angry with drug users. There's a technique about how to control them....” (Caregiver 23)*

Some caregivers (parents) revealed their plan of their patient becoming a monk to have a peaceful mind or performing as a lay attendant at the monasteries. Only a few caregivers (Caregiver 12, 17 and 22) stated that their patients had suicidal thoughts and so they hid all items that could be dangerous to their patients. Some caregivers also stated they sought emotional support especially from family members and family members appreciated their caregiving. One caregiver (wife) explained how she loves her husband and how she plans for the future as follows.

*“I decided not to have a baby in our life. It is not suitable socially and also medically for carrying a baby of an addicted father. And if I had a baby, I would have to share my time to my child. So, I decided to take care of him as my baby for my whole life. I have a plan to send him to a rehabilitation center after he has been discharged from here.....”* (Caregiver 12)

Most of the respondents use financial coping strategies to manage their circumstances since many are suffering from financial difficulties. For example, caregivers borrowed money from relatives and friends, sometimes from organizations with interest in solving these problems. On the other hand, some (Caregiver 2, 4, 5 and 17) said that they sold their properties such as land, building and jewelries. Sometimes, pawning was one of the coping mechanisms pointed out by the caregivers when they needed money urgently. Some caregivers (Caregiver 4, 16 and 30) cut other expenditures such as food and clothing when they had to spend too much for illicit substance used by their patients. One caregiver said that she did not cook anything on the days the patient asks her for money to buy drugs. The following statements indicated how caregivers coped with financial hardship.

*“I always try to meet his needs as much as I can. I pawned my earrings to buy a phone for him. After getting what he wanted, he left home and came back again when nothing was left.....”* (Caregiver 3)

*“I hardly ever buy clothes for myself. I tried to be in a good relationship with doctors and nurses at the hospital. I work and I wear what they give to me...”* (Caregiver 16)

#### 5.6.6.2 Avoidant coping

This is a rare coping method adopted by the caregivers in Myanmar since most of them had no idea how to withdraw from caregiving. Since two thirds of the caregivers in this study were women, substance use was seldom used as coping method to solve the problems. However, a few male respondents (Caregiver 1 and 17) said that they drank alcohol when they were tired and annoyed. No one in the sample reported that they took sleeping pills to escape from sleep disturbance and they said sometimes they watched TV, prayed or slept in the morning when they could not sleep at night. Only a few caregivers (two mothers and one wife) cried and said that they wanted to disengage from this stressful condition since they felt full of responsibility. But no one abandoned their drug addict and all are still involved in caring activities.

*“I guided him (drug using son) but he did not listen to me. I never tried to hurt him but whenever I was annoyed, I drank alcohol usually in the evening and slept....”* (Caregiver 17)

*“I sometimes thought that I would like to withdraw from this trap because it’s like taking care of a baby. Actually, it should be maung-ta-htan-mal-ta-ywat (share the responsibilities together by wife and husband) but now he is not a good leader and not a good follower. I cannot even work calmly because of him...”* (Caregiver 8)

Other forms of coping described by the caregivers were hoping for a good future and concealing patients’ problems. A few caregivers (Caregiver 7 and 18) tried to conceal patient’s hospitalization to reduce stigma. Some (Caregiver 6, 9 and 24) said that they hoped their adolescent could get rid of drugs when they became

mature and a little bit older. Others (Caregiver 13, 14, 16, 20, 25 and 26) hoped to get social and financial support from charitable organizations and the government such as health education, financial aids, etc in the future. One caregiver said that she wished her son to participate in normal activities again such as attending school after discharging from hospital as follows.

*“I believe he will be better soon after having taken prescribed medication at the hospital. He will attend school again and I hope my son is the most handsome among peers. Ah..I have to register and pay tuition at the end of the month....”* (Caregiver 6)

In conclusion, active coping such as doing religious activities including praying, fasting and chanting oath, financial coping, accepting patient’ behavioral problems and planning for the future were the major coping methods cited by the caregivers in Myanmar. Avoidant coping such as disengaging from caring activities and substance use were seldom used by caregivers. Other forms of coping included hoping for support and concealing patient’s drug use problems.

### **5.6.7 Barriers to coping**

For this category, almost all of the respondents raised that there are barriers to coping and it could be noted that stigma and lack of support at different levels were sub themes that emerged under this main theme. According to the findings, stigma was the barrier to financial coping and to seek emotional support while lack of support was the barrier to seek both financial and social support outside the family in Myanmar. Therefore, these two were the barriers to active coping.

#### **5.6.7.1 Stigma**

Regarding stigma, nearly one third of the respondents (Caregiver 2, 9, 12, 13, 14, 16, 19 and 23) said that they received negative reactions from outside of the family such as from relatives, neighbours and friends. They were blamed by their surroundings. Blaming was reported more by mother caregivers of drug addicts. People said that children ended up in this condition because their mother was very indulgent, was not a good guardian and gave money for drugs to children. One

mother caregiver said that a relative stopped supporting her because of her son's drug use and it became a barrier to cope with the financial crisis. She was accused of giving money to buy drugs for her son. She expressed her feeling like this.

*“People blamed me that it was my fault of letting my son be a addict and that I destroyed him by giving money. There is no mother who gives their children money for drugs. There is no mother who encourages them to use drugs...”* (Caregiver 14)

Furthermore, they were looked down by their surroundings because of patients' drug addiction and impolite behaviors. Caregivers were labelled as father, mother or sibling of the junkie. A few mother caregivers (Caregiver 2, 16 and 14) said that even very close relatives tried to end up the relationship since they worried about their own children. They were afraid of their children imitating the behavior of the addicted one. That type of stigma could exaggerate the social isolation of caregivers and become a barrier to seek emotional support. One caregiver explained their negative judgment as follows.

*“I am left behind by the society. There was a person who graduated with a specialization in law and he said that if someone is bandit, the police will arrest only this person. However, if the suspect is involved in drug cases, the whole family cannot escape. They are afraid and so, they neither allow my son nor me to interact with them .....”* (Caregiver 16)

On the other hand, some caregivers mentioned that patients were also exposed to high stigmatization. Caregivers said that they did not have any strength to listen to the gossip about their patients. Sometimes, good friends of their patients did not interact with them anymore because of the drug use problems. Colleagues also gave up on patients and regarded them as a useless people. This kind of stigma upon patients increases the psychological burden of caregivers. One wife expressed her feelings about stigma as follows.

*“What can I say? He has no future. He has been judged as junkie by his colleagues. I am afraid that he cannot enter into society again. I am very depressed of seeing things....”* (Caregiver 12)

That’s why, according to the caregivers’ statement, stigma was the main barrier to seek emotional support, to borrow money and to get financial support outside the family.

#### **5.6.7.2 Lack of support at different levels**

This was also identified as an important sub-theme under the barrier to coping theme. Most of the caregivers mentioned that they receive help and support from family members. However, almost all of the caregivers did not receive any help from outside the family. Only one said that he had the experience of attending a health education program regarding drug use disorders in Rakhine State but he didn’t mention the name of organization. There was no financial or social support, from the community or the state level. One caregiver described that even the local authority of a quarter did not issue the referral documents in time to send the patient to the hospital and gave wrong advice.

*“Family members help each other but there is lack of support even from the local authority. I was greatly surprised by his suggestion because he told us to give alcohol or sleeping pills for my patient to control aggressiveness instead of sending him to hospital...”* (Caregiver 4)

A few caregivers suggested that it would be better to have charitable organizations be present at the existing mental health hospitals to support medication and other necessities for drug addicted patients. One caregiver from Kayin State (nearly 500 km far from Yangon) said that she had to travel to Yangon because of the shortage of treatment centres in the state that she lived. One mother

caregiver said that reinforcing that support was essentially needed for all the family members who lived with drug users as follows.

*“Both financial and educational support is needed for every family member. People may not open up about their problems since they are ashamed or afraid of legal problems. But actually, everyone needs help. I hope every young person including my son will go back to the right way. They are the strength of the country....”* (Caregiver 14)

One male caregiver expressed his disappointment with the existing drug policy as follows.

*“Government should emphasize more to develop supporting programs instead of making policy to be harsh. The police imprisons offenders with only two or three ATS in hand while the large scale traffickers still escape. It shouldn't be....”* (Caregiver 18)

Surprisingly, half of the caregivers who discussed about the lack of support indicated that they did not hope for any support from anywhere because they thought that it was not the responsibility of the public to help and that was shameful to talk about this openly. Some even stated that it was not worth to support drug users by the Government. They thought that they have to handle the problem themselves.

*“I don't think government will support drug users. It's funny, isn't it? So, when your child becomes addicted, it's totally your responsibility. It's too shameful to admit even to the close relatives. So, how could I announce this to the public? I don't want any support for this case. By the way, is there any support program in Myanmar, sa-yar-ma (health professionals)?”* (Caregiver 17)

All in all, it is noticed that most of the caregivers did not get any support financially or socially from community and state level even though family members were well supportive in caregiving activities.

## **5.7 Discussion**

Drug use disorders impose a huge burden on the patient, family members, especially the family caregivers. However, existing studies on the burden of caregivers taking care of patients with drug use disorders in Myanmar is limited. Therefore, this study was carried out with 30 caregivers of patients with drug use disorders by using mixed methods design in Yangon Region of Myanmar. This study found that caregivers incur a large socioeconomic and psychological burden and employ various coping strategies to deal with these. The themes that emerged when coding the data are: socioeconomic burden, psychological burden, coping strategies, barriers to coping, factors initiating drug use, reason for hospitalization and perception of the hospital where they received treatment. Information about the socio-demographic characteristics of caregivers and patients were also collected.

### **5.7.1 Socio demographic characteristics of caregivers and patients**

In the present study, most of the caregivers were aged 45 years and above and the majority were parents of the patients followed by siblings and wives. Most of the caregivers were female, married and the educational attainment of half of the caregivers was lower than high school. These findings are consistent with previous works (Brannan, 2006; Malik et al., 2012; Orr et al., 2013). Mattoo et al (2013) and Ishler et al (2007) found that most of the caregivers were unemployed. However, in this study, only 10% of the caregivers were unemployed and most of them have their own business, which may be because of the large informal sector in Myanmar (Sein et al., 2014). Besides, nearly half of the caregivers in the sample were household heads which means they were the main earner of the family. Therefore, nearly half of the caregivers could spend only less than 5 hours per day with their patient since they had to work. In case of patient characteristics, most of them were male with no monthly income and had psychiatric comorbidity with psychosis and



mood disorders. Most of the patients also misused other substances such as tobacco, alcohol and betel while some had two types of drug dependence. This was observed in other studies as well, in which almost all of patients were male, unemployed and suffered from drug related mental disorders and had misused alcohol (Brannan, 2006; Malik et al., 2012; Mattoo et al., 2013). Nevertheless, in the current study, most of the patients were single which was opposed to Mattoo et al (2013) because patients in the current study were young persons who were aged between 17 and 29. This is because in Myanmar, misuse of substances is significant health problem among youth (MOHS, 2017). According to Jensema & Kham (2016), amphetamine was the major illicit drug used by Myanmar people, especially the young, and this study confirmed this. In the sample, 70% of patients used amphetamine followed by heroin and cannabis and most of the people who used amphetamine were aged 19 to 24.

#### **5.7.2 Factors initiating drug use and reason for hospitalization**

Caregivers revealed the factors causing drug use disorders in their clients. These included peer pressure, family problems and abundance of drugs in the surrounding areas. These were not discussed in previous studies on caregiver burden except one, according to which one mother caregiver described that she is worried that her child was influenced by his peers to use drugs and that they gave the drugs to her child (Sibeko et al., 2016). Moreover, most caregivers took patients to the hospital because of patient's desire to get rid of drugs. Some patients decided to go the hospital because they could not afford money to buy drugs, regretted or felt sorry for the one who gave care to them. So, it may be possible for them to be free from drugs because of their own willingness. This finding of patient's desire to get off drugs in this study corroborates with finding from one study in which patients reported that they sought care at the center with the aim of free themselves from drugs and to get back to normal life (Haskell et al., 2016).

### 5.7.3 Perception of the hospital where treatment is received

According to the studies from Canada and Scotland, caregivers had a negative attitude towards service providers since they haven't got any information and education from them about their patients and they were excluded from the treatment regimen. They wanted to understand more about patients' problems and to know the treatment progress (Choate, 2011; Orr et al., 2013). Moreover, patients in Haskell et al (2016) study were stigmatized by the health professionals and sometimes they were being labelled as stupid. Nurses used to be less attentive in giving care to them. These findings are opposite to those in this study in which all caregivers had a positive opinion of the hospital environment, psychiatrists who took care of their patients and nurses. Caregivers showed heartfelt thanks to the service providers for encouraging and counselling patients to get back to the right way. They said health professionals were very benevolent, patient and had good intention towards patients and they felt that the hospital supported a lot. Therefore, it can be concluded that stigma from health professionals upon drug users is higher in Western countries compared to Myanmar. However, this is hospital-based study and there may be selection bias since the study chose the respondents by using purposeful sampling method.

### 5.7.4 Socioeconomic burden

In the literatures, financial burden was identified as a common burden, mainly in the developing countries especially in case of hospitalization given the high out-of-pocket health expenditures. Rare support from the government, no community level support and job limitations for caregivers exaggerated the financial crisis. Most of the caregivers were unemployed since taking care of a mentally ill person requires a lot of time and includes responsibilities such as cooking, bathing and visiting medical centres to access treatment which can contribute to productivity losses of caregivers (Doku et al., 2015; Isele et al., 2016; Mattoo et al., 2013; Shamsaei et al., 2015). Moreover, patients with mental disorders usually had no job and they were dependent on the family for their health expenditures and other expenditures as well to survive daily. Therefore, a person who took care of a

mentally ill person required more time, money and energy than they could afford and they faced financial burden due to direct medical and non-medical cost such as transport and medication cost during hospitalization of the patients (Iseselo et al., 2016).

In Myanmar, only 0.3 % of mental health expenditure was used for mental health. Since drug use disorders is a major subset of mental disorders, people need to pay out of pocket even in the public hospitals when they seek care for the drug addicts (Myint & Swe, 2016). In addition, the statutory financing system is very restricted and only 1% of population is covered by Social Security Scheme (Sein et al., 2014). So, all the financial burden related to drug use disorders is shifted to family members. According to the qualitative findings, all the respondents faced direct financial losses when patients were hospitalized. Expenses included bed charges, food expenses and transportation cost. Transportation charges was the major non-medical direct cost even for the caregivers who live in Yangon since the hospital was far away from city centre. They incurred transport cost whenever they went to the hospital to consult with a psychiatrist or to meet with their patients. This finding is consistent with Iseselo et al (2016) in which most of the caregivers faced difficulty in transportation since they lived far from hospital and some completely failed to come to hospital to collect medication for patients since they could not afford money for transportation. Moreover, in recent study, accommodation charges were also incurred by the caregivers who are not from Yangon. Therefore, qualitative data allowed to conclude that direct financial loss was higher in caregivers who live outside Yangon because of transportation and accommodation charges during hospitalization of patients and this is reinforced by quantitative analysis by showing higher stress level in people who are not from Yangon. In addition, caregivers also faced other direct non-medical cost related to drug using individuals such as legal fees, religious fees and compensation for accidents caused by drug use.

Mattoo et al (2013) stated that the financial burden was higher for unemployed caregivers. Although the current study did not include any scales to find the association between financial burden and socio demographic variables, based on the qualitative findings unemployed caregivers suffered a larger financial burden.

However, by contrast to other studies, most of the caregivers in this study were employed and so indirect cost of them was high when drug using individuals became hospitalized since they lost their daily income when they accompanied to the hospital with patients.

The findings from other studies revealed that social limitation was a common social burden in caregivers who took care of patients with severe mental illness. Caregivers became socially isolated as they spent most of their time for caring activities and had only little time left for socializing. Sometimes, they could not even give enough time to other family members and some also mentioned that they were exhausted trying to balance the needs of other family members and patients' needs (Choate, 2011; Doku et al., 2015; Iseleso et al., 2016).

Regarding social problems in this study, some caregivers said that they were socially isolated and that they could not participate in normal social activities. Some even couldn't go to church and the monastery due to having drug using individuals at home. Social limitations were more obvious in parent caregivers because parents were worried about their children and they devoted most of their time to them. So, sometimes other children within the family who were not drug addicts were neglected without any intention and this disturbed the family harmony. This confirms the findings of other qualitative studies in which giving not enough time to other family members had a negative impact on the family (Choate, 2011; Doku et al., 2015; Iseleso et al., 2016). Respondents revealed that unacceptable behavior of patients such as stealing family's property, physical and verbal abuse could increase family disruption. Misunderstandings between family members and patients could lead to families breaking up. This finding is highly consistent with one qualitative study in which stealing was a big problem of drug using individuals (Usher et al., 2007). This examined parental experience of having drug using adolescents and caregivers stated that stealing was a common behavioral problem with patients such as stealing items from family members, continued stealing even from outside of the family to get drugs and finally ended up in the jail (Usher et al., 2007).

### 5.7.5 Psychological burden

Sadness, anger, stress, guilt, shame and worry are the main subthemes of psychological burden found from the literature. Patients' hostile behaviors caused anger in caregivers and feelings of guilt, mainly reported by parent caregivers. They blamed themselves for letting their child become an addict. Caregivers became sad and depressed whenever they saw their beloved one with this unacceptable drug problems (Choudhary, 2016; Isele et al., 2016; Usher et al., 2007). In some cases, the physical health of caregivers also deteriorated because of strong emotional crisis and if the emotional feelings became severe, it could result in caregivers developing suicidal thought (Choudhary, 2016; Ishler et al., 2007). Additionally, parents were frightened when their child left home since they always thought that their child was going to run away from home, become even more involved in illegal affairs, use a drug overdose, commit suicide and otherwise damage themselves (Choate, 2011).

One study in India which analyzed the burden on caregivers of substance use disorders by using binomial logistic regression analysis showed that caregivers in rural areas who had low income reported severe psychological burden (Mattoo et al., 2013). In the current study, although caregiver, family and patient level variables were used to find the association with caregiver stress level, only the age of caregiver showed a significant association with caregiver's stress. Stress was higher in younger caregivers because they were not parents of the drug using individuals and they had other responsibilities such as job. The qualitative finding confirms this because some of younger caregivers showed disappointment and shame with patient's behavior. This finding is opposite with one study in which being a parent of the drug addict was a predictor of severe psychological burden in multiple regression analysis (Brannan, 2006). Caregivers who lived outside Yangon and unemployed mothers had higher stress level but it did not show any significance association.

Besides then, stress was more obvious in divorced and widowed caregivers rather than married even though it was statistically insignificant. This was because they shouldered all the responsibilities as they were household heads of the family. The qualitative findings also supported this because the feeling of helplessness was mainly revealed by the caregivers who were the only breadwinner in the family.

Moreover, stress level was higher in caregivers who doesn't have support from the family members related to caregiving activities. The qualitative data also reinforces the quantitative finding as caregivers stated that getting help from family members can relieve the financial difficulties and perceived stress somehow even though support is rare outside the family. This is similar with Ishler et al (2007) in which lack of family support predicted a greater economic burden in caregivers.

In addition, the mean value of caregiver stress level was also higher in caregivers whose patients had no income. This supports Malik et al (2012) who found that the lower the economic status of patients, the higher the caregiver's burden. This is because caregivers had to take full responsibility for patient's needs without any help from patients. According to some caregivers, their patients lost their job when they became addicted. Regarding the patient addiction severity measurement, patient variable which was patient income, showed a statistically significant association with patient addiction severity. The higher the patient income level, the greater the severity of addiction because they could spend more money on drugs. There was also significant positive correlation between caregiver's stress level and patient's severity in which had not been reported in previous studies yet. This positive correlation is also consistent with qualitative findings of this study since anger and embarrassment occurred in caregivers whose patients has greater behavioral problems, Patients who were severely addicted to drug have a greater chance of developing dual disorders, facing relapse and creating conflicts both inside and outside the family. It led to anger, worry and stress in caregivers.

The findings from the qualitative part of the current study revealed that having a negative relationship between caregiver and victim, misunderstanding and family problems could increase the distress in caregivers while a positive opinion of the victim by the caregiver obviously relieved anger and hopelessness in caregivers. According to the findings, worry, fear and grief were the most reported dimensions of psychological burden of caregivers when taking care of persons with drug use disorders. In one study in United States, it was reported that caregivers suffered worry and sadness rather than other emotional feelings such as guilty and shame (Brannan, 2006).

Most of the caregivers were afraid of legal problems such as seeing their patients in the prison and some expressed the fear of patients being killed or they would hurt by other people in the surrounding areas. Fear was mainly reported by female caregivers. A few caregivers indirectly showed the disappointment with existing drug laws and they were afraid of the police, the court of law and imprisonment. This finding reinforces the previous work on drug policy enforcement in Myanmar in which small scale drug users had been sentenced for several years and they were being treated badly in the prison (Jensema & Kham, 2016). In this research, authors described the harsh drug laws in Myanmar, which pushed the family and patients away from seeking treatment and participating in needle and syringe exchange programs. However, it could not be seen in the current study since the target population was caregivers of patients who could access treatment in the hospital.

Furthermore, when caregivers had to worry too much, physical health problems became negative consequences for them. This was also found in Choudhary (2016) in which caregivers reported insomnia, muscle weakness and hypertension as physical health problems they received when giving care. Most caregivers in this study expressed sadness because of seeing ill beloved one with problems and their hope for patient's future was shattered. This linkage between caregiver's grief and patient's substance use problems could be found in several studies (Choudhary, 2016; Shamsaei et al., 2015; Usher et al., 2007).

Grief, hopeless and guilt was incurred more in parent caregivers. There was also a relationship between socioeconomic and psychological burden. Feeling of guilt was more severe when the caregivers were poor. Caregivers thought that they could not support patients well and give enough time since they had to work to survive. This feeling of guilt could be found in two studies where caregivers regretted for neglect their patient and giving too much freedom to them (Choudhary, 2016; Lander et al., 2013). Moreover, patient's behavioral problems such as stealing and having conflicts with family members and their surroundings was the factors that promotes sadness and anger in caregivers. It supports other quantitative studies in

which behavioral problems of patients were predictors of caregiver' worry, shame and anger (Brannan, 2006; Ishler et al., 2007).

#### 5.7.6 Coping strategies

According to findings from the literature, praying and acceptance were found as active coping strategies of caregivers of patients with severe mental disorders. Adopting resolutions such as being more understanding and being a good friend of patients to reduce patients' behavioral problems and controlling them by threatening to cooperate with the police was used by caregivers of drug using adolescents (Cotton, 2015; Iseselo et al., 2016; Templeton et al., 2007). In two studies, one from India and one from Iran, taking cash loans from relatives and cutting other expenditures were regarded as the coping with economic burden (Doku et al., 2015; Shamsaei et al., 2015). Withdrawing from being a caregiver because of the feeling of hopelessness is another way of avoidant coping of caregivers, especially in case of parents of patients with drug use disorders (Choate, 2011; Usher et al., 2007).

According to the findings of this study, most of the respondents adopted the following coping strategies: religion, acceptance and planning while only some thought about withdrawing and consuming alcohol. This is strongly confirmed by two studies which analyzed the coping mechanisms of caregivers of patients with schizophrenia and breast cancer. It was found out that most of the caregivers used active coping while substance use and disengagement was hardly ever used by the caregivers (Kershaw et al., 2004; Ong et al., 2016). Since Myanmar is a Buddhist country, most of the caregivers believed in Buddha and only a few caregivers had other religious affiliations such as Islam and Christianity. However, almost all of the caregivers adopted religious coping since they regarded praying was a main way to escape from the trouble. Some caregivers in the current study also had the desire to send patients to a monastery after discharge from the hospital and this was also found in Ghana, where caregivers revealed that they sent their mentally ill relative to a prayer camp, which made them feel better (Doku et al., 2015).



Accepting and planning for the future were commonly occurring active coping methods of caregivers in Myanmar. They did not try to deny the problem. They tried to understand patients more, tried to have more knowledge about drug use disorders and tried to forgive their patient's aggressive behaviors. Even though there was no health education program in Myanmar regarding drug use disorders at the community level, caregivers watched news from social media, TV and listened from radio to understand more about drug use disorders and how to deal with them. A similar mechanism was reported in the study by Shamsaei et al (2015), according to which reading books to get knowledge about patient's mental disorder is a way to overcome a lack of information. Caregivers had several plans for their patient's future, tried to set limits and sometimes tried to stop patient's addiction or violence by threatening them.

In Myanmar, mental health expenditure was very low like in other developing countries and there is no insurance scheme to cover related health care cost (Sein et al., 2014). So, people need to pay out of pocket even in public hospitals and the financial burden was higher in caregivers of patients with drug use disorders. To cope with financial losses, caregivers borrowed money, sold assets, pawned assets and reduced other expenditures of the household. Withdrawal and substance use was regarded as avoidant coping in the current study. Only a few caregivers thought about disengaging from care giving which was opposite of the findings of Usher et al (2007), who stated that withdrawing was common in parents who endured adolescents' substance addiction. One study reported that substance use and withdrawal was the least common method of coping adopted by caregivers of patients with breast cancer and this is similar with the current study. Concealing patient problems, trying to ignore criticisms from surroundings and surviving with hope were other coping strategies of caregivers. Hope can also be seen in other two qualitative studies Doku et al (2015) and Iseselo et al (2016), according to which hope for miracle, hope for new treatment process and hope for support from self-help group were discussed as other forms of coping.

### 5.7.7 Barriers to coping

Stigma and lack of support were considered to be barriers to coping with different drawbacks while taking care of drug use individuals. Caregivers of mentally ill persons felt depressed when they saw the stigmatization on their patients and they expressed that even the close relatives made negative judgment to them. Sometimes, they tried to cut off the relationship with people surrounding them to hide the patient's drug problem as they were afraid of patients being stigmatized. Being blamed was more common for caregivers who were the mother of an addicted child (Choudhary, 2016; Iseselo et al., 2016; Usher et al., 2007). In India, Tanzania and Iran, because of high stigma and a lack of sympathy, there was no community level support for family members of patients with severe mental disorders and also no social and financial support from the government. In some cases, caregivers revealed that they were neglected by the family members and there was no support even at the household level (Doku et al., 2015; Iseselo et al., 2016).

Caregivers in the current study stated that not only patients but also caregivers were discriminated against by their surroundings and close relatives. According to the Burnet Institute, stigma is higher in Yangon than in other regions and states. One expert from the Burnet Institute answered the interview from the Irrawaddy news and he expressed that although the Burnet Institute tried to expand drop-in centres (needle and syringe exchange programs for injected drug users) in Yangon, it failed because people are afraid of having these centres in their surroundings (Paing, 2017). This is one of the reasons why support became rare at the community level. Stigma also pushed the drug addicted person who tried to withdraw from drugs to go back to the previous situation and to face a relapse (Jensema & Kham, 2016). Caregivers were looked down upon by other people in the surroundings when patients entered conflicts with them. Some parents were blamed and accused by their environment that the children did not grow up well because parents gratified their children's needs without guiding them. This confirms the finding from Australia where parents of substance abused individuals have to live with blame and endure criticisms from their neighbourhood (Usher et al., 2007). However, in this study, even though caregivers wanted to find emotional and

financial support from relatives, these did not allow caregivers and patients to interact with them as they were afraid of legal consequences and they did not want to accept addicts as their relative. As a result, caregivers became isolated and more helpless because of lack of support. So, it can be noted that stigma is common in Myanmar regarding drug use disorders.

According to the findings, in Myanmar, support from the government and other organizations in terms of financial and social support for family members of addicts seems to be lacking at various levels. Generally, there are only two mental health hospitals in Myanmar and most of the drug treatment centres in other states and regions are not well operated. Even though most of the caregivers received help from family members, no one mentioned that they are given any help from the government and the community, including health education programs about drug use disorders. Similar findings can be seen in rural Ghana in which caregivers of patients with mental disorders reported no financial and social support at the community level because of poverty, lack of sympathy and high stigma (Doku et al., 2015). In Tanzania, caregivers of mentally ill persons hoped for support for their patients and also for them from self-help groups in order to improve their well-being (Iseselo et al., 2016). By contrast, in Myanmar, among the caregivers who discussed about the support, half of them even did not even hope for any financial support from the community or the government because they thought it is shameful to speak out loud about the drug problems and it does not concern the public since this issue is sensitive and not widespread. This was opposite with other studies discussed above since most of the caregivers hoped for support.

However, a few caregivers emphasized that they wanted the government to adjust its drug policy again since harsh punishments destroyed and degenerated the lives of many drug users. This is also supported by Jensema & Kham (2016) in which experts said that punishment alone cannot mitigate drug problems in Myanmar. The existing 1993 Narcotic Drugs and Psychotropic Substances Law is so tough and if a person is found with even small amount of illegal drug, they are being sentenced for at least five to ten years (Jensema & Kham, 2016).

## CHAPTER VI

### CONCLUSION AND RECOMMENDATION

There is no published study in Myanmar which analyzes caregivers' burden and coping strategies of caregivers who take care of patients with drug use disorders even though it is very challenging problem. Caregivers' burden cannot be mitigated without exactly knowing what they are actually suffering from, how they solve their problems and what they do to cope with it. Therefore, this study was conducted with the aim of examining caregiver burden and their coping strategies. Moreover, the barriers to coping of caregivers were explored to understand what the barriers were in the finding of financial, social and emotional support.

A mixed methods research design was chosen and applied to all stages of the study including research questions formation, data collection analysis and interpretation. The descriptive statistics were used to interpret socio-demographic characteristics of caregivers, family and patients while independent samples t-test and one-way ANOVA was applied to find the association between the scales included in the study (CSS and ASI) and different independent variables. To find the relationship between two scales, Pearson's correlation coefficient was calculated. For the qualitative data analysis, in-depth interviews were conducted with 30 primary informal caregivers who visited Yangon Mental Health Hospital and fulfilled the inclusion and exclusion criteria, between May and June 2019. Framework analysis method was used to analyze the collected data and all stages of the data analysis were done by using Atlas.ti software by the researcher.

According to the quantitative data analysis, it was found that most of the caregivers were female and parents of drug using patients. Moreover, most of the patients in the sample were male and young adults. They mostly used amphetamines, followed by heroin and cannabis (marijuana). The qualitative findings help to understand the causes of drug use and the abundance of drugs in patients' surroundings emerged as one of the main factor, despite the fact that the drug law in Myanmar is very strict. It is clear that just prisoning and arrests cannot mitigate drug

use problems in Myanmar. According to the 1993 Narcotic Drugs and Psychotropic Substances Law, a person is sentenced to about 5 to 10 years in prison if he or she is found to possess only a small amount of illicit drugs. However, most large scale drug traffickers have remained uncovered and managed to escape (Jensema & Kham, 2016), which a few respondents from this study also expressed. Therefore, they would like to see a change in the response to drug problems in Myanmar such as reforming the existing drug policy by cooperating with international organizations and by strengthening evidence-based research concerning drug use disorders. Myanmar drug policy should be suggested to reform by emphasizing more on health problems suffered by the drug users rather than severe punishment and prisoning. Moreover, peer pressure was another important factor that led adolescents to try drugs. Therefore, it is essential to consider substance use disorders as a part of a school health promotion and prevention program so that students know about the disadvantages and dangers of illicit drugs, especially since drug use problems are mostly encountered by young adults.

Most of the caregivers revealed that they sought care at the mental hospital for their patients because of patient's own will to get rid of drugs. For those who forced patients to go to the hospital, they learned about the hospital from social media, TV and radio. This confirms that the media can help a lot and more health education or educational short films about drug use disorders should be provided through media to receive more information and knowledge regarding drug use disorders. There is also evidence in the literature that getting health education can improve the coping skills of caregivers to more optimistic way. In England, before interviewing to caretakers of substance using patients, they have been given psycho social intervention which last about 12 weeks. After receiving the health education, most of them reported that these intervention could affect them positively to change their coping style to better way (Templeton et al., 2007).

According to the findings discussed in previous chapter, most of the caregivers faced financial losses such as bed charges, food expenses, transportation charges and accommodation charges for hospitalized patients while some encountered non-medical cost such as legal fees, religious fees related to drug use disorders and

compensation for injuries and damages inflicted on others. Other reasons to increase direct medical cost included health care cost for dual disorders and treatment for relapse. What is more, they suffered from indirect costs as well since their daily income were gone when the patient being hospitalized. Feeling of helplessness was more obvious in caregivers who were the main earners of the family. To cope with financial losses, caregivers had to sell their belongings, pawned assets, borrowed money from relatives and others and cut other expenditures (Doku et al., 2015; Iselelo et al., 2016). These were also the coping strategies of caregivers in Myanmar. Income loss was higher in caregivers who were employed and the financial burden was more significant in caregivers who were unemployed. In Myanmar, political commitment to pay more attention to mental and substance use disorder seems to lacking because of high stigma and the absence of evidence based research. Meanwhile, it is of vital importance to consider the substance use disorders as one of the major challenges in Myanmar and the government should increase mental health expenditures to decrease family financial burden since drug use disorder is one of the mental disorders. The establishment of programs that support family members such as home-based occupational chances for caregivers who devoted most of their time to patients at home should be develop as soon as possible to relieve the financial burden of the family.

The transportation charges was one of the direct non-medical cost encountered especially by the caregivers who were not from Yangon. This is because in Myanmar, most of the drug users sought care at Yangon Mental Health Hospital. Also according to the personal conversation with one expert from the Mental Health Hospital, drug users and their family usually seek care at the mental health hospital rather than DTCs. He said, “Because of the reputation of hospital and fear of stigma to go to DTCs in their surroundings, most caregivers come to the hospital to seek care for their patients. Moreover, there is lack of facility and labor force in DTCs and drug users especially who had psychiatric comorbidity use the services provided form the hospital as the main source” (phone interview on 19<sup>th</sup> June). However, there are only two mental health hospitals in Myanmar and the Mental Health Hospital (Mandalay) has only 200 beds. Mental hospitals should be developed and extended

throughout the country to be easily accessible by drug users from other states and regions. It would also be better to offer temporary residence for the caregivers who are from areas outside of Yangon to reduce accommodation expenses when they accompany the patient to the hospital. Moreover, as Myanmar is on the way to achieving UHC by 2030, drug services should be included in the benefit package to significantly decrease out of pocket health expenditure of the family.

What is more, caregivers stated that job limitation is the major challenge encountered by a few patients. Even though patients had a desire to work they could not find a job once they managed to overcome their addiction. In a previous study which explored the experiences of imprisoned drug users qualitatively in Myanmar, it was shown that drug users lost the job because of drug use problems and faced limited job opportunities after having been released from the prison. One said that his family had to pay money to the police during his imprisonment (Jensema & Kham, 2016). In this study, legal fees were also significant and sometimes caregivers had to pay under the table to the police since they were afraid of harsh punishments to their clients. Therefore, in Myanmar, it is very important to change the existing drug policy and to strengthen job opportunities for drug users, who have already withdrawn from drugs to reduce their financial hardship. The government should implement a campaign against stigma to change the public opinion about drug users. It is also recommended to extend the services and quality of existing youth correction centers and rehabilitation centers since the training and education from these centers is the only way for drug users not to use drugs again and to change their mind set in a good way.

Most of the caregivers tried to solve the difficulties they faced by doing religious activities such as praying and fasting, accepting patients' behavior and condition, planning for the future, planning to control patients' aggressiveness by threatening to inform the police and reading news from social media. Financial coping was also adopted by the majority of caregivers. Avoidant coping such as disengaging from caring activities and substance use, however, were seldom used by caregivers.

Stigma from surroundings was also identified as a major barrier to active coping in Myanmar and caregivers were even neglected by their relatives. If they face intense barrier, they will move towards avoidant coping instead of active one and it may lead to develop further problems. There is evidence in the literature that caregivers who adopted avoidant coping had lower mental quality of life (Kershaw et al., 2004). So, the government should carefully consider about how to reduce the barriers to active coping to pull the people who used avoidant coping back to active coping. Campaigns to reduce stigma towards patients with drug use disorders and their families should cover the general population. There is also an example of successful campaign against stigma in developed countries. For example, in England, after establishing of “Time to change” campaign with the aim to reduce stigma related to mental disorders, the stigma from surrounding reduced significantly (Henderson, Evans-Lacko, & Thomicroft, 2013). Moreover, since majority of patients cited religious coping, it is better to establish religious peer groups within the community for the caregivers to actively cope with suffering burden.

Yet, all respondents had a positive opinion of the public hospital and they stated that they were very thankful to the service providers such as psychiatrists, nurses and other staff. They said that psychiatrics were very patient with their patients, explained the disadvantages of drugs well and provided regular counselling to addicts. So, the government should provide more mental health hospitals by cooperating with other local and international organizations in different regions and states to be easily accessible. It is also recommended to extend the services and quality of existing drug treatment centers and drop in centers. These were also important points of service for drug users to be able to seek immediate care.



## CHAPTER VII

### LIMITATION

Since the study was conducted only in Yangon Mental Health Hospital and it could not access the burden of caregivers of drug users who are in the community and who are caregivers of imprisoned drug users, whose burden is most likely even larger. Although this research objective is to explore caregiver burden, coping strategies and barriers to coping using a mixed methods approach, the sample size of 30 caregivers was too small and it could not be representative. In the current study, it included two scales, addiction severity index and caregiver stress scale, however, both scales have not been tested for reliability and validity in Myanmar. So, this is one of the major limitations of the study since there is no evidence that these two scales can be adaptable in Myanmar context. Furthermore, the addiction severity index scale is a patient rated scale. However, in this study, since patients were not included, the severity of patients was rated by caregivers and the responses may be biased.

Another major limitation was the conceptual framework of the current study since it was empirically driven instead of adopting theoretical model related to impact of caregiving. Additionally, all respondents in this study revealed their positive opinion upon the hospital, however, this may be because the current study is hospital-based. Moreover, since the study used purposeful sampling method, caregivers were selected according to the suggestion of psychiatrists and there may be selection bias. Last but not the least, the interviews with respondents and the data transcription and analysis was only performed by the researcher and there may also be unintended bias. Since the interview was performed by using Myanmar language, research had to translate all to English, so translation error for some quotation is possible.

## CHAPTER VIII

### POSSIBLE EXTENSION OF THE STUDY

In this study, conceptual framework was constructed by using deductive approach which means it is based on the evidence from the existing literature. So, in the future, there should be the study which framework is based upon the theoretical model. Secondly, the sample size was too small in the current study because of time limitation and further research should be conducted, with larger sample size to find more supportive evidence for the policy implication. Regarding coping, since the study only used qualitative approach to understand the coping strategies of caregivers of patients with drug use disorders, it is recommended to use Brief COPE scale for the researchers who might want to work on the same topic in order to be complement and to explore the strategic coping mechanisms of caregivers more specifically.

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## APPENDIX

### Appendix 1

#### Questionnaires and topic guide (English version)

#### Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies

##### 1. Introduction

Hello, my name is Khin Zar Khaing Thein and I am studying MSc in Health Economics and Health Care Management in Chulalongkorn University Thailand. I'm conducting research on "Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies".

I would like to ask some questions to help me understand socioeconomic burden, psychological burden, coping strategies and barriers of coping for caregivers of patients with drug use disorders in Myanmar. This research has obtained permission from institutional review board of the Defence Services Medical Research Centre (DSMRC).

The discussion will take about 1 hour. You can decide whether or not you want to speak to me about this.

No one will know your name. You can decide whether or not to answer any questions. If you don't want to answer a question, please tell me. I want to learn from you. There are no right or wrong answers to these questions and your answer will not in affect your relationship with me or with the hospital.

Do you have any questions? Do you agree to participate in the discussion?

## 2. Socio-demographic characteristics of caregiver and family

No	Question	Response	Remark
	Date of interview		
	Respondent's code		
1	Age (age of completed years)	----- years	
2	Gender	Male Female	
3	Marital status	Single Married Divorced Widow Separated	
4	Number of children	-----	
5	Anyone in the family members help with caregiving (If Yes, please state how many people)	Yes No -----	
6	Area of residence	Yangon Others -----	
7	Ethnicity	Bamar Others -----	
8	Religion	Buddhism Christianity Islam Hinduism Others -----	

9	Education	Illiterate Only read and write Primary school passed Middle school passed High school passed University Graduate	
10	Occupation	Dependent Own business Government staff Non-government staff Others -----	
11	Duration of giving care (per day)		
12	Income (Own)/ month	-----MMK	
13	Average family income/ month	-----MMK	
14	Average expenditure/month	Food -----MMK Non-food ----- MMK	
15	Position in family members	Household head Housewife Family member	
16	Types of family	Nuclear Extended Others -----	

17	Education of household head	Illiterate Only read and write Primary school passed Middle school passed High school passed University Graduate	
18	Occupation of household head	Dependent Own business Government staff Non-government staff Others -----	
19	Relationship with patient	Parent Son/daughter Sibling Others -----	

### 3. Socio-demographic characteristics of patient

No	Question	Response	Remark
	Date of interview		
	Respondent's code		
1	Age (age of completed years)	----- years	
2	Gender	Male Female	
3	Marital status	Single Married Divorced Widow Separated	
4	Number of children	-----	
5	Area of residence	Yangon Others -----	
6	Ethnicity	Bamar Others -----	
7	Religion	Buddhism Christianity Islam Hinduism Others	
8	Education	Illiterate Only read and write Primary school passed Middle school passed High school passed Undergraduate Graduate	

9	Occupation	Dependent Own business Government staff Non-government staff Others -----	
10	Income (Patient)/ month	-----MMK	
11	Position in family members	Household head Housewife Family member	
12	Type of drug he/she use	Amphetamine Heroin Others-----	
13	Duration of use	-----	
14	How often they use (per week)	-----	
15	Any misuse with other substances (If Yes, please state the name/s)	Yes No	
16	Any relapse (If Yes, please state how many times)	Yes No -----	
17	Any dual disorders (If Yes, please state the name)	Yes No -----	

#### 4. Addiction Severity Index

No	Questions	Scale rating
1	Has your patient been arrested and charged with any legal problems?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
2	Does he/she experience drug overdose?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
3	Has he/she been treated for any psychological problems?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
4	Does he/she experience serious depression? (Sadness, hopelessness, loss of interest, difficulty with daily functioning)	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
5	Does he/she aggressive with surrounding?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
6	Does he/she experience hallucination?	0 - Not at all 1 - Slightly 2 - Moderately

		3- Considerably 4 - Extremely
7	Does he/she has trouble in understanding, concentration or remembering?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
8	Does he/she has suicidal thoughts?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
9	Is he/she experienced with serious anxious or tension?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely
10	Does he/she think to use drug every time in a day?	0 - Not at all 1 - Slightly 2 - Moderately 3- Considerably 4 - Extremely

### 5. Caregiver Stress Scale

No	Questions	Answers	Code
1	I am happy in my role as a caregiver.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>



2	There is little or nothing I wouldn't do for my patient if it was necessary.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
3	Caring for my patient sometimes takes more time and energy than I have to give.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
4	I sometimes worry whether I am doing enough for my patient.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
5	I feel close to my patient.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
6	I enjoy spending time with my patient.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
7	Having an addicted patient gives me a more certain and optimistic view for the future.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>

8	My patient is an important source of affection for me.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input data-bbox="1267 344 1342 405" type="checkbox"/>
9	The major source of stress in my life is my patient's addiction.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input data-bbox="1267 629 1342 689" type="checkbox"/>
10	Having an addicted patient leaves little time and flexibility in my life.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input data-bbox="1267 913 1342 974" type="checkbox"/>
11	Having an addicted patient has been a financial burden.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input data-bbox="1267 1198 1342 1258" type="checkbox"/>
12	It is difficult to balance different responsibilities because of my patient's addiction.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input data-bbox="1267 1482 1342 1543" type="checkbox"/>
13	The behavior of my addicted patient is often embarrassing or stressful to me.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input data-bbox="1267 1767 1342 1827" type="checkbox"/>

14	If I had it to do over again, I might decide not to have a drug use patient.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
15	I feel overwhelmed by the responsibility of being a primary caregiver.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
16	Having an addicted patient has meant having too few choices and too little control over my life.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
17	I am satisfied as a primary caregiver.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>
18	I find my patient enjoyable.	1. Strongly disagree 2. Disagree 3. Undecided 4. Agree 5. Strongly Agree	<input type="checkbox"/>

## Topic guide

### In-depth-interviews with caregivers of patients with drug use disorders

I would also like to ask your permission to audio-record our discussion. The recording will help me ensure that I don't miss important things you say. It is difficult to record everything accurately using notes only. The recording will not include your name and will only be used by me. All the recorded audios and field notes will be stated only in the way that the researcher can link the responses with persons. It will be deleted one year after the research is completed.

#### 1. Psychological burden

- How much sadness do you feel as a result of your patient's emotional or behavioral problem?
  - *Hopelessness, helplessness, seeing ill beloved one with disorders*
- Do you feel angry because of interpersonal problems between you and patient?
- Are you worrying about your patient's future and family's future? Could you please elaborate?
  - *sexual abuse, accidents, family's well-being*
- What kind of fear do u suffer due to patient's drug use problem?
  - *legal problems, suicide*
- Is there anything that u feel guilty concerning your patient? If so, please explain it.
  - *because of forcing patient to leave home, because of abusing verbally to patient, because of concealing his or her drug use problems*

#### 2. Socioeconomic burden

##### 2.1 Financial burden

- How much extent of financial loss do you suffer due to patient's illness?

- *Hospitalization fees, Medication fees, Transportation fees(per month), money used to buy drugs, legal cost, food, religious activities*

## 2.2 Productivity loss

- Do you suffer any income loss due to patient's illness? Would you elaborate it? Please describe your loss and also your patient loss?
  - *lost job, Unable to get job, time loss, selling land or business*

## 2.3 Social limitation

- Do you feel any type of social isolation as a result of your patient's drug use disorders?
  - *Exclude from social activities due to interruption of personal time, Patients made conflicts with neighborhood, Cut off relationship with friends or relatives to conceal patients' drug use problems, Blaming*

## 2.4 Negative impact on family structure

- How does drug use individual affect on family well-being and harmonization?
  - *Disruption of family activities, any negative effect on family members (in terms of loss of job, education, mentally disrupted), neglect other family members due to time devotion towards patients, conflict each other*

## 3. Coping mechanism

How do u cope with financial burden, social isolation and emotional disturbance?

- What kind of religious coping do you use?
  - *Pray more than before, go to spirit*
- What kind of financial coping do you use?
  - *Reducing other expenditure (food, clothing, education, health), selling assets, pawning, Loan from relatives and friends, loan from institution*
- What kind of social support do you receive?
  - *Help from family and relatives, help from charitable organization, help form government*

- Do you accept your patient drug used conditions? How?
  - *stop shouting and blaming, reduce over-controlling, being understandable towards the problems*
- Have you ever planned anything to cope with your drug use patient's condition?
  - *To cooperate with police, to read books to know more about patient disorders*
- Have you ever thought to withdraw from caregiving or do you withdraw from caregiving?
- Have you tried to use any substance to escape from the problem and sleepless night?

#### 4. Barrier of coping

##### 4.1 Lack of support (financial and social)

- How much support do u get from inside and outside of your family?
  - *Receiving cash/loans from relatives, any support from Government, any support from external donation, social support (health education), appreciation from patient, family members and friends for your caregiving*

##### 4.2 Stigma

Have you ever experience with any negative opinion form environment and health professional? How?

- *effect of stigma and discrimination upon patients or you*

Is there anything you would like to add or do you have any questions regarding all the questions you have to respond above. Thank you very much for your actively participation in this research. I appreciate your participation. Thank you.

Appendix 2

Questionnaire and topic guide (Myanmar version)

မူးယစ်ဆေးစွဲနေသူများ၏ စောင့်ရှောက်ပေးနေသူများအားမေးမြန်းသည့် မေးခွန်းလွှာ

၁။ မိတ်ဆက်ခြင်း

ကျွန်မ ဒေါ်ခင်စာခိုင်သိန်း(မှတ်ပုံတင်အမှတ်-၁၂/လသယ(နိုင်) ၀၆၇၂၈၅) သည် ထိုင်းနိုင်ငံ၊ ဘန်ကောက်မြို့ရှိ ချူလာလောင်ကွန်းတက္ကသိုလ်တွင် ကျန်းမာရေးစီမံခန့်ခွဲမှုနှင့်ဆိုင်သော မဟာဘွဲ့သင်တန်းကို တက်ရောက်နေပါသည်။ ဤသုတေသနသည် မူးယစ်ဆေးစွဲဝေဒနာ သည်များအား စောင့်ရှောက်နေသူများ တွေ့ကြုံခံစားနေရသော အခက်အခဲများ၊ စိတ်ပိုင်းဆိုင်ရာ ထိခိုက်ခံစားမှုများ နှင့် အဆိုပါအခက်အခဲများကို မည်သို့မည်ပုံ ဖြေရှင်းနေရသည်ကို လေ့လာမည့် သုတေသန ဖြစ်ပါသည်။

ကျွန်မသည် စောင့်ရှောက်သူများခံစားနေရသော ငွေရေးကြေးရေးဆိုင်ရာ အခက်အခဲများ၊ လူမှုရေးပြဿနာများ၊ စိတ်ပိုင်းဆိုင်ရာထိခိုက်မှုများ၊ အခက်အခဲဖြေရှင်းသည့် နည်းလမ်းများနှင့် အခက်အခဲဖြေရှင်းရာတွင် အဟန့်အတားဖြစ်စေသော အကြောင်းအရာများကို မေးမြန်းသွားမည် ဖြစ်ပါသည်။ ဆွေးနွေးခြင်းသည် တစ်နာရီခန့်ကြာမြင့်မည် ဖြစ်ပါသည်။ သင်၏အမည်ကို ထည့်သွင်းဖော်ပြမည်မဟုတ်ပါ။ ဤမေးခွန်းများကိုအတွက် အဖြေကို မှန်သည်၊မှားသည်ဟု မသတ်မှတ်ထားပါ။ မဖြေချင်သောမေးခွန်းများကိုလည်း ကျော်သွားခွင့်ရှိပါသည်။ သင်၏အဖြေသည် သင်နှင့်သင်၏ လူနာပေါ်တွင်လည်း ထိခိုက်မှုတစ်စုံတစ်ရာရှိမည် မဟုတ်ပါ။

အထက်ဖော်ပြပါ အကြောင်းအရာများနှင့် ပတ်သက်၍ သင့်၌ မေးမြန်းစရာရှိပါသလား။ ဤ သုတေသနတွင် ပါဝင်ရန် သဘောတူပါသလား။



၂။ စောင့်ရှောက်သူနှင့် မိသားစု၏ ယေဘုယျအချက်အလက်များ

စဉ်	မေးခွန်း	အဖြေ
	နေ့စွဲ	
	ဖြေဆိုသူအညွှန်းနံပါတ်	
၁။	အသက် (ပြည့်ပြီးအသက်)	----- နှစ်
၂။	ကျား/မ	ကျား မ
၃။	အိမ်ထောင်ရေးအခြေအနေ	အပျို/လူပျို အိမ်ထောင်ရှိ အိမ်ထောင်ကွဲ မုဆိုးဖို/မ ကွဲကွာ
၄။	သားသမီးအရေအတွက်	-----
၅။	လူနာအား အဓိကတာဝန်ယူစောင့်ရှောက်ရသောသူ	ဟုတ်သည် မဟုတ်ပါ
၆။	မိသားစုထဲတွင် ပတ်သက်၍ ကူညီမည့်သူ (ရှိသည်ဟု ဖော်ပြပေးပါ) (ရှိသည်ဟု ဖော်ပြလျှင် လူအရေအတွက် ဖော်ပြပေးပါ)	ရှိသည် မရှိပါ
၇။	အခကြေးငွေယူ၍ လူနာအားစောင့်ရှောက်သူ	ဟုတ်သည် မဟုတ်ပါ
၈။	နေထိုင်သည့်နေရာ	ရန်ကုန် အခြား: -----
၉။	လူမျိုး	ဗမာ အခြား: -----
၁၀။	ကိုးကွယ်သည့်ဘာသာ	ဗုဒ္ဓဘာသာ ခရစ်ယာန် အစ္စလာမ် ဟိန္ဒူ အခြား: -----
၁၁။	အမြင့်ဆုံးပညာအရည်အချင်း	စာမတတ် ရေးတတ်/ဖတ်တတ် မူလတန်းအောင် အလယ်တန်းအောင် အထက်တန်းအောင် တက္ကသိုလ် ဘွဲ့ရ



၁၂။	အလုပ်အကိုင်	မိမိ ကိုယ်ပိုင်လုပ်ငန်း အစိုးရဝန်ထမ်း အပြင်ဝန်ထမ်း အခြား: -----
၁၃။	လူနာအားစောင့်ရှောက်ပေးရသည့်အချိန် တစ်ရက်စာ	
၁၄။	သင်၏ဝင်ငွေ (တစ်လစာ)	----- (ကျပ်)
၁၅။	ပျမ်းမျှမိသားစုဝင်ငွေ (တစ်လစာ)	----- (ကျပ်)
၁၆။	ပျမ်းမျှမိသားစုအသုံးစရိတ် (တစ်လစာ)	အစားအသောက် ----(ကျပ်) အစားအသောက်မှလွဲ၍အခြား- ----(ကျပ်)
၁၇။	မိသားစုထဲတွင်သင်၏ ကဏ္ဍ	အိမ်ထောင်ဦးစီး အိမ်ရှင်မ မိသားစုဝင်များ
၁၈။	မိသားစုပုံစံ	မိသားစုတစ်စု စုပေါင်းမိသားစု အခြား: -----
၁၉။	အိမ်ထောင်ဦးစီး၏ ပညာအရည်အချင်း	စာမတတ် ရေးတတ်/ဖတ်တတ် မူလတန်းအောင် အလယ်တန်းအောင် အထက်တန်းအောင် တက္ကသိုလ် ဘွဲ့ရ
၂၀။	အိမ်ထောင်ဦးစီး၏ အလုပ်အကိုင်	မိမိ ကိုယ်ပိုင်လုပ်ငန်း အစိုးရဝန်ထမ်း အပြင်ဝန်ထမ်း အခြား: -----
၂၁။	လူနာနှင့် တော်စပ်ပုံ	မိဘ သားသမီး မောင်နှမ/ညီအစ်မ/ညီအစ်ကို အခြား: -----

၃။ လူနာ၏ ယေဘုယျအချက်အလက်များ

စဉ်	မေးခွန်း	အဖြေ
	နေ့စွဲ	
	ဖြေဆိုသူအညွှန်းနံပါတ်	
၁။	အသက် (ပြည့်ပြီးအသက်)	----- နှစ်
၂။	ကျား/မ	ကျား မ
၃။	အိမ်ထောင်ရေးအခြေအနေ	အပျို/ လူပျို အိမ်ထောင်ရှိ အိမ်ထောင်ကွဲ မုဆိုးဖို/မ ကွဲကွာ
၄။	သားသမီးအရေအတွက်	-----
၅။	နေထိုင်သည့်နေရာ	ရန်ကုန် အခြား: -----
၆။	လူမျိုး	ဗမာ အခြား: -----
၇။	ကိုးကွယ်သည့်ဘာသာ	ဗုဒ္ဓဘာသာ ခရစ်ယာန် အစ္စလာမ် ဟိန္ဒူ အခြား: -----
၈။	အမြင့်ဆုံးပညာအရည်အချင်း	စာမတတ် ရေးတတ်/ဖတ်တတ် မူလတန်းအောင် အလယ်တန်းအောင် အထက်တန်းအောင် တက္ကသိုလ် ဘွဲ့ရ
၉။	အလုပ်အကိုင်	မိမိ ကိုယ်ပိုင်လုပ်ငန်း အစိုးရဝန်ထမ်း အပြင်ဝန်ထမ်း အခြား: -----
၁၀။	လူနာ၏ဝင်ငွေ (တစ်လစာ)	----- (ကျပ်)

၁၁။	မိသားစုထဲတွင် လူနာ၏ ကဏ္ဍ	အိမ်ထောင်ဦးစီး အိမ်ရှင်မ မိသားစုဝင်များ
၁၂။	လူနာအသုံးပြုသော မူးယစ်ဆေးအမည်	အိမ်ဖက်တမင်း ဘိန်းဖြူ (ဟီရီးအင်း) အခြား -----
၁၃။	မူးယစ်ဆေးသုံးစွဲမှုသက်တမ်း	-----
၁၄။	အသုံးပြုသည့်အကြိမ်အရေအတွက် (တစ်ပတ်အတွင်း)	-----
၁၅။	အခြားမူးယစ်ဆေးသော ဆေးဝါးများနှင့် တွဲဖက်သုံးစွဲခြင်း (ရှိသည်ဟု ဖြေဆိုလျှင် အမည်ဖော်ပြပေးပါ)	ရှိသည် မရှိပါ -----
၁၆။	မူးယစ်ဆေးဖြတ်ပြီးသော်လည်း ပြန်လည်သုံးစွဲခြင်း (ရှိသည်ဟု ဖြေဆိုလျှင်တစ်ကြိမ်အရေအတွက် ဖော်ပြပေးပါ)	ရှိသည် မရှိပါ -----
၁၇။	မူးယစ်ဆေးသုံးစွဲမှုနှင့် ပတ်သက်သည့်အခြားသော ရောဂါ များ (ရှိသည်ဟု ဖြေဆိုလျှင်အမည် ဖော်ပြပေးပါ)	ရှိသည် မရှိပါ -----

၄။ မူးယစ်ဆေးစွဲမှု ပြင်းထန်မှုအခြေအနေအား စစ်ဆေးသည့်မေးခွန်းလွှာ

စဉ်	မေးခွန်းများ	မှတ်ချက်
၁။	လူနာသည် ဥပဒေရေးရာ ပြဿနာတစ်ခုခုနှင့် ငြိစွန်း၍ အကျဉ်းကျခံရဖူးပါသလား။	၀ - မပြင်းထန်ပါ ၁ - နည်းနည်းပြင်းထန်သည် ၂ - အတောင်အသင့်ပြင်းထန်သည် ၃ - ပိုမိုပြင်းထန်သည် ၄ - အပြင်းထန်ဆုံးဖြစ်သည်
၂။	လူနာသည် ဆေးအလွန်အကျွံသုံးစွဲခြင်းကြောင့် ရှောင် ရဖူးပါသလား။	၀ - မပြင်းထန်ပါ ၁ - နည်းနည်းပြင်းထန်သည် ၂ - အတောင်အသင့်ပြင်းထန်သည် ၃ - ပိုမိုပြင်းထန်သည် ၄ - အပြင်းထန်ဆုံးဖြစ်သည်
၃။	လူနာသည် စိတ်ကျန်းမာရေးပြဿနာများကြောင့် ကုသမှုခံယူဖူးပါသလား။	၀ - မပြင်းထန်ပါ ၁ - နည်းနည်းပြင်းထန်သည် ၂ - အတောင်အသင့်ပြင်းထန်သည်

		<ul style="list-style-type: none"> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>
၄။	လူနာသည် အပြင်းအထန် စိတ်ဓာတ်ကျခြင်း ရှိပါသလား။	<ul style="list-style-type: none"> <li>၀ - မပြင်းထန်းပါ</li> <li>၁ - နည်းနည်းပြင်းထန်းသည်</li> <li>၂ - အတောင်အသင့်ပြင်းထန်သည်</li> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>
၅။	လူနာသည် ပတ်ဝန်းကျင်အား ရန်လိုခြင်း၊ ကြမ်းတမ်းစွာ ပြုမူခြင်း ရှိပါသလား။	<ul style="list-style-type: none"> <li>၀ - မပြင်းထန်းပါ</li> <li>၁ - နည်းနည်းပြင်းထန်းသည်</li> <li>၂ - အတောင်အသင့်ပြင်းထန်သည်</li> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>
၆။	လူနာသည် ထင်ယောင်ထင်မှား ဖြစ်ခြင်းရှိပါ သလား။ (နားထဲတွင်အသံများကြားနေခြင်း၊ ပုံရိပ်များ မြင်နေခြင်း)	<ul style="list-style-type: none"> <li>၀ - မပြင်းထန်းပါ</li> <li>၁ - နည်းနည်းပြင်းထန်းသည်</li> <li>၂ - အတောင်အသင့်ပြင်းထန်သည်</li> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>
၇။	လူနာသည်နားလည်နိုင်စွမ်း၊ မှတ်မိနိုင်စွမ်း၊ အာရုံစိုက်နိုင်စွမ်းနှင့် ပတ်သတ်၍ အခက်အခဲရှိပါ သလား။	<ul style="list-style-type: none"> <li>၀ - မပြင်းထန်းပါ</li> <li>၁ - နည်းနည်းပြင်းထန်းသည်</li> <li>၂ - အတောင်အသင့်ပြင်းထန်သည်</li> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>
၈။	လူနာသည် ကိုယ်ကိုကိုယ်သတ်သေချင်စိတ် ရှိပါသ လား။	<ul style="list-style-type: none"> <li>၀ - မပြင်းထန်းပါ</li> <li>၁ - နည်းနည်းပြင်းထန်းသည်</li> <li>၂ - အတောင်အသင့်ပြင်းထန်သည်</li> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>
၉။	လူနာသည် အလွန်အမင်း စိတ်ပူပန်ခြင်း၊ စိုးရိမ်လွန်ခြင်းများ ရှိပါသလား။	<ul style="list-style-type: none"> <li>၀ - မပြင်းထန်းပါ</li> <li>၁ - နည်းနည်းပြင်းထန်းသည်</li> <li>၂ - အတောင်အသင့်ပြင်းထန်သည်</li> <li>၃ - ပိုမိုပြင်းထန်သည်</li> <li>၄ - အပြင်းထန်းဆုံးဖြစ်သည်</li> </ul>

၁၀။	လူနာသည် တစ်နေ့လုံး ဆေးသုံးချင်နေသည့် စိတ်ရှိပါသလား။	၀ - မပြင်းထန်းပါ ၁ - နည်းနည်းပြင်းထန်းသည် ၂ - အတောင်အသင့်ပြင်းထန်းသည် ၃ - ပိုမိုပြင်းထန်းသည် ၄ - အပြင်းထန်းဆုံးဖြစ်သည်
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၅။ စောင့်ရှောက်သူ၏ စိတ်ဖိစီးမှုအခြေအနေအား စစ်ဆေးသည့်မေးခွန်းလွှာ

စဉ်	မေးခွန်း	အဖြေ	ကုဒ်
၁။	လူနာ၏စောင့်ရှောက်သူဖြစ်ရသည်ကို ပျော်ပါသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၂။	လူနာ၏လိုအပ်ချက်များနှင့်ပတ်သက်၍ မလုပ်ပေး နိုင်သည်မှာ မရှိသလောက် နည်းပါးသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၃။	လူနာအားစောင့်ရှောက်ပေးရန်အချိန်နှင့်စွမ်းအားသည် ယခုလုပ်ပေးနိုင်သည်ထက် ပိုမိုလိုအပ်သည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၄။	ကျွန်ုပ်၏စောင့်ရှောက်မှုသည်လူနာအတွက်လုံလောက်ရဲ့လားဟု တစ်ခါတစ်လေစိုးရိမ်မိသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၅။	ကျွန်ုပ်နှင့်ကျွန်ုပ်၏ လူနာသည် နီးနီးကပ်ကပ် ဆက်ဆံသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၆။	လူနာနှင့်အတူတူအချိန်ကုန်ဆုံးရခြင်းကို နှစ်သက် သည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ	<input type="checkbox"/>

		၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	
၇။	ဆေးစွဲနေသော လူနာရှိနေခြင်းသည် ကျွန်ုပ်အား ပိုမို တိကျကောင်းမွန်သော အနာဂတ်ကိုပေး သည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၈။	ကျွန်ုပ်၏လူနာသည် ကျွန်ုပ်ချစ်ခင်မြတ်နိုးရသော အရေးကြီးသူတစ်ယောက်ဖြစ်သည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၉။	ကျွန်ုပ်၏လူနာဆေးစွဲနေခြင်းသည် ကျွန်ုပ်ဘဝ၏ အဓိက စိတ်ဖိစီးရခြင်းဖြစ်သည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၀။	ဆေးစွဲလူနာရှိနေခြင်းသည် ကျွန်ုပ်၏ကိုယ်ပိုင် အချိန်နှင့် သက်တောင့်သက်သာ ရှိမှုကို လျော့ကျ စေသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၁။	ဆေးစွဲလူနာရှိနေခြင်းသည် ငွေရေးကြေးရေး ပြဿနာဖြစ်စေသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၂။	လူနာ၏ဆေးစွဲနေမှုကြောင့် ကျွန်ုပ်အတွက် တာဝန်ယူရသော ကိစ္စအရပ်ရပ်ကို ညှိနှိုင်းရန် ခက်ခဲစေသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၃။	ဆေးစွဲလူနာ၏ အပြုအမူများသည် ကျွန်ုပ်အား တစ်ခါတစ်ရံ အရှက်ရစေသည်။	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၄။	အချိန်တွေနောက်ပြန်လှည့်လို့ရခွဲလျှင်	၁။ လုံးဝသဘောမတူပါ	<input type="checkbox"/>

	ကျွန်ုပ်တို့ ဆေးစွဲလူနာမရှိရန် ဆုံးဖြတ်မည်။	၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။		
၁၅။	လူနာအား စောင့်ရှောက်ရသူဖြစ်ခြင်း၊ တာဝန်ယူမှုများနှင့် ဟုခံစားရသည်။	အဓိအားကြောင့် ပြည့်နှက်နေသည်	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၆။	ဆေးစွဲလူနာရှိနေခြင်းသည် ရွေးချယ်စရာများ၊ထိန်းသိမ်းစရာများကို လျော့ကျ စေသည်။	ကျွန်ုပ်၏ဘဝတွင်	၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၇။	လူနာအား အဓိက တာဝန်ယူစောင့်ရှောက်သူ ဖြစ်ရခြင်းကို ကျေနပ်သည်		၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
၁၈။	ကျွန်ုပ်၏လူနာသည် ချစ်ခင်နှစ်လိုဖွယ်ကောင်း သည်။		၁။ လုံးဝသဘောမတူပါ ၂။ သဘောမတူပါ ၃။ မဆုံးဖြတ်နိုင်ပါ ၄။ သဘောတူပါသည် ၅။လုံးဝသဘောတူပါသည်။	<input type="checkbox"/>
			စုစုပေါင်းရမှတ်	<input type="checkbox"/>

ဒုတိယပိုင်းဆွေးနွေးခြင်းအတွက် အသံသွင်းထားရန်နှင့်တောင်းအပ်ပါသည်။  
တစ်နာရီခန့်ဆွေးနွေးခြင်းကို စာဖြင့်လိုက်ရေးလျှင် အရေးကြီးသောအပိုင်းများ  
ကျန်သွားနိုင်သည့် အတွက် အသံ သွင်းရခြင်း ဖြစ်ပါသည်။ သုတေသနပြီးစီး၍  
တစ်နှစ်အကြာတွင် အသံဖိုင်များနှင့် ရေးမှတ်ထားသည်များအားလုံးကို  
ပြန်လည်ဖျက်စီးမည်ဖြစ်ပါသည်။

၁။ စိတ်ပိုင်းဆိုင်ရာ ထိခိုက်နစ်နာမှုကို ဆန်းစစ်ခြင်း

- လူနာရဲ့ အပြုအမူနှင့် စိတ်ပိုင်းဆိုင်ရာပြဿနာများကြောင့် ဘယ်လောက်ထိ ဝမ်းနည်းရလဲ။
  - မျှော်လင့်ချက်မဲ့ခြင်း၊ အကူအညီမဲ့ခြင်း၊ ချစ်ရသော လူနာအား ပြဿနာများနှင့် မြင်တွေ့နေရ သောကြောင့် ဝမ်းနည်းပူဆွေးခြင်း။
- သင်နှင့်သင်၏ လူနာသည် ဆက်ဆံရေး မပြေမလည်ဖြစ်ခြင်းကြောင့် ဒေါသထွက် ရပါသလား။ ရှိလျှင် အသေးစိတ်ပြောပြပေးပါ။
- လူနာအတွက် အမြဲတမ်းစိုးရိမ်နေရပါသလား။ မိသားစုအနာဂတ်အတွက်ရော ပူပန်နေရပါ သလား။
  - လိင်ပိုင်းဆိုင်ရာ စော်ကားခံရမှု၊ မတော်တဆမှုများ၊ ရန်ပွဲများ
- လူနာ၏ဆေးသုံးစွဲမှုကြောင့် သင်သည် တစ်ခုခုကို အမြဲတမ်း ကြောက်ရွံ့နေရပါသလား။ သင်ဘာကြောင့် ထိုသို့ခံစားရသည်ကို ပြောပြပေးပါ။
  - ဥပဒေရေးရာပြဿနာများ၊ ကိုယ့်ကိုကိုယ် သတ်သေရန်ကြိုးစားခြင်း။
- သင်သည်လူနာနှင့် ပတ်သတ်၍ သင့်ကိုယ်သင် အပြစ်ရှိသည်ဟု ခံစားရလား။ သင်ဘာကြောင့် ထိုသို့ခံစားရသည်ကို ပြောပြပေးပါ။
  - ဆူပူမိခြင်း၊ အိမ်မှထွက်ခွာခိုင်းခြင်း၊ ဆေးသုံးစွဲမှု ပြဿနာအား ဖုံးဖိထားမိခြင်း။

၂။ လူမှုရေးနှင့် စီးပွားရေးဆိုင်ရာ ပြဿနာများကို ဆန်းစစ်ခြင်း

၂.၁ ငွေကြေးဆိုင်ရာ ပြဿနာ

- လူနာ၏ဆေးသုံးစွဲမှုကြောင့် မည်သို့သောငွေကြေးရေးဆိုင်ရာ အခက်အခဲများကြုံတွေ့ရ သလဲ။
  - ဆေးရုံစရိတ်၊ ဆေးစရိတ်၊ လမ်းပန်းဆက်သွယ်ရေး ကုန်ကျစရိတ် (တစ်လစာ) မှူးယစ်ဆေး ဝယ်ရန်ကုန်ကျသောစရိတ်၊ အစားအသောက်၊ ဘာသာရေးနှင့်ဆိုင်သော ကုန်ကျစရိတ်များ

၂.၂ လုပ်အားဆုံးရှုံးခြင်း

- လူနာ၏ဆေးသုံးစွဲမှုကြောင့် ဝင်ငွေဆုံးရှုံးမှု ခံစားရပါသလား။ ခံစားရပါကသင်နှင့် သင့်လူနာ၏ဆုံးရှုံးမှုနှစ်ခုလုံးကို ဖော်ပြပေးပါ။



- အလုပ်မရခြင်း၊ အလုပ်ထွက်လိုက်ခြင်း၊ အချိန်ဆုံးရှုံးခြင်း၊ ပိုင်ဆိုင်မှုများ ရောင်းချခြင်း (မြေ၊ အိမ်၊ လုပ်ငန်း၊ ရတနာပစ္စည်း)

၂.၃ လူမှုဆက်ဆံရေးတွင် အနှောင့်အယှက် ဖြစ်ခြင်း

- လူနာ၏ ဆေးသုံးစွဲမှုကြောင့် ပတ်ဝန်းကျင်၊ ဆွေမျိုးအသိုင်းအဝိုင်းနှင့် ဝေးကွာသွားသည်ဟု ခံစားရပါသလား။ ပြောပြပေးပါ။
  - ကိုယ်ပိုင်အချိန်ဆုံးရှုံးခြင်းကြောင့် လူမှုရေး၊ သာရေး၊ နာရေးများတွင် မပါဝင်နိုင်ခြင်း၊ လူနာနှင့် ပတ်ဝန်းကျင် ပဋိပက္ခဖြစ်ပွားခြင်း၊ အပြစ်တင်ဝေဖန်ခံရခြင်း၊ လူနာ၏ဆေးစွဲ ပြဿနာအား ဆွေးမျိုးအသိုင်းအဝိုင်းနှင့် သူငယ်ချင်းများမှ မသိစေရန် အဆက်အသွယ်ဖြတ်ထားခြင်း။

၂.၄ မိသားစုအပေါ်တွင် ကျရောက်နေသော အခက်အခဲများ

- လူနာ၏ဆေးသုံးစွဲမှုသည် မိသားစုစည်းလုံးရေးနှင့် ကောင်းစားရေးများ အပေါ်တွင် မည်သို့အနှောင့်အယှက် ပြုနေပါသနည်း။
  - မိသားစုပျော်ရွှင်မှုကို ထိခိုက်ခြင်း၊ မိသားစုဝင်တစ်ဦးဦး၏ အလုပ်အကိုင်၊ ပညာရေး၊ စိတ် ကျန်းမာရေး ထိခိုက်ခြင်း၊ အချင်းချင်းစုက်ရန်ဖြစ်ပွားခြင်း၊ ဆေးစွဲသူလူနာကို စောင့်ရှောက် နေရခြင်းကြောင့် မိသားစုဝင်များအား လျစ်လျူရှုမိခြင်း။

၃။ အခက်အခဲဖြေရှင်းသည့် နည်းလမ်းများ

- ဘာသာရေးဆိုင်ရာ ယုံကြည်မှုတွေ သုံးပြီးဝန်ထုပ်ဝန်ပိုးများကို ဘယ်လိုဖြေရှင်းသလဲ။
  - အရင်ထက်ပို၍ ဘုရားရှိခိုးခြင်း၊ ဆုတောင်းခြင်း၊ ရိုးရာနတ်များကို ပူဇော်ခြင်း။
- ငွေရေးကြေးရေး အခက်အခဲများကို ဘယ်လိုဖြေရှင်းသလဲ။
  - တစ်ခြားသုံးစွဲမှုစရိတ်များအား လျှော့ချခြင်း (အစားအသောက်၊ အဝတ်အထည်၊ ပညာ ရေး၊ ကျန်းမာရေးစရိတ်များ) ၊ ပိုင်ဆိုင်မှုများ ရောင်းချခြင်း၊ ပေါင်နံ့ခြင်း၊ သူငယ်ချင်းနှင့် ဆွေမျိုးများ ထံမှငွေချေးခြင်း၊ သက်ဆိုင်ရာ အဖွဲ့အစည်းများမှ ငွေချေးခြင်း။
- မည်ကဲ့သို့သော လူမှုရေးဆိုင်ရာ၊ ငွေကြေးဆိုင်ရာ အထောက်အပံ့များ ရရှိပါသလဲ။
  - မိသားစု၏ ထောက်ပံ့မှု ၊ အစိုးရ၏ထောက်ပံ့မှု၊ အဖွဲ့အစည်းများ၏ ထောက်ပံ့မှု
- သင်သည် ဆေးစွဲဝေဒနာသည်၏ အခြေအနေကို လက်သင့်ခံပါသလား။
  - ဆူပူမှုများလျှော့ချခြင်း၊ အပြစ်မတင်တော့ခြင်း၊ အလွန်အကျွံထိန်းချုပ်မှုများ မလုပ်တော့ ခြင်း၊ လူနာ၏ပြဿနာများကို နားလည်ပေးခြင်း။
- စောင့်ရှောက်သူအဖြစ်မှ နှုတ်ထွက်ရန်တွေးဖူးပါသလား ၊ နှုတ်ထွက်ဖူးပါသလား။

- အခက်အခဲများကို ခံနိုင်ရည်ရှိရန်နှင့် အိပ်ပျက်ညများမှ လွတ်မြောက်ရန် အရက်နှင့်တစ်ခြား ဆေးဝါးများကို သုံးစွဲဖူးပါသလား။
- လူနာ၏ဆေးသုံးစွဲမှု လျှော့ချရန် ၊ ရပ်တန့်သွားရန် ဌာနဆိုင်ရာရဲများနှင့် ပူးပေါင်း၍ ကြိုးစားဖူးပါသလား။

၄။ အခက်အခဲ ဖြေရှင်းရာတွင်အဟန့်အတား ဖြစ်စေသည့်အရာများ  
 ၄.၁ အကူအညီကင်းမဲ့ခြင်း (ငွေရေးကြေးရေးဆိုင်ရာနှင့် လူမှုရေးဆိုင်ရာ)

- ဆေးစွဲလူနာအား စောင့်ရှောက်ခြင်းအတွက် မိသားစုဝင်များမှဖြစ်စေ မိသားစုအပြင်ဘက်မှ ဖြစ်စေ အကူအညီရရှိပါသလား
  - ငွေကြေးအထောက်အပံ့ ရရှိခြင်း၊ ချေးငွေရရှိခြင်း ပြင်ပအဖွဲ့အစည်းများမှ အကူအညီ ရရှိခြင်း ကျန်းမာရေး ပညာပေးအစီအစဉ်၊ လူနာမှအသိမှတ်ပြုခြင်း မိသားစုဝင်နှင့် သူငယ်ချင်းများမှသင်၏ စောင့်ရှောက်မှုအတွက် ချီးကျူးခြင်း

၄-၂ ခွဲခြားဆက်ဆံခံရခြင်း

- ဆရာဝန်များ၊ သူနာပြုဆရာမများနှင့် ပတ်ဝန်းကျင် ၊ ဆွေမျိုးများထံမှ ခွဲခြားမှု တစ်စုံတစ်ရာ ကို ခံစားရပါသလား ။ ရှိလျှင် အသေးစိတ် ပြောပြပေးပါ။
  - သင့်အပေါ် ရှောင်ဖယ်ခြင်း ၊ သင့်လူနာအပေါ် ရှောင်ဖယ်ဆက်ဆံခြင်း

အထက်ဖော်ပြပါ အကြောင်းအရာများနှင့် ပတ်သက်၍ သင့်၌ မေးမြန်းစရာ တစ်စုံတစ်ရာ ရှိပါသလား ၊ ဒါမှမဟုတ် ထပ်လောင်းပြောပြချင်သော အရာများ ကျန်ပါသေးသလား။ အချိန်ပေး၍ မေးခွန်းများကို ဖြေကြားပေးသည့်အတွက် အထူးကျေးဇူးတင်ရှိပါသည်။ ဤသုတေသနတွင် ပူးပေါင်း ပါဝင်ပေးသည့်အတွက်လည်း သင်၏ ပါဝင်မှုအား လေးစားပါသည်။ ကျေးဇူးတင်ပါသည်။

## Appendix 3

## Informed Consent Form for Qualitative Research

**INSTITUTIONAL REVIEW BOARD**  
**DEFENCE SERVICES MEDICAL RESEARCH CENTRE**  
**DIRECTORATE OF MEDICAL SERVICES**  
**MINISTRY OF DEFENCE, REPUBLIC OF THE UNION OF MYANMAR**

This informed consent form is for the respondents who we are inviting to participate in research, titled “Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies”.

Name of Principal Investigator: Khin Zar Khaing Thein

Name of Organization : MSc student in Health Economics and Health Care Management, Chulalongkorn University, Thailand

Name of Funding Organization : self

Title of the Study : “Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies”

**PART I: Information Sheet**

**1. Introduction**

I am Khin Zar Khaing Thein, a master student attending M.Sc. in Health Economics and Health Care Management at Faculty of Economics, Chulalongkorn University, Thailand. I am doing research on the caregivers’ burden of drug use disorders which is very important issue to be emphasized in our country. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

## **2. Purpose of the research**

The main purpose of this research is to explore what are the main problems faced by the people who take care of patients with drug use disorders. The purpose of the research is to find the ways to reduce this burden. I believe that you can help me by telling what you suffer in terms of financially, socially, psychologically by your drug using clients. I also want to learn about how different caregivers cope with various problems that they encountered and what are the barriers of coping.

## **3. Type of Research Intervention**

This research will involve your participation in a face to face in depth interview for approximately 1 hour.

## **4. Participant Selection**

Informal primary caregivers of drug users who have registered at Yangon Mental Health Hospital are being invited to take part in this research because I feel that your experience as a caregiver can contribute much to my understanding and knowledge of burden of drug use disorders.

## **5. Voluntary Participation**

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate, all the services your patient receive at this hospital will continue and nothing will change. You may change your mind later and stop participating even if you agreed earlier.

## **6. Procedures**

Firstly, structured questions will be asked to know socio demographic characteristics of you, your patient and your family. A set of guideline questions which contains socioeconomic burden (financial strains, social limitation and family problems), psychological burden, coping strategies and barriers of coping will be asked to you. It will take approximately 1 hour. It is important to know that patient's severity questionnaires will be answered by caregivers since patients with drug use disorders will not be participated in this research.

During the interview, a comfortable place at the hospital will be managed. If it is better for you, the interview can take place in your home or workplace. If you do not wish to answer any of the questions during the interview, you may say so and

the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except researcher will access to the information documented during your interview.

### **7. Duration**

The interview you have to answer will take about 1 hour.

### **8. Risks and Discomforts**

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, this is not wished to happen by the researcher. You do not have to answer any question or take part in the interview if you feel the questions are too personal or if talking about them makes you uncomfortable.

### **9. Benefits**

There will be no direct benefit to you. However, if the respondent's stress level and emotional feeling is approaching to the pathology level, he or she will be advised to consult with psychiatric as soon as possible. Moreover, if the respondents will say that they suffer stigma even from doctors and nurses in the hospital, it will be informed to the hospital superintendent and department head.

Your participation will be likely to help the researcher to explore the caregiver burden of drug users in details. The problems cannot be solved if we don't know what burden you are actually enduring, what make you hurt about your drug users, how you are coping with these burden and what are the common barriers of coping. By knowing this in details, this study can imply planners to support family members in terms of financial and social support, to establish anti-stigma campaign to change public opinion upon drug users and their family and also contribute as baseline information for decision-makers to set the drug use disorders as a priority health program in Myanmar.

### **10. Incentives**

You will not be provided any incentive to take part in the research. However, souvenir will be given for appreciation.

## **11. Confidentiality**

The participant's private information will be kept confidential and it will not be subject to an individual disclosure, but will be included in the research report as part of the overall results. The research undertakes that all information provided by you will be used only for the purpose of study. Everything that you say when answering the questions will be kept private and confidential. Your name will not be revealed in any written data or report resulting from this study.

## **12. Sharing the Results**

The knowledge that we get from doing this research will be shared with you before it is made widely available to the public. Confidential information will not be shared. The findings of the research will be published in academic journals, paper and oral presentation in conferences, so that other interested people may learn from the research.

## **13. Right to refuse or withdraw**

You do not have to take part in this research if you do not wish to do so. You may also stop participating in the research at any time you choose. It is your choice and all of your rights will still be respected.

## **14. Who to Contact**

If you have any questions about this research, please feel free to contact Ms. Khin Zar Khaing Thein at mobile number 0943105606. The address is Building 9/11, fourth floor, Damaryone Street, Mingalar Taung Nyunt Township, Yangon, Myanmar.

If you wish to ask questions later, you can also contact to Dr Kyaw Soe Htun, Joint Secretary, Institutional Review Board (IRB), Defence Services Medical Research Centre (DSMRC), Ph no. 09428218044, Email. [kyawsoehtun@dsmrc.org](mailto:kyawsoehtun@dsmrc.org).

## Part II: Certificate of Consent

I hereby express my consent to participate as an interviewee in the research project entitled “Caring for patients with drug use disorders in Yangon region, Myanmar: Socioeconomic and psychological burden and coping strategies”. I am informed on the research purpose, type, procedure, duration, benefits and risks. I thoroughly read the information details in the information sheet given to me. I have been informed that the risks are minimal and may include only discomfort. I am aware that there may be no benefit to me personally and that I will not be compensated. I have been provided with the name of a researcher who can be easily contacted using the number and address I was given.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study and understand that I have the right to withdraw from the [discussion/interview] at any time without in any way affecting my patient medical care.

Name of participant \_\_\_\_\_

Signature of participant \_\_\_\_\_

Date \_\_\_\_\_

Day/month/year

If illiterate,

Thumb print of participant

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness \_\_\_\_\_

Signature of witness \_\_\_\_\_

Date \_\_\_\_\_

Day/month/year

I have accurately read or witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of researcher \_\_\_\_\_

Signature of researcher \_\_\_\_\_

Date \_\_\_\_\_

Day/month/year


A copy of this Informed Consent Form has been provided to the participant \_\_\_\_\_  
(initialed by the researcher)





## Appendix 4

## Ethical approval form



**Defence Services Medical Research Centre**  
**Institutional Review Board**  
 Nay Pyi Taw, Myanmar  
 Phone: +95-9-428218044, Email: [dsmrirb@dsmr.org](mailto:dsmrirb@dsmr.org)

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Ref: IRB/ 2019/ 15 Dated: May 4, 2019


To,

Ms. Khin Zar Khaing Thein  
 MSc Student in Health Economics and Health Care Management  
 Chulalongkorn University, Thailand


The Institutional Review Board of the Defence Services Medical Research Centre reviewed your research project titled "Caring for Patients with Drug Use Disorders in Yangon Region, Myanmar: Socioeconomic and Psychological Burden and Coping Strategies" on April 23, 2019.

After deliberating on your project, the IRB approves the project to be conducted in the present (revised/ endorsed) form.

The IRB expects to receive the progress report of the study with any changes in the protocol and informed consent and a copy of the final report before May 3, 2020.




[Captain Kyaw Soe Htun]  
 Joint Secretary, DSMRC IRB  
 MBBS, MMedSc(Medical Jurisprudence)



[Brig Gen Tin Maung Hlaing]  
 Chairperson, DSMRC IRB  
 MBBS, MMedSc(PLTM), MFHM(Thailand)  
 DrPH(Epidemiology)(Philippines), MA(Defense Studies)  
 FACH(USA), FPPH(UK), FACP(Sing)  
 CONSULTANT OF PUBLIC HEALTH MEDICINE

Defence Services Medical Research Centre  
 Institutional Review Board  
 (PWA - 00223430, 3080 - 0020411, 001 - 0001235)  
 APPROVED  
 Document No. IRB/2019/115  
 Date: May 4, 2019



## Appendix 5

## Operational definition of Variables

The following table showed the definition of independent variable that involved in the quantitative questionnaires to access socio demographic characteristic of caregivers and patients.

No	Variable	Operational definition	Sources
1	Age (caregiver/patient)	It refers to self-reported completed years of age of the caregiver/patient, categorized by 1= ≤30 2= 31-44 3= 45 and older	(Haskell et al., 2016)
2	Gender (caregiver/patient)	The socially constructed roles and responsibilities assigned to women and men in a given culture or location and the societal structure that support them, categorized by 1=Male 2=Female	(Ishler et al., 2007)
3	Marital Status (caregiver/patient)	The status of current bonding between men and women, categorized by 1=Single 2= Married 3=Divorced 4=Widowed 5=Separated	(Ishler et al., 2007)

4	Number of children (caregiver/patient)	Total number of all children alive born by the caregiver/patient, categorized by 1=1, 2, 3 2=>3	
5	Helper	Someone in the family who help caregiver during taking care of patient, categorized by 0=No 1=Yes If yes, total number will be specified	
6	Area of residence (caregiver/patient)	The place where caregiver/patient lived, Categorized by 1=Yangon 2=Others	(Mattoo et al., 2013)
7	Ethnicity (caregiver/patient)	Ethnic group or class of categorical persons with some common features, categorized by 1=Bamar 2=Others	(Ishler et al., 2007)
8	Religion (caregiver/patient)	Belief in god as creator and controller of universe, categorized by 1=Buddhism 2=Christianity 3=Islam 4=Hinduism 5=Others	(Malik et al., 2012)
9	Education (caregiver/patient/ Household head)	The completed highest education level of caregiver/patient/household head, categorized by 1=Illiterate	(Malik et al., 2012)

		<p>2=Only read and write</p> <p>3=Primary school passed</p> <p>4=Middle school passed</p> <p>5=High school passed</p> <p>6=Undergraduate</p> <p>7=Graduate</p>	
10	Occupation (caregiver/patient/ Household head)	<p>Current main job of the caregiver/patient/household head which can earn money, categorized by</p> <p>1=Dependent</p> <p>2=Own business</p> <p>3=Government staff</p> <p>4=Non-government staff</p> <p>5=Others</p>	(Mattoo et al., 2013)
11	Type of family	<p>The type of family structure, categorized by</p> <p>1=Nuclear</p> <p>2=Extended</p>	(Mattoo et al., 2013)
12	Position in family members (caregiver/patient)	<p>Position of caregiver/patient among family members, categorized by</p> <p>1=Household head</p> <p>2=Housewife</p> <p>3=Family member</p>	
13	Relationship with patient	<p>Relationship between caregiver and patient, categorized by</p> <p>1=Parent</p> <p>2=Son/daughter</p> <p>3=Sibling</p> <p>4=Husband/wife</p> <p>5=Others</p>	(Doku et al., 2015)

14	Income per month (caregiver/patient)	The total income of caregiver/patient per month in MMK, categorized by 1=No income 2= ≤100,000 MMK ( ≤ 65 USD) 3=100,001-250,000 MMK (65 – 165 USD) 4=>250,000 MMK (>165 USD)	(Mattoo et al., 2013)
15	Average family income per month	Combination of monthly income of all the family members per month in MMK, categorized by 1= ≤300,000 MMK (≤200 USD) 2= 300,001-700,000 MMK (200-450 USD) 3= >700,000 MMK (>450 USD)	(Choudhary, 2016)
16	Average expenditure per month (Food)	Combination of monthly expenditure for food, categorized by 1= ≤100,000 MMK ( ≤ 65 USD) 2= 100,001-300,000 MMK (65 – 200 USD) 3= >300,000 (>200 USD)	(Clark & E. Drake, 1994)
17	Average expenditure per month (Non-Food)	Combination of monthly expenditure for non-food, categorized by 1= ≤100,000 MMK ( ≤ 65 USD) 2= 100,001-300,000 MMK (65 – 200 USD) 3= >300,000 (>200 USD)	(Clark & E. Drake, 1994)
18	Duration of giving care (per day)	Total hours of caring for patient by caregiver per day, categorized by 1= 1-5 2= 6-10 3= >10	(Kronenberg et al., 2016)
19	Type of drug	Type of illegal drugs patient abused, categorized by 1=Amphetamine	(Malik et al., 2012)

		2=Heroin 3=Cannabis (marijuana) 4=Others	
20	Duaration of drug use	Total years of patient's addiction to certain illegal drugs, categorized by 1= $\leq 2$ 2= $> 2$	(Malik et al., 2012)
21	Number of drug abuse per week	Total number of drug used by patient per week 1= $\leq 3$ 2= $> 3$	
22	Misuse	Patient use other psychoactive substance together with illegal drug they used, categorized by 0=No 1=Yes If yes, the name of psychoactive substances will be specified.	(Malik et al., 2012)
23	Relapse	Patient has the history of drug withdrawal at hospital, categorized by 0=No 1=Yes If yes, total number of relapse will be specified.	
24	Dual disorders	Patient has co morbidity with other disorders due to drug use problem (psychosis, mood disorders, HCV, HIV) because of drug use, categorized by 0=No 1=Yes If yes, the name of dual disorders will be specified.	(Choate, 2011)

## Appendix 6

Table 1. Socio demographic characteristics of caregivers

Variables	Frequency	Percent
<b>Age (Years)</b>		
≤30	4	13.3
31-44	10	33.3
≥45	16	53.3
<b>Sex</b>		
Male	11	36.7
Female	19	63.3
<b>Marital status</b>		
Single	3	10.0
Married	24	80.0
Divorced	1	3.3
Widow	2	6.7
Separated	0	0.0
<b>No of children</b>		
1,2,3	20	66.7
>3	10	33.3
<b>Residence</b>		
Yangon	25	83.3
Others	5	16.7
<b>Ethnicity</b>		
Bamar	22	73.3
Others	8	26.7
<b>Religion</b>		
Buddhism	27	90.0
Christianity	1	3.3
Islam	2	6.7
Hinduism	0	0.0
<b>Education</b>		
Illiterate	0	0.0
Only read and write	1	3.3
Primary school passed	4	13.3
Middle school passed	10	33.3
High school passed	2	6.7

Undergraduate	1	3.3
Graduate	12	40
<b>Occupation</b>		
Unemployed	3	10.0
Own business	19	63.3
Government staff	3	10.0
Non-government staff	3	10.0
Others	2	6.7
<b>Income per month(Caregiver)(n=29)</b>		
No income	3	10.3
≤100,000 MMK ( ≤ 65 USD)	4	13.8
100,001-250,000 MMK (65 – 165 USD)	6	20.7
>250,000 MMK (>165 USD)	16	55.2
<b>Income per month(Household)</b>		
≤300,000 MMK (≤200 USD)	7	23.3
300,001-700,000 MMK (200-450 USD)	13	43.3
>700,000 MMK (>450 USD)	10	33.3
<b>Food expenditure per month (n=28)</b>		
≤100,000 MMK ( ≤ 65 USD)	2	7.1
100,001-300,000 MMK (65 – 200 USD)	17	60.7
>300,000 (>200 USD)	9	32.1
<b>Non-food expenditure per month (n=25)</b>		
≤100,000 MMK ( ≤ 65 USD)	13	52
100,001-300,000 (65 – 200 USD)	7	28
>300,000 (>200 USD)	5	20
<b>Position in the family</b>		
Household head	12	40.0
Housewife	14	46.7
Family member	4	13.3
<b>Family Type</b>		
Nuclear	15	50.0
Extended	15	50.0
<b>Education of household head</b>		
Illiterate	1	3.3
Only read and write	0	0.0
Primary school passed	1	3.3
Middle school passed	16	53.3



High school passed	3	10.0
Undergraduate	1	3.3
Graduate	8	26.7
<b>Occupation of household head</b>		
Unemployed	3	10.0
Own business	17	56.7
Government staff	5	16.7
Non-government staff	3	10.0
Others	2	6.7
<b>Relationship with patient</b>		
Parent	18	60.0
Son	1	3.3
Sibling	6	20.0
Wife	4	13.3
Uncle	1	3.3
<b>Contact hours per day</b>		
Unspecified	4	13.3
1-5	11	36.7
6-10	13	43.3
>10	2	6.7
<b>No of family members who helps in care giving</b>		
0	11	36.7
1	13	43.3
2	3	10.0
3	3	10.0

Table 2. Socio demographic characteristics of patients

Variables	Frequency	Percent
<b>Age (Years)</b>		
≤18	3	10
19-24	12	40
25-29	5	16.7
30-34	3	10
≥35	7	23.3

<b>Sex</b>		
Male	29	96.7
Female	1	3.3
<b>Marital status</b>		
Single	20	66.7
Married	7	23.3
Divorced	3	10.0
Widow	0	0.0
Separated	0	0.0
<b>Residence</b>		
Yangon	25	83.3
Others	5	16.7
<b>Ethnicity</b>		
Bamar	23	76.7
Others	7	23.3
<b>Religion</b>		
Buddhism	27	90.0
Christianity	1	3.3
Islam	2	6.7
Hinduism	0	0
<b>Education</b>		
Illiterate	0	0.0
Only read and write	0	0.0
Primary school passed	0	0.0
Middle school passed	19	63.3
High school passed	0	0.0
Undergraduate	8	26.7
Graduate	3	10.0
<b>Occupation</b>		
Unemployed	19	63.3
Own business	8	26.7
Government staff	0	0.0
Non-government staff	0	0.0
Assist in family's business	3	10.0

<b>Income per month</b>		
No income	22	73.3
≤100,000 MMK ( ≤ 65 USD)	1	3.3
100,001-250,000 MMK (65 – 165 USD)	1	3.3
>250,000 MMK (>165 USD)	6	20.0
<b>Position in the family</b>		
Household head	3	10.0
Housewife	0	0.0
Family member	27	90.0
<b>Duration of dependence</b>		
≤2 years	13	43.3
>2 years	17	56.7

Table 3. Relapse and dual disorders

Variables	Frequency	Percent
<b>Relapse relate to duration of caregiving</b>		
Yes	13	43.3
No	17	56.7
<b>No of relapse (n=13)</b>		
1-3 times	11	84.6
>3 times	2	15.4
<b>Dual disorder</b>		
Yes	21	70
No	9	30
<b>Name of dual disorder (n=21)</b>		
Psychosis	14	66.6
Mood disorders	3	14.3
HIV	1	4.8
HCV	1	4.8
HIV & HCV	2	9.5
<b>Frequency of drug abuse per week (n= 27)</b>		
≤3	6	22.2%
>3	21	77.8%

Table 4. Caregiver stress (n=30) average score

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
	Freq (%)	Freq (%)	Freq (%)	Freq (%)	Freq (%)
<b>Positive statement</b>					
I am happy in my role as a caregiver.	3(10.0)	10(33.3)	2(6.7)	8(26.7)	7(23.3)
There is little or nothing I wouldn't do for my patient if it was necessary.	3(10.0)	18(60.0)	4(13.3)	5(16.7)	0
I feel close to my patient.	3(10.0)	15(50.0)	0	8(26.7)	4(13.3)
I enjoy spending time with my patient.	3(10.0)	15(50.0)	2(6.7)	7(23.3)	3(10.0)
Having an addicted patient gives me a more certain and optimistic view for the future.	1(3.3)	1(3.3)	0	6(20.0)	22(73.3)
My patient is an important source of affection for me	9(30)	18(60)	1(3.3)	2(6.7)	0
I am satisfied as a primary caregiver	3(10.0)	16(53.3)	1(3.3)	6(20.0)	4(13.3)
I find my patient enjoyable.	5(16.7)	19(63.3)	2(6.7)	3(10.0)	1(3.3)
<b>Negative statement</b>					
Caring for my patient sometimes takes more time and energy than I have to give.	2(6.7)	13(43.3)	6(20.0)	7(23.3)	2(6.7)
I sometimes worry whether I am doing	6(20.0)	14(46.7)	3(10.0)	7(23.3)	0

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
	Freq (%)	Freq (%)	Freq (%)	Freq (%)	Freq (%)
enough for my patient.					
The major source of stress in my life is my patient's addiction	12(40.0)	12(40.0)	1(3.3)	2(6.7)	3(10.0)
Having an addicted patient leaves little time and flexibility in my life	10(33.3)	10(33.3)	0	8(26.7)	2(6.7)
Having an addicted patient has been a financial burden.	11(36.7)	13(43.3)	1(3.3)		1(3.3)
It is difficult to balance different responsibilities because of my patient's addiction.	8(26.7)	13(43.3)	1(3.3)	7(23.3)	1(3.3)
The behavior of my addicted patient is often embarrassing or stressful to me.	13(43.3)	10(33.3)	0	6(20.0)	1(3.3)
If I had it to do over again, I might decide not to have a drug use patient.	17(56.7)	11(36.7)	0	1(3.3)	1(3.3)
I feel overwhelmed by the responsibility of being a primary caregiver	2(6.7)	13(43.3)	2(6.7)	10(33.3)	3(10.0)

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
	Freq (%)	Freq (%)	Freq (%)	Freq (%)	Freq (%)
Having an addicted patient has meant having too few choices and too little control over my life.	4(13.3)	18(60.0)	2(6.7)	4(13.3)	2(6.7)

Table 5. Addiction Severity (n=30) average score

	Not at all	Slightly	Moderately	Considerably	Extremely
	Freq (%)	Freq (%)	Freq (%)	Freq (%)	Freq (%)
Has your patient been arrested and charged with any legal problems?	27(90)	0	3(10.0)	0	0
Does he/she experience drug overdose?	27(90)	1(3.3)	1(3.3)	0	1(3.3)
Has he/she been treated for any psychological problems?	15(50)	5(16.7)	7(23.3)	0	3(10.0)
Does he/she experience serious depression? (Sadness, hopelessness, loss of interest, difficulty with	19(63.3)	4(13.3)	6(20.0)	0	1(3.3)

	Not at all	Slightly	Moderately	Considerably	Extremely
	Freq (%)	Freq (%)	Freq (%)	Freq (%)	Freq (%)
daily functioning)					
Does he/she aggressive with surrounding?	19(63.3)	3(10.0)	3(10.0)	3(10.0)	2(6.7)
Does he/she experience hallucination?	13(43.3)	6(20)	4(13.3)	3(10.0)	4(13.3)
Does he/she have trouble in understanding, concentration or remembering?	25(83.3)	1(3.3)	2(6.7)	1(3.3)	1(3.3)
Does he/she have suicidal thoughts?	25(83.3)	2(6.7)	1(3.3)	1(3.3)	1(3.3)
Is he/she experienced with serious anxious or tension?	25(83.3)	1(3.3)	1(3.3)	2(6.7)	1(3.3)
Does he/she think to use drug every time in a day?	15(50)	5(16.7)	6(20.0)	3(10.0)	1(3.3)

## VITA

**NAME** Ms. Khin Zar Khaing Thein

**DATE OF BIRTH** 30 May 1994

**PLACE OF BIRTH** Lashio

**INSTITUTIONS ATTENDED** University of Medical Technology, Yangon, Myanmar

**HOME ADDRESS** 9/11,4th floor, Damaryone Street, Mingalar Taung Nyunt  
Township, Yangon, Myanmar

