

**BEING A YOUNG WOMAN WITH PHYSICAL DISABILITIES:
LIFE EXPERIENCES AND THEIR SEXUAL AND
REPRODUCTIVE HEALTH PRACTICES**

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**A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS (HEALTH SOCIAL SCIENCE)
FACULTY OF GRADUATE STUDIES
MAHIDOL UNIVERSITY
2015**

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ACKNOWLEDGEMENTS

I would like to express my deepest thanks to “The 60th Supreme Reign of His Majesty King Bhumibol Adulyadej Scholarhsip”, Faculty of Graduate Studies and Hongwiwatana Fund Fellowships from Center of Health Policy Studies, Faculty of Social Sciences and Humanities, Mahidol University for financial support.

I would like to express my deepest appreciation to Associate Professor Pimpawong Boonmongkon, my major advisor for her excellent academic guidance, continuous encouragement and her patient and heartfelt kindness throughout the process of my study.

I would extend my special thanks to Lecturer Panitee Brown who came from a long way to complement my exam and provide me helpful commends.

My special thanks and appreciations are extended for Asst. Prof. Penchen Pradubmook Sherer, Asst. Prof. Thomas E. Guadamuz and Lect. Seung Chun Paek for their support, academic guidance and encouragement for the study. My great thanks are extended for Assoc. Prof. Luechai Sringernyuang and all the professors, teachers and of the Department of Society and Health for their guidance, support and encouragement.

I would like to express my great thanks to The Leprosy Mission Myanmar organization and Country Director Dr. Zaw Moe Aung and all the staffs for helping me in the field site and collecting data.

I owe my special thanks for my entire friend especially Do Thi Lan Anh, Mai Nay Chi Hnin Pwint Oo and Margarita Kotusova for their kind support and networking necessary for materializing of this study and other support.

Finally, I would like to express my special appreciation to beloved family for encouraging and supporting me for my whole study time. My thanks are also extended to those who gave me all kinds of support throughout my study.

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ABSTRACT

This research aimed to explore how the discourses on women with physical disability and family responses towards the family member with disabilities, which influence the self and subjectivity of women with disabilities (WWDs), and how does it impact their sexual and reproductive health practices. Qualitative research design was used for this study. Data were collected using in-depth interviews and key informant interviews. Fifteen young women with physical disabilities were recruited through the international non-government organization. For key informant interview, three mothers and three community members were recruited in the study. To analyze the data, theoretical concepts of discourse, bio-power, and sexuality, concepts developed by Michel Foucault and concepts from Critical Interpretive Medical Anthropology has been used.

The findings showed that most of the discourse came from the medical knowledge which was related to the body impairment and capacity of a person. The discourse had an influence on the notion of the self and subjectivities of young women with physical disabilities as in seeing themselves as unattractive, asexual, abnormal, in addition, they lacked confident in engaging sexual relationship which made them feel incapable in personal relationship. The family attitudes and support towards the WWDs also had an influence on the notion of self and subjectivity of WWDs. Individuals also felt the negative attitudes regarding disabilities as a result of bad karma or sins from a previous life. Feeling of shame from being disabled lead WWDs to have negative notion of self and subjectivity which leads these young women to be unaware of their reproductive organ and sexuality, lack of knowledge of harmful SRH practices and problems, and lack of understanding of their vulnerability to sexual harassment and sexual violence.

There is a need of an advocacy of SRH with clear information for not only WWDs but also for other community members. Existing laws and policies for the person with disabilities need to be advocated to enhance fully understanding of women with disabilities and their sexuality in an attempt to reduce the stigmatization, negative attitudes and beliefs against these women, and to provide the effective inclusive development environment for the women with disabilities.

KEY WORDS: DISCOURSE/ WOMEN WITH PHYSICAL DISABILITIES/
NOTION OF SELF AND SUBJECTIVIES/ SEXUAL AND
REPRODUCTIVE HEALTH PRACTICES

119 pages

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LIST OF ABBREVIATIONS

CRPD	Convention on the Rights of Person with Disabilities
DRC	Disable Resource Center
INGO	International Non-Government Organization
NGO	Non-Government Organization
PWD	Person with Disabilities
TLMM	The Leprosy Mission Myanmar
SRH	Sexual and Reproductive Health
UN	United Nations
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
WHO	World Health Organization
WWD	Women with disabilities

CHAPTER I

INTRODUCTION

1. 1 Background

According to WHO report (2011), it is stated that more than one billion people in the world have some form of disability. It reported that many people with disabilities do not have equal access to health care, education, and employment opportunities, and they do not receive services related to the disability and they are experienced exclusion from everyday life activities. According to the Nations *Convention on the Rights of Persons with Disabilities* (CRPD), disability becomes human rights issue. The report stated that disability is also an important development issue showing that persons with disabilities experience of poorer quality socioeconomic outcomes and poverty than persons without disabilities (WHO report, 2011). In the report of WHO in 2008 reported that about 650 million people has different types of disabilities which is a barrier to their participation in the activities within the society especially in the middle income and low income countries (Kangere 2003, World Health Organization 2008).

According to SIDA's statistics (2012), the First Myanmar National Disability Survey is conducted by the Department of Social Welfare and the Leprosy Mission Myanmar in 2010. It is indicated that a total of 2.3% of Myanmar's population are people with disabilities which equal to 1.3 % of people lived with disability. The data showed that 68.2% are persons with physical impairment, 13.3% are persons with visual impairment, 10.4% are persons with hearing impairment and 8.1% have some form of intellectual disability. The reports also stated that the socio economic status of people with disabilities is lower than other people who don't have impairment, only 15 % accessed any current livelihood, less than 10 % is attending high school or having access to health care. The world report on disability also mentioned that people with disability have limited opportunities of participation in community life and activities,

and they are excluded from the welfare programs which could improve their quality of life.

1.2 Justification

Disability is world largest marginalized minor. According to the CRPD, disability is understood as a social issue. It is a social issue because it is the interaction between the people with disabilities and the other people in which the interaction between those people provides many barriers which may delay full and effective participation of person with disabilities to have basic equality like other people in society. (Article 1, Convention on the Rights of Persons with Disability). Furthermore, in the report of UN in 2006 stated that only 45 countries have anti-discrimination and disability specific law (UN, 2006). Even in a developed country like Britain, persons with disabilities are more likely to be victims of violence or rape, according to a 2004 British study, and the person with disabilities are less likely to obtain police intervention, legal protection or preventive care. By looking at this we can understand how the disabled people have been discriminated and the disability issues has been neglected or far left behind from other non- disabled group. In addition, disability is not about only impairment, it is about the attitudes towards the person with disabilities and the barriers around the person with disabilities which make person with impairment into disabled people. The UNICEF also reported that children with disabilities received less service than other people by service providers and they are in greater risk of violence than non-disabled children

(http://www.unicef.org/disabilities/index_66543.html).

In Myanmar, the government announced poverty reduction strategy in 2011. However, persons with disabilities are not mentioned or targeted in this strategy. In addition, Myanmar has stated the right for education in the constitution of 2008. There are a few special schools and vocational training centers for different kinds of disabilities, most of them located in urban areas. In the constitution of Myanmar, in the article 32 proclaims, “the Union shall: care for mothers and children, orphans, fallen Defense Services personnel’s children, the aged and the disabled”. The government and non- governmental organization are trying to implement the

development program for disabled people. As the country is in transition process since 2011, the government and other organizations are trying to achieve the goals from CRPD and human rights for disabled people. Furthermore, in the health policy of Myanmar, it declared “to raise the level of health of the country and promote the physical and mental well-being of the people with the objective of achieving "Health for all" goal, using primary health care approach”. It means that government has emphasized on the importance of inclusive community for all people. However, in the health legislation part, the laws do not mention anything for the disability. On the contrast, in the government health plan for 2011-2016, it stated that “to ensure quality health care for citizens by improving quality of curative services as a priority measure and strengthening measures for disability prevention and rehabilitation”. Therefore, since the government has signed on the CRPD, the disability rights and disability services within the community become important. Moreover, the doubled marginalized group like women with disabilities issues needs to be involved in their health program too. Especially the sexual and reproductive health issues have been neglected among the women with disabilities. Therefore, for the equality and for the inclusive development, the reproductive health issues of women with disabilities are also important.

1.2.1 Why the need to study disabilities?

According to the UN Development Program (UNDP), about 8% of person with disabilities are living in the developing countries. According to the WHO report in 2011, disability issues becomes great concern as the rate of prevalence of disability becomes higher. The population of disabilities is rising due to the aging population and chronic health conditions such as diabetes, cardiovascular disease, cancer, mental health disorders are increased. Moreover, according to the available data, many disabled people are the poorest of the poor. To create the equal community and to fulfill the Millennium Development Goals and CRPD, the disabled population becomes important for the community. WHO reported that to achieve the long-lasting, vastly better development prospects that lie at the heart of the 2015 Millennium Development Goals and beyond, we must empower people living with disabilities and

remove the barriers which prevent them to participate in their communities; getting a quality education, finding decent work, and having their voices heard (WHO, 2011).

1.2.2 Why study disability in Myanmar?

In Myanmar, many of the services focus on the livelihood, special education and empowerment. However, health issues have been neglected for so long. However, recently, in 2010, the national disability survey had been conducted around the country and in 2011, Myanmar has signed to the CRPD. All the disability movement becomes strong and people and health care providers started to have interest in the disability issues. However, many of people including health care providers still have less awareness and understanding about the disability and their health issues. A law on Rehabilitation and Employment of persons with disabilities was first enacted in 1958, and has since been revised and amended. A National Plan of Action for Persons with Disabilities (2010-2012) was launched in 2010 with the objective to improve opportunities for persons with disabilities to contribute to the country's development. The three-year plan, to be implemented in 120 townships, aims to reach 130,000 persons with disabilities nationally.

However, most laws and policies are still not adapted to the CRPD, but there are on-on-going processes to address these gaps. Several operational constraints have been identified, including the limited capacity of agencies, particularly given the "extreme" needs, lack of financial resources, few employment opportunities for people with a disability and the limited number of agencies willing to focus on disability issues in Myanmar (Sida, 2012). From Sida organization article, it is stated that social protection in Myanmar is largely limited to social insurance schemes that are available only to formal workers. There are numbers of social welfare programs for particularly disadvantaged groups, but public expenditure on these programs is limited and the number of people that they assisted is very small (Sida, 2012).

Furthermore, the medical discourse and the discourse on the disability are also barriers for disabled people to access many services and they are also barriers to understand the disability. Social protection in Myanmar is largely limited to social insurance schemes that are available only to formal workers. In Myanmar, there are very few models of a barrier-free environment. For example, a hospital would need to

have slopes, accessible toilets, and wide entrances for people with a physical disability; they would need to have information in Braille or audio form for people with a visual impairment; and would need to have sign language interpreters for people with a hearing impairment. Sida also reported that there is a need for more examples of simple, low-cost, barrier-free environments (Sida, 2012). As Myanmar is developing country and it has been isolated for so many years from the outside world, there are many problems including health, education and economy. Even non-disabled people faced with many suffering from that, person with disabilities are more likely to suffer than the non-disabled people. According to Salai Vanni Bawi, 2012, disabled people have faced with discrimination and exclusion in many levels based on their impairment and varying personal issues.

1.2.3 Why focus on women with disabilities in Myanmar?

Among the person with disabilities, women are more likely to be vulnerable and double stigmatized group. Lonsdale mentioned that being women they have low status and according to the culture, women are always in a second place and they have to follow the men. Lloyd mentioned that the difficulties of women with disabilities is even worse, since they are faced with the double burden of being female and being disabled (Lloyd 1992, Lonsdale 1990, as cited in Addlakha, 2009). Moreover, ChigierNosek and Sexton stated that if the women are disabled their status becomes lower and they have to depend on others for their living. ChigierNosek also stated that the situation of women with disabilities is tenser because they are suffered from the double burden of gender and disability-based oppression (ChigierNosek 2001(a); Nosek 2001(b) and Sexton 1994, as cited in Addlakha, 2009). All in all, women with disabilities are experienced multiply disadvantaged and excluded depend on their gender and disabilities.

(<http://www.un.org/disabilities/convention/facts.shtml>).

In addition, according to the culture and religion, women are not as noble as men. Therefore, the issue of women with disabilities has been neglected for many decades and still they don't have much choice to access any kind of services including sexual and reproductive health which is one of the important things for women. Because of the limited resources and services, disability will become huge challenges

for the community in the future and there is a great demand for more health social sciences research on disability.

1.2.4 The importance of research on women's sexual and reproductive health in Myanmar?

The UNFPA and Ministry of Health Myanmar (1999) stated that women with disabilities are highly at risk to abuse and violence. Additionally, women with disabilities face more difficulties than women without disabilities in accessing sexual reproductive health services due to sexuality being a taboo subject in Burmese culture. This situation becomes more difficult as knowledge about disabilities is low among family members, society and health care providers. Therefore, the issue of sexual reproductive health for women with disabilities is an important one. However, because of the myth of asexuality and the disfigurement of the disabled people, women with disabilities do not have equal access to health care.

Anderson and Kitchin explained that society generally believes that women with disability do not need to be sexually active and reproductive since they will produce imperfect baby. In addition, disabled people are commonly understood as an asexual or incapable to take part in sexual activity, or sexual 'monsters' who are unable to control their sexual drives and feelings (Anderson and Kitchin, 2000). However, ifpa stated that because of the myth of asexuality and the disfigurement of the disabled people, women with disabilities do not have equal rights compare to the general women (ifpa, 2007). In Sida article, it was mentioned that sexual and reproductive health is an important aspect of the quality of life for women with disabilities. Women with disabilities have high risk of getting HIV and sexually transmitted infections. Women with disabilities are up to three times more likely to be victims of physical and sexual abuse and rape and have less access to physical, psychological and judicial interventions. Women with disabilities often experience forced sterilization, forced abortion and forced marriage (Sida, 2012). According to the National disability survey in Myanmar, 2.3 % of Myanmar population has some form of disability but disability and development is still under-researched. There are only very few study about the disability and most of the people do not understand about the disability and their health issue. In Myanmar, most of the disability issues

are managed by Ministry of Social Welfare. However, as a health issue, it has been left. Moreover, even health care providers have limited knowledge about the health issues of disabled people. For the sexual and reproductive health (SRH), there are organizations that give services for SRH. However, women with disabilities have been left and have no access the SRH services because many health provider are ignorant to realize that women with disability is sexually active and reproductive. They do not realize that women with disability have their own sexual and reproductive rights and they concern about their sexual and reproductive health problems. Women with disabilities described health care providers as insensitive or lacking awareness of disabilities issues as they impact reproductive health care. Thierry stated that health care professionals need to be aware of the reproductive health care issues facing women with disabilities and take every opportunity to address them (Thierry, 2006). They also influenced on the inclusive community and development for disabled people's life. By understanding the community, family and individual's belief, knowledge and practices of sexual and reproductive health care, it can be supportive to health care services and also better quality of life of women with disabilities.

In this study, the sexual and reproductive health means the usual practices and regular practices during menstruation such as food restriction, hygiene practices and also harmful practices while having white discharges. Moreover, it includes what kind of medicine is taken during menstruation or before menstruation and what do the young women with disabilities do if they have white discharges.

1.2.5 Why study discourse on sexuality?

In this study, discourse on disability means the knowledge and the language that the people use to express the problematic meaning of the disability. In addition, it included everyday language and expression of the disability and ideas of the disability produced by the people in the community. According to Foucault, one of the most significant forces shaping our experiences is language and people use language to explain the ideas and feelings to others. Moreover, through the discourse, the discursive practices have been produced from these discourses. It is also included the meaning of disability and being disabled. In addition, the discourses allow cultural values, beliefs and attitudes, and social hierarchies directed people's orientation

towards each other and also to the social treatment of individuals and groups. Mostly the dominant concepts, definitions and images of disability are created and produced by non-disabled people (Morris 1991 & 1993, cited in Reinikainen, 2006).

Sometimes, people use language to explain things to them. Discourse can be understood as language in action which allows people to make sense of and see things. Danaher, Schirato and Webb described that the discursive explanations shape the understanding of people and capacity to distinguish the valuable from the valueless, truth from the false and the right from the wrong (Danaher, Schirato and Webb, 2000).

Danaher, Schirato and Webb stated that norms and standards are established and policed and people come to understand the relationship between sexuality and the society's rules. Sexuality is simply an arrangement of discourses and structures of power (Danaher, Schirato and Webb, 2000). In 2003, in the article it is stated that the problems of disabled sexuality are not caused by the impairment but by the way people with particular impairment are viewed and treated in society (Weeks, Holland and Waites, 2003).

The reason for choosing to study discourse on sexuality is the discourses can be seen in any level of society including, community level, family level and individual level. While seeking for SRH (sexual and reproductive health), disabled people have faced with so many barriers including the cultural norms, beliefs about sexuality and practices according to cultural beliefs. However, these things might have influenced by the discourses. Therefore, to understand the barriers and problems of the disability, it is important to understand the discourses which influenced on the people ideas, concepts and beliefs first.

1.2.6 Why study family response towards women with disabilities?

Family plays an important role in supporting person with disabilities. Family response in this study includes their attitudes towards the family members with disabilities. Moreover, it includes the feeling of shame, pity and the other negative attitudes. The support includes both mentally and physically and the other supports like economic support, social support, and educational support.

The family response need to be study because some forms of violence against women with disabilities are come from the family. In the study from Women's Health West Journal in 2013, it is stated that some forms of family violence are specific to the context of the victim having a disability but it can be different from one another. In this journal it is described the forms of violence such as "denying, threatening to withdraw care or services, ignoring requests for assistance, threatening to punish or abandon the woman, threatening to institutionalize the woman, and denying a woman's right to her own sexual choices for example, choose sexual partners, contraception, marry, have children or choices not to have sex, marry or have children and restricting or violating the woman's privacy including access to services and information". Therefore, whether the young women with disabilities received fully understanding of their disability and their sexuality from their family is important.

1.2.7 Why study self and subjectivity of women with physical disabilities?

Addlakha pointed out that disabled people are continuously discriminated and are seen as a person to neglect, prejudice, revulsion, rejection and pity. Furthermore, constructions of the disabled by the non-disabled have the dual effect which showed the complete marginalization and disempowerment of a whole population group and negative stereotypes by disabled persons themselves. The acceptance of the negative stereotypes by themselves translated into passivity, dependency, isolation, low self-esteem and a complete loss of initiative (Addlakha, 2009).

Perduta-Fulginiti stated that earlier qualitative study of women with physical disabilities also showed that the negative messages such as being a burden to the family or positive expectations regarding a woman's potential influenced the women's self-esteem. In addition, women with disabilities need to cope with assaults on their self-esteem generated by negative societal attitudes such as "ill, ignorant, without emotion, asexual, pitiful, and incapable of employment" (Perduta-Fulginiti, 1996, as cited in Nosek, 2003).

Moreover, Addlakha stated that adolescents with disabilities may feel indifferent in integrated settings where the experience of being different and excluded

from the society may be intensified, if conscious efforts are not made to involve them in different activities (Addlakha, 2009). Therefore, to understand how they feel about their self and subjectivity is important as it might be the major reason why they are engaging in different activities and why they cannot participate or practice some kind of specific activities or practices.

In this research, the researcher will study the notion of self and subjectivities which is important to understand how it influenced by the discourses from their environment does. The notion of self in this study includes the notion of their body impairment and disfigurement and their sexual self-image about whether they think they are sexually attractive or not. The subjectivities include the feeling of incapacity, sexual confident and about being controlled, and surveillance or regulated their own body and sexuality.

1.3 Research Objective

1.3.1 General Research Objective

To explore how the discourses on women with physical disability and family responses towards the family members with disabilities influence the self and subjectivity of women with disabilities and have impacts on their sexual and reproductive health practices.

1.3.2 Specific Research Objectives

- To explore discourse among community members on women with physical disability.
- To understand what are the family responses to young women with physical disability
- To explore self and subjectivity of young women with physical disabilities

- To understand how discourse on women with physical disability and family reactions influence the notion of self and subjectivity of young women with physical disability and have impacts on their sexual and reproductive health practices.

1.4 Research Questions

1.4.1 General Research Question

The main research question is what are the discourses from the community members and family members on women with physical disability and how does it affect to the notion of self and subjectivity of young women with physical disabilities and how do this subjectivity affect to the sexual and reproductive health practices.

1.4.2 Specific Research Questions

- What are the discourses on disability and women with physical disabilities?
- What are the discourses on sexuality of the women with physical disabilities?
- How does the family member give social support and their attitudes towards to the women with disabilities?
 - What are the self and subjectivity of young women with disabilities?
 - How do the discourses of community and family influences to the notion of self and subjectivity of women with physical disabilities?
- How does it have impact on the SRH practices of young women with disabilities?

CHAPTER II

LITERATURE REVIEW AND CONCEPTUALIZATION

2.1 THEORITICAL CONCEPTS

2.1.1 Critical Interpretive Medical Anthropology

The focus of a critical interpretive approach is about all knowledge relating to the body, health and illness which are culturally constructed, negotiated and renegotiated in a dynamic process through time and space. When the inequalities and hierarchy are institutionalized, people would impose by means of a dominant cultural ideology which inflict a negative self-image, distress and often ill health on the underprivileged and disenfranchised (Lock and Scheper-Hughes, 1990). In addition,

“Critical interpretive medical anthropology is to describe the variety of metaphorical conceptions (conscious and unconscious) about the body associated narratives and then to show the social, political, and individual uses to which these conceptions are applied in practice” (Lock and Scheper-Hughes, 1990).

A critical interpretive perspective, it drew for inspiration upon some aspects of generally anthropological discourse about the body. As human body itself is culturally constructed, this perspective talks about three bodies. The individual body refers to self-evident level and understood as the lived phenomena of the lived experience of the body self. Western notion of the individual described that *“Individual is a quasi-sacred, legal, moral and psychological entity whose rights are limited only by the rights of other equally autonomous individuals”* (LaFontaine 1985:124, cited in Lock and Scheper-Hughes, 1990). In addition, the individual body-self is likely to be attached with or engaged by the social body. The identity of I or the self is a state of permanent perception which is unique to the individual and stable through the life span until death (Weber 1983:399, as cited in Lock and Scheper-Hughes, 1990). Peter Manning and Horacio Fabrega (1973), which is cited in Lock

and Scheper-Hughes, 1990, summarized that body and self are understood as distinct and separable objects.

Secondly, the social body is referred to the uses of the body as a natural representation which need to think about nature, society and culture (Douglas, 1970, as cited in Lock and Scheper- Hughes, 1990). Furthermore, *“The social body is the body which is useful in sustaining particular views of society and social relations”* (Lock and Scheper- Hughes, 1990).

Lastly, *“The body politic refers to the regulation, surveillance and the control of bodies (individual and collective) in reproduction and sexuality, work, leisure and sickness”* (Lock and Scheper- Hughes, 1990). It also explained about the power and control over the individual and social bodies which focus more than descriptions and collective representations of the natural and the cultural. On the other hand, the anthropology relationship of the body and the body politic leads to the regulation and control of not only to the individuals but also to the population. Therefore, the sexuality, gender and reproduction also refer the same as a bio power in the Foucault (Lock and Scheper- Hughes, 1990).

The physical disabilities and impairment are obvious and the individual body of women with disabilities is an inevitable thing that people can see easily. However, these young women and the society described the impaired body as a disabled body and abnormal according to their belief and the culture also described the impaired person as disgraceful and unable to do anything. In addition, mostly the women with disabled are portrayed as asexual or sexually not active according to the religion belief, culture and the way the people understand the sexuality. Therefore, these young women with physical disabilities control their body and sexuality and on the other hand, the culture, religion and the other people attitudes towards them is also controlling their body and sexuality.

2.1.2 Concepts of Disability and Impairment

2.1.2.1 Impairment

WHO defined that “Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in

executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations”

(WHO, <http://www.who.int/topics/disabilities/en/>).

One of the articles said that the concerns about physical appearance which affected the considerable proportion of the general population (Gilbert & Thompson, 2002, as cited in Rumsey & Harcourt, 2003). In addition, in the article said that some concerns relate to inborn features, for example, body shape, facial features. In addition, during a life course, changes to external appearance occur but some of which are desired, while others are not (Newell, 2 as cited in Rumsey & Harcourt, 2003). Macgregor (1979) argued that a visible difference comprises a “social disability,” and the author said that it has impact on the thoughts, feelings and behaviors of affected people which is also noticed by other people. Social disability involves a complex interaction of social and individual factors. Visible disfigurement can have a profound psychological impact upon the individual concerned. In the report of UNICEF in 2013, it was stated that difficulties include adverse effects on body image, quality of life, and self-esteem. It is also influences on physical, cultural, and psychosocial factors. In addition, Negative beliefs about the causes of disability and the limitations of people with disabilities are often firmly detained and difficult to terminate. UN reported that disability also associated with punishment for past sins or bad luck, and may be considered ‘contagious’ (UNICEF, 2013).

“Body image refers to the collective and idiosyncratic representations an individual entertains about the body in its relationship to the environment, including internal and external perceptions, memories, affects, cognitions and actions. Most of the physical disabled people are physically and mentally influenced by cultural ideology upon their disabilities” (Teleporos and McCabe, 2002). It is also stated because of the negative influences on the body image people have been distress and feel vulnerable and underprivileged. Therefore, Teleporos and McCabe, 2002 mentioned that for women with physical disabilities, they suffer double pressure as in many places and they defined beauty of a woman with perfect body and they have their own ideal body image. The author explained that for women with physical disabilities, since they were young they have been treated differently by their community or family (Teleporos and McCabe, 2002). Therefore,

they think that their body is different from others and they have many things that they cannot do as a disabled person. Furthermore, Hannaford, 1985 stated that people who cannot come close enough to the ideal body may feel themselves as devalued people because of their devalued bodies (Hannaford, 1985, as cited in Teleporos and McCabe, 2002).

2.1.2.2 Disability

The definition of disability from WHO is “*A disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives*” (<http://www.who.int/topics/disabilities/en/>, WHO). In this WHO article, it is also mentioned that the supporters of the social model claimed that disability is not an inevitable consequence of impairment and it is the misunderstanding of the productive constraints of modern power.

Tremain explained that individual models of disability conceptualized that the disability of individual state of affairs is an unfortunate consequences of personal attribute or characteristic. However in the terms of the social model, the impairment is not equal or cause of disability it is rather explained that disability is a form of social disadvantage, which imposed on a person’s impairment (Tremain, 2002). In the report of WHO in 2011 mentioned that disability is “*an evolving concept*”, but it is also said that “*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others*”. WHO also defined that disability as an interaction means that “disability” is not an attribute of the person. They are barriers prevented person with disabilities to delay in their day to day lives for progress on improving social participation (WHO, 2011).

Green, Davis, Karshmer, Marsh and Straight, 2005 stated that disabled people faced with labeling, stereotyping, separation, status loss and discrimination within the context of power differential. Furthermore, it indicated that disability can be conceived of as four intersecting circles of experience: the body, identity, culture, and structure. While traditional scholarship has focused on bodily impairments and their negative impact on individual identity, the Social Model has

drawn attention to the disabling impact of structural and cultural factors (Green, Davis, Karshmer, Marsh and Straight, 2005).

2.1.3 Discourse

“The term discourse refers to a group of ideas or patterned way of thinking which can be identified in textual or verbal communications, and can also be located in wider social structures” (Powers, 1996, p. 209, cited by Thaweesit, 2005). Another definition of discourse is “*Discourse generally refer to a type of language associated with an institution, and includes the idea and statements with express an institution’s value*” (Danaher, Schirato and Webb, 2000). Danaher, Schirato and Webb 2000 also said that discourse can be defined as “*language in action: they are the windows*”, which permits things to be seen through them or sensible (Danaher, Schirato and Webb, 2000). In addition , the authors stated that the discourses or explanation influence our understanding of ourselves and to make us be able to differentiate which are the worthy, truth or right from worthless, false or wrong. According to Foucault, these different discourses shape, regulate and control our thoughts and action (Danaher, Schirato & Webb, 2000). In other words, people’s subjectivity and identity about what they think, know and talk about are created or constituted by discourse (Jones, 2003¹). Furthermore, in the article of Tremain mentioned that Foucault’s concept of bio-power refers to “the strategic tendency of relatively recent forms of power / knowledge to work toward an increasingly comprehensive management of life: both the life of the individual and the life of the species” (Allen, 1999. Cited in Shelly Tremain,n.a). Foucault connected bio-power with race, sexuality and techniques which is aimed to modify and controlled biological phenomena related to human life. Foucault also tried to challenge the problems of how individuals are subjected through techniques of domination. (1997a, 281-282, cited in Kasper.S. Kristensen, Thesis paper, 2013). The problems are centered on two sets of relations which are power and knowledge and in the framework of bio-power; the power and knowledge are embodied in regulatory techniques by which human life can be modified. Foucault also replaced the notion of power with variety of different phenomena entitling the relationship between government and its targets. This include Foucault’s famous notion of governmentality, security, pastoral power and police.

Bio-power is also understood as something which is interconnected all the specific fields which in turn connected to population and its management (Kasper.S. Kristensen, Thesis paper, 2013).

Furthermore, Hughes and Paterson also stated that Foucauldian approach to disability was a way to map the constitution of impairment and examined how regimes of truth about bodies of disability have been dominant to their governance and control. (Hughes and Paterson, 1197:332). They again said that Foucault's argument is that the materiality of the body cannot be dissociated from the historically contingent practices that bring it into being, that is objectivize it (cf. Hughes and Paterson, 1197:333-4). In the article of Shelley Tremain in 2002, it is said that some pertinent arguments in Foucault, which provide and historical context for the emergence of impairment as an object of knowledge / power and historical emergence of natural impairment and natural sex as discursive objects. In addition, the discursive objects are called impairment which is claimed to be the embodiment of natural deficit or lack. Furthermore, it is obscured the fact that the constitutive power relations which is defined and circumscribe it have already been delimited dimensions of its reification (Shelley Tremain, 2002).

Furthermore, according to Foucault, it is explained that the modern body was created as the effect and object of medical examination, which could be used, abused, transformed and subjugated. Clinical descriptions elaborated in the course of the examinations constituted new objects of knowledge and information created new realities and introduced new, inescapable rituals into daily life, rituals whose participants became epistemologically dependent on the newly created objects (Foucault.1973a, in Duden, 1991). Foucault also explained that to be a subject is to be subject to someone else by control and dependence and tied to one's own identity by a conscience or self-knowledge and subjects are objectivized as mad or sane, sick or healthy, criminal or good and as a consequence come to understand themselves scientifically (Foucault, 1983[1982]). Rabinow stated that subject becomes attached to a personal and social identity (Rabinow, 1984).

2.1.4 Sexual and Reproductive Health and Rights

In the International Conference on Population and Development in Cairo (ICPD), 1994, reproductive health is defined as “*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and process*” (UN, 1994). In the research of Phan Thi Uyen in 2008, it is stated that it means not only the absence of negative ill-health but the positive well-being of reproductive system and function. It expanded from reproduction to satisfying sexual life and health, the wholeness of health at both levels which is individual physical, psychological and social institutional level of well-being. Sexual and reproductive health rights are recognized as the notion of reproductive health and rights to information, techniques and reproductive health care of all age-groups in society (Phan Thi Uyen, 2008). Sexual and reproductive health rights are;

- 1) Reproductive and sexual health throughout the life cycle
- 2) Reproductive self-determination including: right to voluntary choice of marriage and right to determine the number, timing and spacing of one's children
- 3) Equality and equity for women and men in all spheres of life
- 4) Sexual and reproductive security including freedom from sexual violence and coercion.

Cottingham and myntti in 2002 mentioned that the new definition moves beyond conventional family planning to control population than to address reproductive health as development and human rights issue, it covered three academic and development issues namely, “*a range of physical and psychological conditions, a principle for organizing health care services, and a paradigm for social change*” (Cottingham & Myntti, 2002: 86, as cited in Phan Thi Uyen, 2008). Hardon stated that the scope of sexual reproductive health includes infertility, menopause lack of safe abortion for unwanted pregnancy, pregnancy related to death or illness, regulatory of fertility, contraceptive prevalence, and sexually transmitted diseases, HIV and sexually violence and having safe sex (Hardon, 1995).

Furthermore, Cook, Dicken and Fathalla in 2003 stated that reproductive health implied that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and have free decision to do them when and how

often. Reproductive health care is defined as “*the constellation of methods, techniques and services that contribute to reproductive health and well-being by preventing and solving reproductive health problems*” (Cook, Dickens and Fathalla, 2003). UN report explained that sexual health means not merely counseling and care related to reproduction and sexually transmitted diseases but also the enhancement of life and personal relations and (UN, 1994). Cook, Dickens and Fathalla also described that sexual health should include the ability to enjoy mutually fulfilling sexual relationship, freedom from sexual abuse, coercion, or harassment, have safety from sexually transmitted diseases and success in preventing unwanted pregnancy (Cook, Dickens and Fathalla, 2003).

2.1.5 Sexuality of disabled persons

Dixon Muller defined that sexuality encompasses personal and social meanings as well as sexual behavior and biology. A comprehensive view of sexuality includes social roles, personality, gender and sexual identity, biology, sexual behavior, relationships, thoughts and feelings. Sexuality indicated at individual level, it is physical capacity for sexual arousal and pleasure (libido), and at social level; it is personalized and shared gestures, acts, relationships and the attached meanings which are socially and culturally constructed and varied in cultural and historical contexts (Dixon-Muller, 1993b).

Basson defined that the sexual self-image of women with disabilities may have influence by the societal attitudes. A specific issue can change when woman becomes disabled person such as woman's self-image, and fears of losing independence and of being viewed as “sick” can erode sexual confidence are (Basson, 1998). Furthermore, Basson also stated that some men defined disabled women as sexual make inappropriate, unwanted and exploitative advances. Therefore, a disabled person's sexual identity must be stressed (Basson, 1998). In addition, Basson explained that sexuality is an area of distress, exclusion and self-doubt for persons with disabilities. Society viewed body of person with disabilities as asexual. While able-bodied persons may legitimately claimed aspirations for the body beautiful and an exhilarating sex life, many people think that persons with disabilities are automatically excluded from any hope of love and sex” (Basson, 1998).

As Anne Finger poignantly points out:

“Sexuality is often the source of our deepest oppression; it is often the source of our deepest pain. It’s easier for us to talk about – and formulate strategies for changing discrimination in employment, education and housing than to talk about our exclusion from sexuality and reproduction (1992: 8).”

In short, Addlakha mentioned that women with disabilities do not have the same options of marriage and motherhood as non-disabled women. Adolescents and young people with disabilities have to cope with all physical changes, emotional anxieties and social conflicts of able-bodied adolescents, in addition to those produced by their disabilities (Addlakha, 2009). Addlakha also explained that absence of role models with disabilities and negative social perceptions of persons with disabilities are the major stumbling blocks for youth with disabilities because they are struggling to cope with both the pain and excitement of growing up in general, and the personal challenges posed by disability in particular.

2.1.6 Notion of self and Subjectivity

Kleinman defined that subjectivity referred to an essential individuality or uniqueness, the awareness of one’s perceived states. To understand human subjectivity, a biologically grounded universal human nature or take refuge in abstract are not alternative but a historical ethical discourse which need to affirm the variability, heterogeneity, and contingency of our subjectivities as they describe in the realm of experience (Kleinman and Fitz Henry, 2007). In the book of Kleinman in 2007 also stated that experience is inter-subjective which involved practices, negotiations and contestations with others with whom people are connected. Our evolving subjectivities also return to those symbols and interactions, reconfiguring, re-patterning, which are sometimes even completely reinterpreting the symbols and social interactions of our local worlds. Rabinow in 1984 stated that subjects are portrayed as mad or sane, sick or healthy, criminal or good and as a consequence of understanding themselves scientifically (Foucault, 1983[1982]). Subject are becoming attached to a personal and social identity (Rabinow, 1984).

In the paper or Rorty, in 2007 stated that Rousseau provided at least three distinct layers of three reflective self which are the presumptive self, the self “in nature”, and the biological self as it might exist apart from the influence of family or society. Then, the “I” or self is existing only insofar as it is conscious of itself. The social self is defined as a subject to others and a subject to himself only through others. In addition, to regain and fulfill nature of self, the self must become rationally self-legislating. For example, experiencing himself as a citizen, man freely wills actions are accorded with the general will. Rorty stated that in nature, subjectivity is instinctual and in society, it is understood as emotional. In addition, in political citizenship, it is defined as rational and universal (Rorty, 2007). Fichte defined that self-consciousness is a condition for experience (Fichte, as cited in Rorty, 2007). Loyola and Sartre stated that the choice of the content of self-awareness may be transformative or performatively constitutive (Loyola and Sartre, as cited in Rorty, 2007). Rorty also defined that subjectivity is contrasted with objectivity, as in another way, it is a self-constituting performance. Furthermore Rorty mentioned that in some usages in which subjective reflection is individuated and it revealed the structure of any and every mind’s necessarily self-validating ideas. These concepts of subjectivity have dramatically different roles in the reflective experience phenomena (Rorty, 2007).

Notion of self and subjectivity upon their impairment, body image and sexuality is important for the women with disabilities. It is important to understand how they think about themselves and their sexuality which could probably influence in their practices of sexual and reproductive health. If we cannot understand how they think about themselves, it would become one of the barriers for them to access the sexual and reproductive health care because most of the people believe that disabled person is asexual and they cannot be a good wife or mother. Sometimes people think that they are completely different from the non-disabled people.

2.1.7 Marginalization

Marginalization can be defined as a form of acute and persistent disadvantage which is rooted in underlying social inequalities. Most disadvantaged groups of the society are girls and women, hard-to-reach groups such as indigenous

people and ethnic minorities, poor households, people living in informal settlements, individuals with disabilities, rural populations, nomadic populations those affected by armed conflict and HIV and AIDS and street and working children (EFA, 2009).

In the student of sociology website, it is explained that marginalization has been defined as a complex process of specific groups of people who are lower or outer edge of society. It effectively pushed these groups of people to the margin of society economically, politically, culturally and socially following the policy of exclusion. In addition, it is explained that the exclusion leads to have equal access to productive resources and opportunities for the recognition of their productive human potential and opportunities for their full capacity utilization. Furthermore, it is also said that this pushed the community to poverty, misery, low wage and discrimination and livelihood insecurity. Their upward social mobility is being limited. Moreover, it is stated that politically the process of relegation denies people to have equal access to the formal power structure and participation in the decision making processes lead to subordination to and dependency on the economically and politically dominant groups of society. As a consequence of the economic, political and cultural deprivation, a massive portion of the population emerged to be socially ignorant, illiterate, uneducated and dependent. Therefore, that population has to live on the margins of society because of lacking of basic necessities of life.

(<http://www.sociologyguide.com/civil-society/marginalization.php>, 2015)

2.2 Related Literature Reviews

2.2.1 Discourse on disability and women with disabilities

Anderson stated that according to the Delight S. Moyo, many physical disabilities is not a reason which prevented an active sexual and reproductive life but the social messages about incapability which are the discourses on PWDs limit their potential (Anderson 2005, Coltrane and Schmitt 2005).

Reinikainen stated that culture and its public discourses constructed, circulated and represented the common sense and truths about the disability and meanings of disability. Susan Wendell stated (1996,as cited in Reinikainen, 2006) that

the biggest obstacle in the deconstruction of disabling is the social constraints and barriers, for example by legislation and socio-political reforms which lied in the other cultural constructions of disability produced the otherness for disabled people. Wendell stated that this other means that disabled people are represented as distinct who are apart from the assumed normality as well as apart from the 'normal' and the 'natural' majority (Wendell 1996, as cited in Reinikainen, 2006). Mark Priestley (1999) stresses the role of individualizing cultural discourses and representations of disability, for example, in social work and other welfare services which prevent the realization of enabling disability policy. According to Sue Cambell (1994), women and disabled people, among many other disadvantaged people in society, are labelled as being bitter and oversensitive (Reinikainen, 2006). Reinikainen also stated that the texts about the disabled women defined meanings of 'being disabled' by using the other discourse and emphasizing on that being a disabled woman means they do not belong to the range of normality and normal life (Reinikainen, 2006). In addition, these discourses and representations present disability as a personal problem and limitation which is caused by a person's physical or mental impairment and disadvantages faced by disabled individuals as unavoidable and natural consequences of their impairments.

2.2.2 Family attitude and reaction to women/person with disability

Westbrook, Legge and Pennay stated that negative social attitudes toward people with disabilities are expressed in terms of exclusion from, or lack of access to, social roles, activities and facilities. Thus people with disabilities are less likely to be educated, to work, to marry or unable to go to public places (Westbrook, Legge and Pennay, 1993). Bywaters, Ali, Fazil, Wallace, Singh stated that some parents and care giver of disabled people indicated that the impairment is a consequence of illness or treatment such as mother's illness during pregnancy, the child's illness early in their lives, the side-effects of medication or the failure of a doctor to diagnose the child's illness swiftly enough. Some parents referred to God in explaining their child's impairment (2003). Furthermore, they mentioned that a number of parents expressed feelings of shame or received end of negative disabled attitudes from others towards their children (Bywaters, Ali, Fazil, Wallace, Singh, 2003).

Bywaters, Ali, Fazil, Wallace, Singh, 2003, also stated that feelings of shame are from the parents are being unwilling to share the care of their children with others and their preference for relying on the privacy of their extended family. These attitudes lead to low expectations of their children's future as adults and to reduce willingness of parents to encourage their children to achieve maximum independence.

2.2.3 Community reaction to people with disability

In the report of UNICEF, it is mentioned that stigmatization and discrimination occurred as a consequence of lack of understanding and knowledge of the causes of disability. The implications of disabilities include fear of difference, fear of contagion or contamination, or negative religious or cultural views of disability. It is further compounded by poverty, social segregation, humanitarian crises, lack of services and support, and an unsympathetic and inaccessible environment (UNICEF, 2013).

In addition, UNICEF reported that cultural, legal and institutional barriers render girls and young women with disabilities as the victims of two-fold discrimination which are the consequences of both their gender and their disability. Moreover, parents, educators, and counselors are often uncomfortable about discussing sexual and reproductive health with young people with disabilities (UNICEF, 2013).

2.2.4 Self and subjectivity of women/person with disability

European Disability Forum (2010) pointed out that women with disabilities who experienced a great degree of marginalization may be translated into lower levels of self-esteem, more financial dependency on the family and/or the persons responsible for supporting them, greater socio-emotional dependency and support needs, lower levels of personal and social development, lack of awareness on sexuality and low consideration of self-body image, etc.

Luborsky's study in 1994 indicated that impairments limit the capability to do basic daily tasks that sustain the body and the spirit. In valued personal life, eating, moving around, bathing are taking part and in social life, holding a job and leisure activities are required extra efforts. In addition, it mentioned that being unable to fully

perform normatively valued activities and roles in the workplace, home, and community challenged core identity of the individual as a full adult person. Cultural images for incapacity and dependency conveyed the meanings of being childlike dependent.

2.2.5 Sexual and reproductive health problems and practices among women with disability.

Monga and Lefebvre stated that the society can be doubted that disabled people needed access to services that provide advice and health care relating to sexual issues. Despite common stereotyping to the contrary, and attempts to treat disabled people as asexual and self-image related to sexuality are not existing (Monga & Lefebvre, 1995, as cited in Anderson and Kitchin, 2000).

Becker, Stuifbergen and Tinkle illustrated that women with disabilities reported that the lack of basic knowledge basic reproductive health is because of restricted access to such information as an adolescent. The study also showed that Women with physical disabilities experienced the limited contraceptive choice or lack of information about contraceptive (Becker, Stuifbergen and Tinkle, 1997).

In addition, Becker, Stuifbergen and Tinkle explained that women identified several barriers to reproductive health care including structural, interaction with health care providers, lack of information or difficulty to access information, and sometimes they have been treated as a asexual being. Furthermore they do not receive information about STDs (Becker, Stuifbergen and Tinkle, 1997).

2.3 Explanation of conceptual framework

Disability is not just a health issue it is also development issue to many societies. However, in many level of the society have some kind of discourses over the disability and their sexuality. In the society, both the community members and the family have some kinds of discourses on the women with disabilities. As they women with disabilities are marginalized group and they have less power, the discourses have much effect on their individuals and their opinion or notion of their impairment and their sexuality. Foucault's concept of bio-power refers to the strategic tendency of

relatively recent forms of power/ knowledge to work toward an increasingly comprehensive management of life: both the life of the individual and the life of the species (Allen, 1999, as cited in Tremain, 2002). Moreover, the Foucault's critical disability theory can explain what are the discourses upon the women with disabilities and how their practices manipulates and objectivized the women with physical disabilities as sick or healthy, good or bad, asexual or sexual which are attached to the personal and social identity of the individuals. In addition, the discourse might also directly influence on the SRH practices.

Furthermore, critical interpretive medical anthropology concepts will help to see the variety of metaphorical conceptions (conscious and unconscious) about the body and associated narratives and then to show the social, political, and individual uses to which these conceptions are applied in practice (Lock and Scheper-Hughes, 1990). It is also draw for inspiration upon some facets of general anthropological discourse about the body and it tells that human body itself is culturally constructed. Therefore, the critical interpretive approach will help to understand notion of the self and subjectivity. In the notion of self and subjectivity, the critical interpretive approach can be explain to understand how the individual notion of self upon their disfigure body and impairment and sexual self-image of women with physical disabilities. Moreover, according to the body politic, the critical interpretive medical anthropology will provide understanding about the how the body being control, surveillance and how the women with disabilities regulated their own body and their sexuality.

Finally, the last is to understand what kind of sexual and reproductive health practices are practicing among young women with physical disabilities. At the same time, the notion of self and subjectivity influences on their practices. For example, if they think that their body is incapable or asexual; their practices might be different from non-disabled women. To access the better health care quality sometimes depends on the people's subjectivity. In addition, the discourse and family responses can be also a consequence of the notion of self and subjectivities.

2.4 Conceptual framework

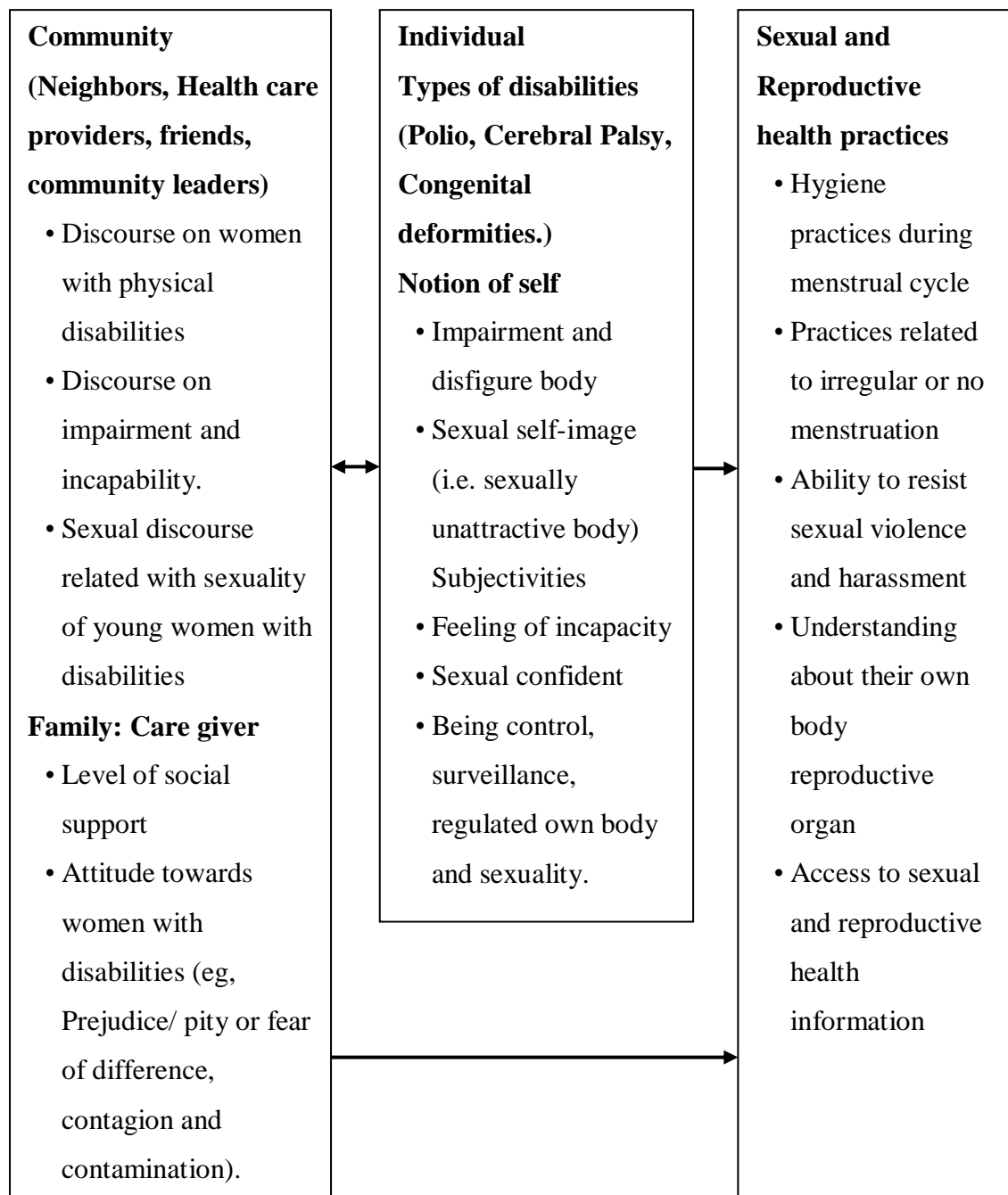


Figure 2.1 Conceptual framework

CHAPTER III

RESEARCH METHODOLOGY

3.1 Research Design

This study aims to explore what are the discourses on the women with disability and family response to women with disability and how these discourses and family responses influence women affect self and subjectivity of women disability and have impacts on and their sexual and reproductive health problems and practices. In addition, the study would like to understand the family attitudes and social supports.

Foucault discourse theory and critical interpretive medical anthropology concept were used as theoretical lens. Qualitative, explanatory research design was used to explore discourses on the disability and sexuality of the women with physical disabilities. It also helps to explore notion of self and subjectivities of women with physical disabilities which has impacts on their own sexuality and reproductive health practices.

3.2 Research site selection

Research was conducted in Hlaing Tharyar Township, Northern District of Yangon. The research site is purposively collected based on 2 criteria 1) it is the township where there are the highest numbers of people with physical disability in the country 2) it is the township in which researcher had an experience in working with people with disability and the NGO's staff who worked with people with physical disability for 2 years. It was settled in 1985 and the total population is about 340332, according to 2008 data. Hlaing Tharyar is the most developed of the new satellite towns founded in the 1980s, Hlaing Tharyar Industrial zone consisted of mostly garment and other light industries, is one of the largest industrial parks in the country. Most of the people living in this area are grass root level people and therefore are marginalized. People know this area as a slum area because there are sex workers,

leprosy patients, disabled people, low-income wage, HIV patients and many other marginalized groups. There are also many International Non-Government Organizations (INGOs) and local nongovernmental organizations (NGOs) working in this area for different kinds of projects for those marginalized people. Currently, Hlaing Tharyar was announced as one of the highest rate in criminal cases. The researcher chose this area as a research site for the following reasons;

- 1) It has high density of marginalized people as well as high density of person with disabilities.
- 2) As not many researches are conducted in the community, the researcher believes that this area is still full with information resources which are still untouched.
- 3) It is an area full with different kind of organizations and people with different background, the different perception, thinking and idea will lead to the rich information resources for the research.

3.3 Entering into the research field

Hlaing Tharyar Township is one of the townships that are really hard to get permission for doing research. It needs many steps to get permission. However, the researcher contact with one of the INGOs working in that area which is also researcher's previous job. The leprosy Mission Myanmar is one of the leading INGOs for services for person with disabilities in the country. Firstly, the researcher went to meet with the country director of this INGO and give the approval letter from the University. The country received the letter and gives approval and also asked his colleagues in the site area to help the researcher. As the organization is already got the permission from the government, the researcher didn't need to do any other permission letter to do the research. The next day, researcher went to the site office and meets with the site coordinator and also introduced with other staff form the site office. Then, explained about the research and how the researcher wants to conduct in the community. There are many wards divided in this township. The research was conducted start from the next week after meeting with the staff from the office and also local volunteers.

3.4 Recruitment process

The participants were chosen purposively. The target population is the young women who are 13-18 with physical disabilities. For the community members, 3 mothers of women with physical disabilities were chosen for understanding the family attitudes and the social supports. Furthermore, 4 community members were chosen to explore the discourses in the community.

After deciding to choose the Hlaing Tharyar Township, the researcher made contact with the country directory of The Leprosy Mission Myanmar and had discussion about how to conduct the research in the area, the current situation of the area and asked about the permission process. Then, once, the researcher arrived to Yangon at the end of June 2014 for data collection, the researcher made phone contact with the country director and made an appointment to meet with him. After getting appointment date, the next day, the researcher went to meet with the country director and gave the approval letter from the university. The country has accepted to help and gave contact to her colleagues in the site office to help the researcher in finding participants. He also gave an address to make contact with the Myanmar Independent Living Initiative (MILI), which is also a local organization established by the person with disabilities. The organization also has information and they are also published magazine, pamphlets and journals for person with disabilities every month. Therefore, after meeting with the country director, the researcher also went to MILI to get some information about the latest news and information about the activities of person with disabilities. The researcher meets with the program manager of the MILI and received some information about the latest activities and also received the pamphlets and magazine which is recently published for June 2014 and other journals published for June 2014.

After that researcher contact to the site office in Hlaing Tharyar and have discussion about research from phone with site coordinator. The researcher decided to meet some young women with physical disabilities at site office first as the area is so large and some places cannot go alone and local volunteer knows better about the area and young women with physical disabilities. So, to meet with both the local volunteer and some young women with physical disabilities, the date has been confirmed to meet on next week.

Next week on the first week of July, the researcher went to the site office and met with the local volunteer who is also actively participating in many community activities. That day is also a day that the site office has given physiotherapy care to the person with disabilities. The office open for physiotherapy care one day a week and the other day they are going into the site and give physiotherapy care and trainings. The local volunteer brought 5 girls who have physical impairment to meet with the researcher. Then, the researcher made a conversation with the young girls and their family member who came along with them one by one. After that the researcher chose carefully to 3 girls according to the criteria. The other 2 girls are younger than the 12 years old. At the same time, the researcher let them know that she is a student and the researcher from Mahidol University. She showed them her ID card and started explaining them the purpose of meeting with them. Following that the researcher gave a detailed explanation about the research, the ethic and the needs of their voluntary support. They were explained about their rights of decision on participation and dropped out anytime due to any inconveniences. The researcher made conversation with them in order to let them had feeling of closed friendliness with the researcher so that rapport building was started. After that the researcher asked consent from those girls' parents as they are under 18 years old. The researcher allowed them to make free decision and voluntary participation. The researcher provided the translated participant information sheet to them. However, some participants and their parents have no education. That's why the researcher needs to read for them and explain sentence by sentence to them until they understand. Then, the researcher made discussion with them in order to lead them consideration and to have voluntary participation. The researcher did provided her contact number and address to them to support in trust building and to get contact with them for their participation. After that, researcher had phone contact with them and got the voluntary participants. Both verbal and written consent received from the participants.

Then place for interview is according to the participant's choice. Next two days after getting consent, the researcher started to visit the participants' house with the local volunteer. As the local volunteer is from the INGO, it is easy to go somewhere in the township freely as the permission process and the authority are very strict in the area about doing research or doing some events. Therefore, wherever visit

to the participants, the officer from the NGO suggests taking the volunteer in case, the authority would not ask too much questions or the local volunteer will help for the permission to do research in the community without difficulty. Before started the interview, the researcher re-explained the information about research again and ensured their true understanding and willingness of participation. The other participants were also find while visiting to the community and asked the local volunteer and the participants about whether other people who would like to participate in the research as a participant. The process of getting consent and explaining about the information are the same with the first 3 participants.

Although the researcher planned to recruit from the 3 most obvious kind of physical disabilities, in an actual situation, there is also other kind of physical impairment which is obvious as a physical appearance. Therefore, researcher included some kinds of physical disabilities which have obvious physical impairment. However, according to the plan, those physical disabilities are started since they were born or since they were young. In addition, I chose the participants who are age from 13 to 20 to understand their sexuality, sexual and reproductive health.

To recruit the community members as research participants, the researcher approached to two or three people at the same time while visiting to the community and asked whether they can participate voluntarily. The local volunteer also helps to find the research participants for community members. A volunteer introduced the researcher to one self-help group and one community based organization which has worked for the person with disabilities. After that the researcher got the voluntary participants for key informant interviews.

3.5 Research participant selection criteria

The in-depth interviews were conducted on fifteen participants who are young women with physical disabilities and only 1 person is currently receiving support from NGO and other are not getting support currently. Some of the participants were received support from NGOs 2 or 3 years ago. Three or 4 times visit including at least 2 times interview or discussion with participants were conducted at the place where the participants were comfortable to take interview. In addition, seven

Key informant interviews were conducted and selected the participants purposively without age limitation or education limitation. The ideas and understanding about disability, sexuality of women with physical disabilities, attitudes towards women with physical disabilities, social support and level of support from community members, notion of self and subjectivities upon their body image and sexuality, sexual and reproductive health practices and the discourses were explored.

3.5.1 Participant selection criteria for young women with physical disabilities

13 -18 years old young women with physical disabilities, who are not married yet living in Hlaing Tharyar Township, Yangon were recruited. They have suffered physical disabilities from both at birth and later. The participants will have either formal or non-formal education. The participants are physical disabilities since birth and living in the Hlaing Tharyar Township for very long time and who is still in their teenage. I chose to young women who are age between 13 and 20 and who are single because they do not have experiences and they have many barriers to access the information about sexuality and SRH as most of the people in Burmese society believed that unmarried women and teenager should not know about sexuality and SRH because they are still young and they will get the wrong ideas if they know about sexuality and SRH. Then people believed that if they understand sexuality and SRH, they have more possibility to have sex in the early age and they will engage in dating at the early age. Therefore, they young women might have faced more SRH problems and they might face many barriers while seeking for SRH care.

3.5.2 Participant selection criteria for family Members

Close family members, parents or caretakers who live together with women with disabilities (Eg. Aunt, Uncle, Siblings, grandparents, etc). Among participants who are the family members, my first priority is mother because mostly mother have closer relationship than other family members. Mostly daughters share their feeling with the mothers. Therefore, if the participants live with both mother and father, mother was mostly likely to be a participant. However, if the participants

stayed with grandparents, father or care givers, and the one who voluntarily participate was recruited.

3.5.3 Participant selection criteria for health care providers

Health Care Providers including nurse, doctors, health care volunteer or physiotherapist, staff from the disabled resource center who give health care services and have knowledge and aware about disability were chose. Health care providers include nurse, doctors, health care volunteer and physiotherapist. Physiotherapist and staff from the disabled resource center was the first priority because mostly they physical disabilities have more communication and dealing with these two kinds of health care providers in this research area. The health care providers who have experience at giving health care services or physiotherapy care and have spent more time with physical disabilities than any other health care providers was recruited because they already have trust from the disabled person, good communication with disabled person and they have much knowledge than other health care providers who are not familiar or less in touch with the disabled person. At least 6 months they have been working with women with physical disabilities because within 6 months they can have trust from disabled person and they understand well about their health problems and their social problems by building rapport between them.

3.5.4 Participant selection criteria for community members

Neighbors and friends and community leaders who are closed to women with disabilities or who are in touch with disabled people. Within neighbors, friends and community members, being close or being in touch means, they have closer friendship or they know the women with physical disabilities for long time at least 6 month. Moreover, the researcher asked to the woman with disabilities that who would be their closest friends or neighbors or community members. Then, according to their voluntary participation, the participants were chose.

One community members is a person with disabilities and who is currently working in the self-help group. The community members who is familiar or currently working for the services or social activities with person with disabilities and who lived

in the Hlaing Tharyar township and have experienced more than 6 months working with the person with physical disabilities.

3.6 Research Methods

In order to answer the research questions and to reach the research objectives, methods of qualitative data collection were used. It includes in-depth interview and key informant interviews. Total 22 participants were involved in this study. There were 15 participants being recruited for in-depth interview and 7 participants being recruited for key informant interviews.

3.6.1 In-depth Interview

Altogether, fifteen participants were interviewed in the in-depth interview. Before starting to the interview, meeting in the office first, visiting their house and informal discussion to build rapport with them and to get their voluntary participation were done first. When the actual interviews had started the researcher explained about the research, the ethic and their right as research participants. After making sure of their understanding, the researcher confirmed their voluntary participation with oral consent and asked their agreement for the tape recording, note taking and photo taking. Their interviews were carried out after their agreement.

At first, the participants feel shy to express their feeling. However, as the participants are female and the researcher is also a female, therefore, building trust between the researcher and participants is faster than expected. In addition, understanding on the participants and their situation as a woman makes me act more friendly and closer during with the research participants during each interview. However, very limited numbers of photos were taken during the conversation due to the inconvenient and reluctant of some participants. Some of the participants know the researcher since the researcher used to work in the Disabled Resource Center. Therefore, building a rapport is faster and the participants feel like a sister to the researcher. However, when it came to ask about the sexuality and their SRH practices, mostly the participants are hesitant to talk. Therefore, the researcher needs to change the method of interviewing into sharing experiences and knowledge between

participants and the researcher. Then, the participants become to feel at ease to talk about these issues.

I explained my current status as a student whenever before the interview again. In-depth interview were taken in different places according to the convenience of the participants. Some of the participants' houses are very small, very close to other house and there are many family members living in the house which has no room. Therefore, for that kind of participants, the researcher asks the participants in what places they want to have the in-depth interview. The entire interview last 1 -2 hours and most of the participants were interview for at least 2 times. Sometimes I listened to their story and the things they would like to say rather than asking my own research questions. In this manner I came to understand more and more about their life and their sexuality and reproductive health practices and the relating factors.

In the follow up meeting, the missing points were mainly focused first in order to get the complete picture in relate to their sexuality, SRH practices and their notion of self and subjectivities. After that main points of previous discussion were asked to validate the data and to confirm the data.

3.6.2 Key Informant Interview

Key informants interview were conducted with seven persons from different background. One physiotherapist, one university student, one members of community based organization, one neighbors who is also an active volunteer in many social activities in the area and three mother of women with physical disabilities who have come from different background. The interviews were carried out separately according to their availability and the place convenient for them. The physiotherapist and two mothers were interviewed in the site office of TLM. The members of community based organization and a neighbor were interviewed in their house and office. One mother was interviewed in her house. The university student is a friend of one of the women with physical disabilities and she wanted to have interview in her friend's house.

3.6.3 Field notes writing

All the activities in research such as the objective, findings, the subject feelings, interpretation and suggestions obtained from the interviews, and chatting were jotted down in the field note writing. In addition, mistakes and the problems that the researcher encountered during the research process were also jotted down for the lesson learnt. All the field notes then elaborated and integrated with the findings from the in-depth interviews and key informant interviews so that a holistic picture with regards to the research objective was provided.

3.7 Research Tools

- 1) In-depth interview guidelines
- 2) Key informant interview guidelines
- 3) Notes taking with note book and pen
- 4) Camera
- 5) Audio recorder for voice recording.

In addition to the above mentioned items, I myself was performed as a research instrument. She was the main guiding instrument involved in the whole research process to achieve the research objectives. The guidelines for in-depth interview and key informant interview were developed based on the conceptual framework. The guidelines were not translated into Myanmar because direct translation to Burmese language is not easy as some words don't have the same meaning like the original English one. Therefore, during the interview the guidelines were explained one sentence by sentence to the participants and modified accordingly based on the understanding and feasibility encountering during the interview. The camera carried along with the researcher and voice recording was taken throughout the process of interviews. Note taking was also done during the interview.

3.8 Field Work Period

The whole field work period was 5 months. The period started from July 2014 to November 2014. Period for data collection was from first week of July to

November 2014. The final analyzing and report writing was from December 2014 – March 2015.

The researcher was starting from finding out young women with physical disabilities in the site office of TLMM start from the last week of June 2014. Starting from that time the researcher meeting with some young women with physical disabilities and discussed, gave information about the research project's objectives and asked for participation voluntarily. The interviews were started at the second week of July and at the middle of September, researcher finished interviewing 10 participants and at the same time, key informants were interviewed. Then to have more information the researcher found more participants and more key informants. The researcher do follow up, discussion, chatting, checking the information from the previous participants and analyze the answers and visit to the previous participants and do interview or informal conversation at the same time. At the end of every interview, the researcher translated field notes and translated the voice recording file. Then, transcribed and analyzed in order to be able to find out the missing point and to validate the consistency of information. Interpretation and report writing was carried between January and March along with the content analysis.

3.9 Data processing and analysis

Data processing and data analysis was done along with the data collection. After each and every interviews and visiting to the participant's house, the information was jotted down as field note. Immediately, the jotted field notes were expended with the transcribed data from the voice recorder and translated into English. The expended data were read time by time and the researcher made sense of the data. The open coding was done first. Then, NVIVO software was used for analyzing data and doing closed coding. After all, the data were classified. The coding was validated by major advisor and the same categorized groups were organized. Some documents like journals, pamphlets and magazine were reviewed to understand the discourses. Both Foucauldian and Fairclough's theoretical of discourse analysis were used to analyze the documents and to analyze everyday discursive practices from the community or family and to analyze which discourses are produced and reproduced. By reading field

notes and transcribed it into paragraph and analyze the discourse through this field notes.

3.10 Validity of the data

3.10.1 Researcher's identity, Trust building and Inter-subjectivity

The research is a very sensitive issue for Burmese people. According to the culture, people do not talk about the things related to sexual and reproductive health. People usually hesitate to discuss with the health care providers like doctors, nurses, etc about this issue. It is also an unfamiliar issue and the natures of the participants are also shy, unconfident, isolated and discriminated. Therefore, trust between the researcher and the informants were the most essential task. It was not only for smooth operation of research, but also to provide the true, quality data from the participants without bias and reliable. Therefore, trust building between researcher and the participants played an important role from the start of the research and along the entire research.

Although the researcher is a female and the participants are also female, it was still a big challenge to both of the researcher and the participants. I introduced myself that I came from the same residential population like them. As some of the participants already knew the researcher as a site coordinator from the Disabled Resource Center of TLMM 5 years ago, the researcher needs to make sure her current identity as a student from Mahidol University. In addition, the researcher needs to make sure the purpose of the research and why she was meeting with her. The researcher showed them her student ID card and explaining carefully about the purpose of visiting. As the issues about sexuality and reproductive health were very unfamiliar even to the key informants, the researcher took time patiently to give about the research objectives and the scope of sexual and reproductive health. I took time to visit them several time to build trust and rapport. I explained about my previous job, and told them that I have cousin who is the same age as them and lives in the same house, a teenager and a cousin who is a person with disabilities. I let them know that

she can understand them as a teenager and a person with disabilities as I also deal with my cousin.

I showed my friendliness and showed them that I treated them like my own sister. For the first time meeting with them, they called me “teacher” because they call all the staff from the disabled resources center or people who comes from the university like that. However, after trust building was done, they called the researcher “Sister” and it makes them felt free to share without any reluctance throughout the interview. I made them feel that I was also a teenager and I also had experiences as a teenager and sharing experiences make them felt free to talk about their sexuality, their feeling, their subjectivities and their sexual and reproductive health practices.

The interviews were conducted starting with informal conversation and when it becomes more familiar the interview were started formally. However, the researcher remained herself to avoid power relationship as being a researcher and a graduate student. And try to be a lay person as them. I listened to their story with sympathy and respect as it is important throughout the process in pursuing and sustaining trust from them.

The researcher paid attention without any interruption during conversation and respect their ideas and concept and their behavior without making judgment on it.

3.10.2 Reflexivity

Researcher kept herself conscious to be aware of her own bias which might arise and influence the data collection and the interaction with informants. The bias may arise from her previous knowledge, her personal status, experiences, educational status and theoretical concepts of the research. However, researcher reminded herself to focus and emphasized on the insider point of views. Researcher reflects her actions and her conversation not to influence by her own bias.

3.10.3 Triangulation

Triangulation refers to the use of more than one approach to the investigation of a research question in order to enhance confidence in the ensuing findings (Bryman,N.A). Method triangulation refers to the use of more than one method for gathering data (Denzin, 1970. cited from Bryman n.a). In this method

triangulation was done by collected the data from different methods including in-depth interviews, key informant interview and observation. In addition, I applied more than one theoretical lens in supporting this research to achieve theory triangulation.

3.11 Ethical consideration

The researcher had the online Institutional Review Board (IRB) Exam and the passing result was submitted to the IRB of Mahidol University for conducting the research before going to the field. This research was conducted after getting the approval from the IRB, Mahidol University.

3.11.1 Privacy

The privacy of all participants was assured and their privacy was being respected. As the research includes sensitive issue, the privacy of participants was the main concern. The researcher considered for the place of interview that are private for interview communication, to generate more fruitful information and for the conveniences of the participants, the location of the interviews was adjusted and chosen based on the participants and the privacy and safety of the both researcher and informants. There was no third person walked passed by or overheard the conversation.

3.11.2 Informed consent

The participants were explained about all the rights include the right to be sufficiently informed about. They were also explained about the right to make free decision about the participation in the research, the right to withdraw at any time for any reason, the right of decision on mentioning their real name or pseudonyms in the research report.

The translated information sheets including information, researcher's identity and contact address were given to the participant to validate that the researcher was part of their community and for any necessary inquiry and contact. The participants were recruited with oral consent first. And most of the participants are under age of 18. Therefore parental consents were also taken from parents. Then, the

written consent paper was provided to both the participants and their parents (mother or father) to receive consent. Permission of tape recording, note taking, photo taking was asked before starting of every interview.

3.11.3 Confidentiality

As the research touched culturally and religiously sensitive issues, the confidentiality was also considered as an important matter. Preventing from being harmed and feeling of well being of participants was important in conducting qualitative research. Thus, all participants' identification such as names and places were replaced with pseudonyms in the report. Every information and experience shared by participants was kept secret. All the materials used in the study were promised to keep under safety. In addition, the approval of the utilization and publication of their provided information in direct quotations in the report was asked.

3.11.4 Benefit and reciprocity

Small gifts were provided after interviewing as a token to compensate their time sharing and appreciation of their contribution at the end of interviews. Sometimes, the participants chose somewhere they are comfortable to have interview with the researcher one by one. Therefore, the researcher provided some money for their transportation. In addition, the researcher provided lunch and tea or snack for the participants during interviews.

Moreover, mostly the sexual and reproductive health issue is unfamiliar to the many people in the Burmese community. Therefore, the researcher provided information about sexual and reproductive health to every participant and when the participants asked questions about them, the researcher answered one by one and explained until they understand. The participants were really satisfied as some of them admit that they would like to know that kind of information for long time ago but nobody provided any information for them. The researcher also provided the information about where they can receive sexual and reproductive health care and give direction where they can get more information. Therefore, it was expected that at the end of the research period, the participants gain knowledge about the sexual and

reproductive health and understanding about their own body, sexuality, changes during teenage and where they can go for their sexual and reproductive health care.

The findings and evidences gained from this research are expected to be shared to health policy maker and provide recommendations for governmental institutions, private institutions and non-governmental organizations to assist women with physical disabilities in the area of sexual and reproductive health. Moreover, the findings and evidences expected to provide information to the health care providers and health care services to give the better information and services to the women with disabilities while overcoming the cultural and religious barriers.

CHAPTER IV

RESEARCH FINDINGS

In this chapter, the researcher starts with describing general social context of Hlaing Tharyar and socio demographic characteristic of participants. It answered the discourse on the disability, discourses on the women with disabilities and the discourses on the sexuality of the women with physical disabilities. Moreover, in these findings, the family attitudes, friend's attitudes and community attitudes towards women with physical disabilities are also answered. Then, how these discourses, attitudes and support from the community members have impact on the notion of self and subjectivities are also included. Furthermore, this finding includes how the community member's reactions towards women with physical disabilities and self and subjectivities of women with disabilities have impact on the sexual and reproductive health practices.

4.1 General Social context of Hlaing Tharyar Township, Yangon

Yangon is a former capital of Myanmar. Yangon is the country's largest city with a population of over five million, and it is the most important commercial centre, although the military government officially relocated the capital to Naypyidaw in March 2006.

In the profile of Yangon city, Yangon was founded as Dagon in the early 11th century (1028–1043) by Mon people, who conquered Lower Burma at that time. Dagon was a small fishing village in which the center is Shwedagon Pagoda. In 1755, King Alaungpaya conquered Dagon, renamed it as "Yangon", and added settlements around Dagon. The British captured Yangon during the First Anglo-Burmese War (1824–26), but returned it to Burmese administration after the war. The city was destroyed by fire in 1841. Yangon is administered by the Yangon City Development Committee (YCDC). YCDC also coordinates urban planning. The city is divided into

four districts. The districts combined have a total of 33 townships. Each township is managed by a committee of township leaders, who make decisions regarding city beautification and infrastructure. Yangon is the most populated city in Myanmar although estimates of the size of its population vary widely. (All population figures are estimates since no official census has been conducted in Myanmar since 1983) A UN estimate puts the population as 4.35 million in 2010 but a 2009 U.S. State Department estimate puts it at 5.5 million.

Hlaing Tharyar is one of the townships within the Northern district of Yangon. It was settled in 1985 and the total population is about 340332, according to 2008 data. Hlaing Thayar is the most developed of the new satellite towns founded in the 1980s, Hlaing Tharyar Industrial zone consisted of mostly garment and other light industries, is one of the largest industrial parks in the country. Showpiece gated communities of the wealthy like the FMI City and Pun Hlaing Garden Residences in the southeastern part of the township are the domain of the country's elite and are arguably among the best communities in the country.

After Cyclone Nargis, the township experienced a jump in population due to refugees. Transportation to the township is also convenient and easy. The township has 46 primary schools, eight middle schools and four high schools. Yangon Technological University also maintains a campus in Hlaing Thayar. In this area, there are also famous private hospitals, a public hospital, and many clinics and pharmacies.

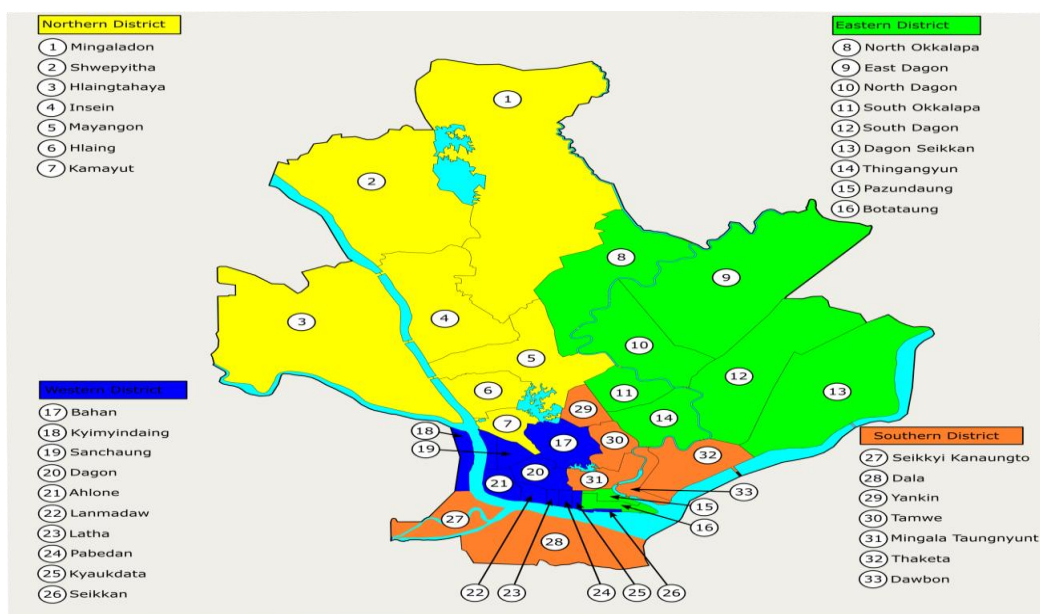


Figure 4.1 Map of Townships in Yangon

However, most of the people living in this area are grass root level people and therefore are marginalized. People know this area as a slum area because there are sex workers, leprosy patients, disabled people, daily workers, HIV patients and more than 100 brothels and mobile sex workers live around this place. There are also more than 10 International Non-Government Organizations (INGOs) and around 30 or more local nongovernmental organizations who work for these vulnerable populations. Despite Hlaing Tharyar being an industrialized zone of Yangon, the quality of life of people in this area is still poor. Extreme poverty in this area makes people suffer from social and economic problems. Poorly constructed roads, improper housing and poor sanitation also lead to many health problems in this area. In addition, they rent the land to build their houses for between 5000-15000 Kyats (5-15 US\$) per month on an income of daily wages of between 500-2000 Kyats per day (0.5 -2 US\$). Low education also leads to the poverty in this area. In addition, the crime rate in this area is also high. All in all, this area is highly discriminated because marginalized groups live in this area and mostly they are beggars, daily workers and the unemployed. INGOs and Local NGOs work in this area for different kinds of projects for those marginalized people.

Hlaing Tharyar is one of the major areas for many diverse groups. Most of the people living in Hlaing Tharyar are Buddhist. However, other religion, Christian, Islam and Hindu are also living in this place. Most of the people are Burmese and other ethnicity like Karen, Mon, Chin, India, Chinese, etc are living in this place too. After Nargis Cyclone, the migrants from delta area moved to Hlaing Tharyar and population become dense.

Hlaing Tharyar is situated along the Yangon River. As soon as crossing the river, a large and elite residential FMI city and many factories of this Industrial zone can be seen clearly. However, as soon as passed this elite residential area, there are many houses build with bamboo and plastic cover in every corner of the road and along the road. Most of the people living in this area are living illegally near the corner of the factories or along the main roads.



Figure 4.2 Roads in Hlaing Tharyar Township

In this township, people who have enough money buy the landscape and then divided too many parts and they lent to the poor people. Therefore, houses are very closed to each other and very narrow and small. Most of the people living in the place which has been own by factories and not yet build. That's why they are living illegally in other people land. Most of the houses were built by plastic bags or bamboo which is only 12 feet in length and 10 feet in width. The houses don't usually have doors and rooms. All the family members live in the one place. In addition, a crime rate is also high in this township.



Figure 4.3 The houses illegally built near the factories



Figure 4.4 The house of the participant

In summary, Hlaing Tharyar is one of the urban areas of Yangon which is one of the most developed cities of Myanmar. However, the living condition is poor and most of the residents are low educated or lack of education. Furthermore, poor sanitation problem, lots of socio- economic problems, diverse groups of people who are marginalized and inequity of business opportunity shaped a clear social class are the characteristic of this area. Even among the Yangon resident, if someone tells that he or she is from Hlaing Tharyar, the first impression is look down among the other resident. Mostly people know this area full with marginalized people, people who are poor, who are uneducated, who are aggressive, possibly the criminals. Lots of Non-governmental organizations and local organizations are helping these marginalized people in this area. However, the safety of the place is still low and people can clearly see the poor development of this area. Although government helps for infrastructure and non-government organization helps the socio-economic life of marginalized people, there are many things to take care of and the poverty still challenges the development, social and economic equality of people in this area.

4.2 Socio Demographic Characteristics

4.2.1 Women with Physical disabilities

Mostly, these young women with physical disabilities are coming from poor family. Just two or three of them are from lower middle class family. Most of them are migrated from another province to Yangon. Some of them are mobile families from one place to another. They live in one place for at least 2 years and then they move to another place.

Mostly they are living in a bad living condition. As this township is a big slum area, the houses are very close to each other without even have a door. The whole family about 7 or 8 people lives together in the small house with no room and doors. They have to rent for the place and then they build the small houses. In this area, mostly people are uneducated and they are daily workers. Moreover, this area has recorded as one of the highest criminal rates in Yangon.

Many of the families in this area are daily laborers and this area is an industrial zone. Therefore, they are working in factories. Many parents cannot afford their children for their education. When their children reached to secondary school, mostly they ask the children to leave the school and work in the factories. For the young women with disabilities, they are not the priority for education in the family. Therefore, mostly they live in the house and they were isolated from the community. Even they attend the school and have contact with community, they do not have much confident to communicate with other people. However, most of the girls that I have interviewed are attending school and even they do not attend the school, they have contact with some organization that helps them to participate in the community activities. Therefore, they are not much isolated from the community. Moreover, most of the families in this area are extended family. At least, two families are living together in the same house and also grandparents and other relatives are sometimes living together in the same house.

Furthermore, they have different kinds of physical disabilities. Some are obvious but some are not significant. In this study, different types of physical disabilities such as polio, paralysis, congenital deformities and cerebral palsy are the major disabilities within the fifteen participants. Mostly more than half of the participants have visually significant disabilities. Six participants have cerebral palsy since they were infants and because of the cerebral palsy their whole body has difficulties while they walk or do something as their muscles are stiff. They cannot control their body and it is obvious that they have physical disabilities as this disability is limited to their mobility. Polio is also obvious and people can notice immediately that the participants have physical disabilities. However, most of the people are misunderstood or confused between polio and cerebral palsy although they have different characteristics. If the participants have polio, her lower body parts are smaller or her legs are smaller. If the participants has cerebral palsy, her whole body is stiff or floppy and while walking they cannot control their balance. However, the participants who have congenital deformities think that their disability can hide from being notice. Mostly, the participants with congenital deformities do not have legs in this study. Therefore, they use pseudo legs and they believe that with the pseudo legs they are like normal people and nobody notice about their impairment. However, three of the

participants has other kind of disabilities which they have an obvious disfigurement. For example, one of the participants has bend spinal cord and her hip joint had been undergoing surgery. Therefore, she looks short because of her bend spinal cord and her legs are also disfigured. Another participant has paralysis due to accident when she was 14 years old. She cannot walk, she cannot hear clearly and her eyes are also become deformed. Therefore, she feels ashamed of her image.

In addition, more than half of the participants are student and they are polite and hard working in studying. However, they are frustrated about their disability because they think that it is a limitation to their capability. However, the participants encourage themselves that if they become educated person, they can be a normal person like other and people will not look down by other people as a person with disabilities. On the other hand, most of the participants are depending on the other people so much because they think that they cannot live independently and the families also think that they need to be protected and some family members think that they cannot live independently. In addition, they do not want to go outside and dealing with other people as they feel ashamed of themselves and they are afraid that other people will look down on them and discriminate them. Most of the participants said that they prefer living inside the house than going outside. Moreover, more than half of the participants said that they do not want to make friend with other people as mostly people look at them as a disabled person and discriminate them. Therefore, although they have friends, it just a few people. All in all, they participants are afraid or lack of confident to deal with other people and it is difficult for them to trust other people and make friends with other people.

Some of them are students and some of them are not student. Therefore, their daily routines are quite different. For the students, they explained that they have difficulties in transportation for going to school. Someone has to send them to school but for some student, they can go by themselves. Most of the participants who are students go to school with someone who is not only family but also the family hired trishaw for them to send to school every day. As in this area, the road are in poor condition and no barrier free, makes the person with physical disabilities difficult to go to somewhere without the assistances. For the young women who are not student mostly stay in their house alone. Some of them are taught by their parents at home.

However, some participants said that they would like to go outside as staying alone in the house makes them bored although they have some family members at home with them. During the weekend, some participants explained that they would like to join to the religious festival or some events but they could not join as they have difficulty to go out. Some explained that their family does not allow them to go out or mostly the family members go out by themselves. As most of the places are crowded, the family worry that they will be lost in the crowded place and some think that to go out with them is a burden and need special care for them. Most of them are not living in Hlaing Tharyar Township since they were young. They are migrated from another area. Therefore, when they moved to Hlaing Tharyar, they have to adapt life of Hlaing Tharyar. Some of the participants explained that they are afraid at first because they worried that people will not warmly treat like the places they were lived before. It is true that at first they were bullied. If they go to school, people make fun of them and insult them. However, now living here for more than 4 or 5 years make them more adaptable to the place. However, they still feel that they are discriminated by other people.

Moreover, the condition of the study area is also a problem and make more vulnerable towards the women. It is because as it was mentioned before, their houses are so close to each other and mostly houses doesn't have proper door or room. Some people doesn't have toilet. Therefore, they have to use public toilet. Some have toilet but they are not very good. Moreover, when they take a bath, they do not have a private place for taking a bath. Sometimes, their shower place is in front of their house where all of the people who passing can see what they are doing and how they take showering. All in all, mostly other people can see most of the thing they do, for example, changing clothes or taking shower. As this area is not a very safe place, this is one of the reasons which can lead to sexual harassment cases.

Table 4.1 Socio Demographic Characters of young women with disabilities

No	Name	Age	Types of disabilities	Education background	Family background
1.	Hla	14	Cerebral palsy (Hands and legs are stiff, floppy, cannot crawl, difficulties in moving their hands, legs and body and might not stand properly if it is too serious.)	Non	Parent, 1 older sister, 1 younger sister and 2 younger brother
2.	Wai	14	Torticollis (Abnormal, asymmetrical head or neck position)	High school	Live together with mother, 2 older sister and other relatives.
3.	Mar	13	Polio (Mostly the lower body part such as legs and hip are not in balance position or legs becomes small and cannot walk properly)	Non-formal education	Live in the center for person with disabilities.

Table 4.1 Socio Demographic Characters of young women with disabilities (cont.)

4.	Hnin	14	Cerebral palsy	Secondary School	Live together with grandmother, uncle and aunt. Parents died since she was infant.
5.	Zin	14	Cerebral palsy	Non	Father died 4 years ago. Live together with mother and older brother and sister in law.
6.	Aye	14	Cerebral palsy	Secondary School	Parent and 2 younger brothers.
7.	Moe	14	Hip Joint Deformities due to Tuberculosis (TB hip joint). Her back bone is bending. Her upper and lower body parts don't have balance posture. She becomes short due to bend bone.	Secondary school	Live together with mother. Father leave them since she was young.
8.	Thandar	14	Congenital deformities (2 legs are bending backwards, cannot sit, move by crawling)	Secondary School	Parents and she is the youngest daughter among 5 siblings. She has a brother who is the same disability as her.

Table 4.1 Socio Demographic Characters of young women with disabilities (cont.)

9.	Ei	16	Congenital deformities (Missing one leg)	Secondary school	Parents and 2 older brothers. Live together with other relatives.
10.	Pyone	18	Congenital deformities (Missing One leg)	Bachelor degree student	Live together with younger siblings and mother.
11.	Yi	16	Paralysis due to Tumor in the brain and accident in the factory when she was 14 years old	Secondary School	Live together with parents and 3 siblings.
12.	Myat	16	Cerebral Palsy	Non- Formal Education	Only daughter live together with parents.
13.	Myo	17	Polio	Secondary School	Live together with grandmother. Parents and other family members live in another house just close to her house.
14.	May	20	Her two legs joint are abnormally large, so that she has difficulties in walking and Blindness	Non	Father Died. Mother live with her new husband and family. Live together with 2 younger siblings. Older brother lives in another province.

Table 4.1 Socio Demographic Characters of young women with disabilities (cont.)

15.	Htwe	19	Cerebral Palsy	High School	Father, Step- mother and her two sons. They are living together in the same house. She has 5 siblings. But they are living with their own family
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4.2.2 Community Members and family members

There are 4 community members and 3 mothers of women with physical disabilities have been interviewed. Mostly, these people are familiar or have closed relationship with the young women with physical disabilities. To understand the discourses, attitudes towards young women with physical disabilities and social support from the community, I have interviewed 7 key informants who are from different background. However, they have been familiar with the disability issues and they are closed people to the women with physical disabilities. Moreover, they have been participated in many activities relating to the disability and person with disabilities. One of the friends of women with physical disabilities also interviewed and she answered about her feelings towards her friends and how other people response to the women with physical disabilities.

The social support and attitudes take an important part in life of woman with physical disabilities. The way people see the disabilities and their understanding about the disability and sexuality has effect on woman with physical disabilities in different ways. It has effect on their health, education, daily life and the information which is effective for them in their daily life.

The support can be seen in two levels, family and the community. Mostly the young women with disabilities get the support from the family. Mostly they get the protection, educational support, and emotional or mental support from the family. On the other hand, some supports are coming from the community including neighbors,

community organizations like NGOs and religious or social group within the community. The community gives supports that can be seen like training, giving information about where they can access the health care, educational support or for livelihood and vocational training.

Table 4.2: Socio Demographic Characters of Community members

No	Name	Age	Occupation	Education Background
1.	Oo	22	Physiotherapist	Bachelor degree
2.	Thin	18	Student	Second year university student
3.	Maw	34	Working at the gourmet factory and members of self-help group	High School
4.	Win	53	Housewife and Volunteer (Community based organization)	High School
5.	Ni	34	Housewife	Secondary school
6.	Aye	47	Retired teacher	Bachelor degree
7.	Kyi	51	Selling snacks and food	Secondary School

4.3 Discourse on impairment and incapability

4.3.1 Cut legs and hands: Medical Discourse on impaired body part

In the community, there are lots of terms using for the disability. Usually people are used to call them according to their body impairment. Most of the terms were provided directly due to their impairment. These terms reflected the body impairment and sometimes it becomes the symbol for person with disabilities. For example, people see someone without legs or hands; they named “*Chae Pyat, Lat Yat*”, “*Dokita*”. It means people with Cut legs and hands, people who suffer from a very big problem. Moreover, when the person use the wheelchair, they called “the

wheelchair person”, “Polio”, etc. These terms are familiar terms in the community. People easily call those terms when they see person with disabilities.

One of the participants explained that she has been called as a “Quail” because one of her legs is shorter than another one. As the bird, “Quail” is lifting one leg while sleeping; if people see them they think it has only one leg. Therefore, she told that since she was young she is named as “Quail”

“One of my neighbors calls me “Quail”. At first I think it is a bird name. Then people told me he called me because quail stand with one leg and the other is much shorter. Then I realized why he called me quail. (Maw, members of self-help group)”

According to these participants, it showed that people with disabilities are living under the discourse which is clearly described their body impairment. This discourse is coming out from the medical knowledge. If someone does not have legs and hands, they called “*Chae Pyat, Lat Pyat*” and it has symbolic meaning of their missing body parts. People use to call the person with disabilities and the terms are depended on their impairment and missing body parts.

4.3.2 “*Ma Than Ma Swan and Ma Than Swan*”: From not strong, not capable to not strong but capable: State Discourse

“*Ma Than Swan*” is a word that most of people in Myanmar are familiar with. This is the term that the government officially uses to call the person with disabilities. Long time ago people called “*Ma Than Ma Swan*”. It means “Not strong, not capable”. Before that people call the person with disabilities in many different ways according to their body impairment. However, later on, people called “*Ma Than Ma Swan*”, it means not strong and not capable. It was officially used in everywhere.

The term “*Ma Than Ma Swan*” was written in the constitution of Myanmar. Many of the people with disabilities wanted to change it because they felt that it is completely discriminated them and it oppressed their capability. However, the Department of Social Welfare resisted changing it because it was against the constitution. It has been started using the term “*Ma Than Ma Swan*” since 1958. Then, around in 90s, one of the members from parliament proposed to change this term into “*Ma Than Swan*” which means “not strong, but capable”. Since, that time the

Department of Social Welfare and other community organizations advocated the person with disabilities to call “Ma Than Swan”. In 2013, constitutional referendum its overall change including this particular words.

People wanted to change the term that is used for person with disabilities as they have been advocated with the UN Convention on the rights of person with disabilities and they want to translate “Person with disabilities” into Burmese word. Moreover, people wanted to change the word “*Ma Than Ma Swan*” because most of the person with disabilities feels that the word discriminated them and outcast them from the society. Therefore, most of the person with disabilities resisted to call “*Ma Than Ma Swan*”.

Furthermore, in Myanmar, if we use “*Ma Than Swan*”, everyone understand that it is “person with disabilities”. However, using “Ma Than Swan” means not only “Not strong”, it has a symbolic meaning that “the person has some kind of body impairment”. It has a sense of impairment. The government wants to have man power and the productivity from each person within the state. However, the person with disabilities has been clearly described as not strong person according to the term “*Ma Than Swan*” and it follows with the concept that they cannot have the same capability like other people.

The other participants, a mother of young woman with physical disabilities shared her opinion about calling “Ma Than Ma Swan” or “Ma Than Swan”.

“I’ve heard that most of the people called “Ma Than Ma Swan”. So when I heard about it I just try to fix the term they used, instead of “Ma than ma swan”, I asked them to use “Ma Than Swan”. I think when we use “Ma than ma swan”, that terms make person with disability to feel outcast from the society and make PWD to be depressed. For “Ma than swan”, the word makes much better feeling for the PWDs” (Kyi, mother of young women with physical disabilities).

In addition, according to the state, people need to be productive and useful for the country. However, when they called “*Ma Than Swan*”, people look them as people with disabilities who cannot have the same productivity like other people for the country. Although most of the people are talking about the job opportunity for the person with disabilities, the owner also does not want to give a job to the person with

disabilities because they think that they cannot work like other people who do not have impairment or they will take more time and less productivity than other people.

4.3.3 “*Lu Kaung and Ma Kaung Thu*”: Medical Discourse on normality

In the community, most of the people said “*Lu Kaung and Ma Kaung Thu*”. According to the Burmese Language if it is directly translated, “*Lu Kaung*” means people who are good or good people and “*Ma Kaung Thu*” means people who have bad thing or bad person. However, the idea or concept of good and bad in this sense is not about people who doing good things and who are doing bad things. While the researcher asked why they used this language for person with disabilities, they answered that “*Lu kaung*” means a person who do not have any impairment and who have a normal physical appearance like other people. “*Ma Kaung Thu*” means a person who have impairment and who cannot work like other people and who do not look like a normal person. Therefore, the researcher continued asking about what is normal person, they answered that normal person mean a person who have good legs, hands, body and who does not even have a flaw on the body and who do not have any impairment.

When people use “*Lu Kaung and Ma Kaung Thu*”, it is not about a good person and morally deviant bad person. It comes from the medical knowledge. According to the medical knowledge, the body must have full body parts and impairment is medically something wrong with the body. Furthermore, the meaning of “*Lu Kaung*” and “*Ma Kaung Thu*” in this sense is somehow related to the meaning of normal and abnormal. In the dictionary, they explained “Normal” from the medical point of view as follow; free from any infection or other form of disease or malformation, or from experimental therapy or manipulation. Therefore, when people do not have full body parts and have impairment and malformation of body parts they are described as a deviant from normal. Therefore, when people in the community used “*Lu Kaung*” and “*Ma Kaung Thu*”, it has a symbolic meaning to “Normal” and “Abnormal”.

In addition, the participants explained that “*Lu Kaung*” is normal person and they have capability and can work. However, “*Ma Kaung Thu*” is not a normal

person who have body disfigurement and impairment and who cannot work or does not have capability to work like other people.

4.4 Discourse on sexuality

Burmese society is a conservative and strictly follows the cultural norms and traditional practices. As time passes, some of the norms and practices become faded in the modern society. However, sex is still a taboo in the society.

In addition, while talking about sexual and reproductive health, people are still confused and their concepts and thinking about sexual and reproductive health is as negative as talking about sex. Women do not usually discuss about their sexual and reproductive health or they are not openly talked about it within the family and even to the health care provider. Whenever, women have some problem about sexual and reproductive health, they do not usually go to the health care center as they believe that talking about it is a shameful thing. In this study, the researcher was exploring the sexual discourses related to the sexual and reproductive health of women with physical disabilities and interpreting their feelings, understandings and knowledge about the sexuality, sexual and reproductive health. The findings showed that women with physical disabilities have been experiencing difficulties to express their sexuality being as a woman and being as a person with disabilities due to the sexual discourses and the sexual discourses have so much influenced on their practices related to their sexuality and their SRH.

4.4.1 Moral Discourse on Sexuality

Most of the participants answered that sexuality is a shameful and polluted acts and it is for married women or couple. Sex for unmarried women is sinful and bad acts. It is insignificant for the unmarried women. One of the key informants explained as follow;

“Sexuality is a shameful thing and I have learnt that it is not something that we should do before marriage. If you ask me about sexuality, in my mind the first thing I’m thinking about having sex. Is it true? I’m not sure. I think sexuality is not a very important thing. I think it is something which

is important only after marriage. As a Buddhist, life is too short and there are many thing important than sexuality” (Hay, Health care provider).

According to this health care provider, sexuality is a shameful thing and it is only doing during adulthood. If it is happened before marriage, it is a bad thing and those people are morally deviant.

It is also a moral discourse. Sex is a taboo for the Burmese society according to culture and religion it is a dirty thing. While interviewing, the key informants and young women with physical disabilities response to the researcher that even talking about sexuality is a dirty thing in their concepts. While answering about their sexuality, they just whispered because they do not want other people to hear what they said and they are afraid that other people will criticize them as bad girls. They are afraid that if they talk about sexuality or discussed about sexual and reproductive health, people might think that they are morally deviant.

One key informant explained that young women with disabilities can love and can have relationship if they want. However, it is better to have relationship when they become adult not in the teenage time. It is because the informant believed that sexual desire and sexual act is only allowed to do when people married. Moreover, women need to take valuable on their body to be pure without sex before marriage.

Another key informant said that according to the religion and culture, sex is a morally deviant thing and sex is a dirty thing. She explained that she is a member of one religion group. According to their group believed, she cannot do some kind of sexual act. If she is engaging to much in sexual act, she believed that her soul and body become contaminate so that other people can easily hex her and curse her. Therefore, she explained that as a woman, we should not have too much sexual desire and even after marriage, if women can avoid sex it is good. That’s why young women who are not married yet should be more careful not to engaging in sexual relationship because people will assume her as a bad girl or morally deviant person if she has sexual relationship with somebody.

“But mostly women don’t show her feeling first and it is because of culture, dignity, religion and parents. According to the religion, sex is a dirty thing. For me, I injected some kind of drug on my body and it is because of my religious belief. It is a drug for preventing from witchcraft

and hexing. For example, if I do oral sex, the drug won't be effective.”
(Maw, self-help group member)

In addition, in this area of research study, most of the people are poor. The economic background of the each family is not very much different. The education level is also not much different. However, their understanding about sexuality and sexual desire are the same as they think it is a shameful and bad thing.

4.4.2 Sexual discourse on the young women with physical disabilities

One of the objectives of this study is to understand the discourses on the young women with physical disabilities who are age between 13 or 20. While they are still in their teenage, the study showed that they are influenced by these discourses and their sexuality has been oppressed. However, some participants have some kind of fantasy in their life about boys. They want to date with some boys who are honest and who they can rely on. It is because they think that they are not strong and do not have capability like other people. So they need someone who can take care of them, who can understand their disability and who can support them in their everyday life activities.

4.4.2.1 “Stay away from boy”

The participants explained that their teacher, neighbors and family told them to stay away from boys when they become teenagers.

Wai, a girl with congenital deformities who is a high school student

She is a young woman with physical disabilities. She has congenital deformities called Torticollis since she was born. Her neck is slant and her body position is asymmetrical. She shared her experience about what she is done according to her mother saying and while she did not get near to the boys. She explained that since she started having menstruation, her mother told her that she has to stay away from boy during menstruation.

“I never asked her why I shouldn't stay close to boys during menstruation. All I do is follow her words. She never told me which part of boys I should not have contact during menstruation. That's why all I do is stay away from boys. I

don't even talk to boys because I'm afraid that I will be pregnant. My friends also know about me as I've told them. So if a boy comes near to me, they shout the boy to go away from me. If my friends who are boys come and talk to me, I just say go away and if they don't go, I go outside and wait until they leave my table." (Wai, Torticolli, a high school student).

Furthermore, other participants answered the similar answers that they have been told to stay away from boys. They said that they should not stay close to boys and if they stay close or talk with boys they will get scold. Therefore, most of the participants claim that they don't have many friends who are boys. Only one or two participants said that they have friends who are boy but only few friends. When the researcher asked them that do they have any friends who are friends, they seriously denied that they don't have and they don't make friends with boys because their family and teachers would not like it.

4.4.2.2 "No date and relation with boy": Not engaging in sexual expression

No dating or no boyfriend is also one of the sexual discourses that the young women with physical disabilities have been faced.

Htwe: A high school student who has cerebral palsy

Htwe is a 19 years old high school student who has cerebral since she was 2 months old. Her whole body muscle is stiff but not too serious and she has difficulties in her movement. She thinks that young women with disabilities should not date because they have been already discriminated because of their impairment and she is worried that if they date people will criticize more.

"I don't think girls with disabilities should date because since we are born with impairment, we have been criticizing so much. If we dated, people will definitely criticize us more. They will gossip. I'm really worried about it and scare that other people will talk about me behind my back." (Htwe, Cerebral palsy, a high school student)

She explained more about dating. She said her teacher said that she should not date and dating is not good for her. Dating can prevent her go get better

things in life including it would disturb her education. She said that her teacher asked for a promise not to date or have boyfriend.

Furthermore, the other participants also claimed that they should not date or have boyfriend in their teenage time. More than half of the participants out of 15 participants said that they will not date because dating is not good for them because as they are disabled person nobody will like them for real and boys will date them just for fun. In addition, the participants described that their family and their neighbors told them that they should not have boyfriend or dating. However, they do not really understand why they have been told not to date but the concept of no dating is rooted in their mind.

However, some participants showed the resistant to this idea. One of the participants said that she is flirting with someone she likes at school. However, she is really afraid that her mother will know about it. She said she keep secret from her mother. Moreover, she said her friends have boyfriends and she wants one too. However, she is afraid that her mother will scold her and angry. Therefore, also she flirts with the boy she likes; however, they are not dating yet.

4.4.2.3 Sex before marriage is a shameful thing but I will be criticized more because I'm not only a girl but also "*Ma Than Ma Swan*"

All the participants and key informants has the same idea about sex. They have similar opinion upon sex which is "Sex is not for the unmarried people and it is only possible or should have done within marriage".

Some participants explained that they know that other people who are the same age as them have sexual relationship with their partner. However, the participants believed that it is impossible and inappropriate acts. Only the older participants who are in their late teenage time like 17- 20 years old answered that they know that some people have sexual relationship before marriage. However, they could not accept it as a possible thing. The key informants also think that sex is just for the married people. They also accepted that having sex before marriage is inappropriate thing. One of the participants explained her opinion about why sex is possible within marriage and not before marriage as follows;

“Even if I have boyfriend, I would never do like other couples. I mean having sexual relationship before marriage because it is a shameful thing and everybody will criticize about it and look down on me because I’m not only a girl but also “Ma Than ma Swan” (May, a girl with congenital deformities and blindness).

She explained that as a woman having sex before marriage is a shameful thing and if the other people or neighbors know it, they will definitely look down and it is possible to outcast within the neighbors. She also said that if people know that woman who has sexual relationship before marriage, they will not only criticize but also discriminate. Therefore, in the Burmese society, sex is possible and appropriate only within marriage.

4.4.2.4 Date on later age or little chance to date

The young women with physical disabilities who are participants and the key informants have the same idea of not dating in the early age. They believed those teenagers are not supposed to date. They think that date on later age, for example, over 20 is good. But for teenager, no dating or have boyfriend. The participants explained about date on later age as follows;

“We should date over 20 because we are mature at that time. If is younger than 25, we shouldn’t have boyfriend because we are too young”. (Htwe, Cerebral palsy, A high school student).
“I don’t think girl should not date so early because they just start their puberty time. They don’t know much about people. It is ok to have boyfriend at age of 18 and 19. Because at that age we can control ourselves and have enough consideration about what is good and what is bad. If boyfriend is not good, they can also decide to break up immediately. If I date, I will date after I’m 19. I don’t think I can marry because I’m almost always staying inside the house. There’s little chance to meet with others”. (Myo, Polio, Secondary Student).

The study showed that teenage time is not good for women to date because they are still too young for dating. Moreover, the participants think that

they do not have ability to consider what is right and what is wrong or what is good and bad for them. In addition, they think that dating or having relationship is for people who are mature and old enough to take care of themselves. Therefore, they accepted that date is not for the teenager and date on later age.

4.5 Social Support towards women with physical disabilities

Social support is needed and important for person with disabilities. It is more important for young women with disabilities. In this part, there are two parts including social support at family level and social support at community level. At the family level, most of the family members are poor and their living condition is bad. They have so many family members in a very little room and struggling for their day life. However, they try to give protection to their family members who are person with disabilities as much as they can. If parents go out and find money, their other siblings take care of these young women or for the student, their family try to make convenient for the transportation to school as they afraid something might happened on the way. They hired someone who is closed to them or their relatives to take care of their daughters. However, they are still not able to give full protection to the young women with physical disabilities. Therefore, they are always worried and some family explained that they do not know how to give full protection to them.

For the community level, there are lots of organization and social groups helping different kind of vulnerable groups. And sometimes, the neighbors who close to the young women with disabilities are also helping. However, these areas are still poor and the socioeconomic status is still low. The support and help from the community are limited and it cannot always be matched with the needs of the young women with disabilities. Therefore, in this finding part, the researcher explained about the finding in two parts including social support at family level and social support at community level.

4.5.1 Social Support at family level

4.5.1.1 Protection

Family support towards the women with physical disabilities is one of the important matters which have much effect on the holistic development. The first priority of the support that young women with physical disabilities received from the family is protection from the potential harmful things to them. The family believed that they need protection as a woman and a person with physical disabilities. As it mentioned in Chapter 3, the study site is not a safe place for women as it has high rate of criminal cases and the living condition is poor. Therefore, protection becomes the first priority for the family to support these young girls. Mostly, the family never leaves them alone.

One mother said that she doesn't even leave her daughter with her cousin who is boys. She worries for her daughter. So she said that she try her best to protect her not to be in trouble or to protect from the sexual violence or harassment. Furthermore, the other woman who have a daughter with physical disabilities said that to look after and make her daughter safe is her first priority as her daughter is teenager now. She also explained that Hlaing Tharyar is not a safe place for a young girl as there are people with bad characters are living and she said that she heard from other people that some young women with intellectual disabilities have been rape. So she worries for her daughter and for her daughter safety is very important to her. Therefore, she takes her daughter whenever she goes as much as possible. If she has to leave her daughter in her house, she asked other women from her neighbors to look after her daughter. Therefore, families in this area have much concern on the safety and protection for their daughters who are physically disabled and who are teenagers.

However, one thing is the family members still worry that they cannot always stay with them. Therefore, they are worrying about how they can protect them. In addition, most of the family members does not know the way to protect their daughter if they are away from them while working and going outside. Sometimes they asked their neighbors to look after her when they are going out. However, they still not feel secure to leave their daughter with the neighbors.

4.5.1.2 Educational Support

The researcher interviewed to three mothers and all of them are enthusiastic to support education for their daughters. Although the background of these family members is not the same, their main purpose is to support for their daughters' education. The parents believed that if their daughter has an education, they would not be look down by other people and they would be treated as normal. Moreover, parents want their daughter's to have education because they believed that even they passed away one day their daughter can have a better life and independently living by her own ability, make salary of their own and having a secure life as an educated person. The key informants shared their opinion about supporting for the education of their daughters as follows;

Some parents think their children don't need higher education. Even we can see this kind of opinion towards normal children. But for me, I never think like that. I always think about her development. (Aye, retired teacher)

Education, I want her to become outstanding person although she is a person with disabilities. (Ni, Housewife)

However, some family cannot support education because of their economic situation. However, one family said that they didn't support education because they think that their daughter cannot study because she is a person with disabilities. Another family said that in the family, there are 3 daughters and 2 sons. They have limited economic resources for them to support education. So the parents decided to support to the sons and they said that their daughters are not good at studying. When the researcher asked about the disabled daughter, they said she is disabled and they think although they support her education, she would not become anything in the future. So, they said they decided to support their sons only. Sometimes, the young women with disabilities cannot study higher education like university as the family cannot support anymore. So, in this area not only young women with disabilities but also the other women have low education status as most of the family cannot support much because of the economic situation.

4.5.1.3 Emotional and mental support

To support for their mental wellness is the most important parts of the family members. While the researcher was in the study site, through observation, most of the family members are mentally supportive to their daughters. They support them not to feel inferiority of themselves. One of the participants shared her experiences.

“I don’t want her to feel inferiority. I think she better needs to learn how to communicate with other people and independently living and not too depend on parent” (Ni, Housewife)

Moreover, the mothers also tried to make other family members to support mentally and physically to young women with physical disabilities.

“I think other family member also needs to take care of her. They shouldn’t outcast to her. I told my two sons that they should take care of their sister. Whatever they do, they have to do together with their sister and not to leave her alone” (Ni, Housewife)

“Her father also has interest in disability issue. After he got pension and no job, I help him not to feel depress. I make him to be more interested in disability issues for the sake of our daughter. I take him to the special school where my daughter is attending. After that he becomes the president of the parents group. Then he also attended so many trainings for disabled” (Aye, Retired Teacher)

On the other hand, some parents do not support so much. They are keeping their daughters inside their house and not let them go outside. Some participants who are physical disabilities persons answer that they want to go to school. However, the family members do not support them because they do not have enough money to send them or they do not have time for the disabled family members as they were struggling with their daily surviving economic problems.

Through this study, the researcher found out that the young women with physical disabilities who have more support from the family members have more confident upon themselves and they have some hopes for their future, however, in the contrary, those who does not get the support or less support from the family are losing their confident and hope for the future.

4.5.2 Social Support at the community level

In the study site, there are lots of NGO, INGO and local groups which helps to the needy people. However, the neighbors and friends are also important for women with physical disabilities. In the Burmese society, one of the beautiful things is helping each other and people are still taking care of their neighbors. There are also lots of local volunteer from different group for giving help in the community. They give different kind of help. For example, health care, for free funeral services, fund for education for the children who can't afford school fees. The community members pass the information to each other about where they can get the services and facilities they need. It is also a helpful way for these young women with physical disabilities.

One of the findings from this study is the young women with physical disabilities gets some kind of social support from the local volunteers and organizations beside from the family support. They received the information for the health care services such as physiotherapy care, for education, for vocational trainings and other sources for their knowledge. One of the participants answered that she didn't have chance to go out from her house and knows nothing about the society. She has been all alone in the house. However, she met with the local volunteer and has an opportunity to know more about the society. She felt that her life changed when she has a chance to see the other people and deal with other people.

“When I was young, my family members leave me at the house whenever they go out. After I moved here and met with a volunteer who help disabled people, I think my life change. I can go out now” (Hla, a teenage girl who has Cerebral palsy)

Furthermore, beside from INGOs and NGOs, some local groups such religious group, women groups and social groups also help the women with disabilities if they need help. However, the support from these community

organizations and groups are very limited. They cannot cover the whole population of the person with disabilities in this area. Moreover, sometimes the support from the organization is given according to their organizations' criteria and objectives. Therefore, sometimes it doesn't match with the needs of young women with disabilities. Furthermore, understanding of disabilities and health issues of disabilities is still limited knowledge for the community members. In the research, out of fifteen participants, only 2 participants have currently received support from the organization and 2 others received livelihood 4 years ago. Currently, the other participants do not receive any support from organization or community group.

Another source of the support is neighbors. According to the study, some participants get support from their neighbors. One of the participants said her neighbors take care of her as her parents are not staying with her. She got the information about menstruation and other sexual and reproductive health related things from her neighbors. Moreover, the neighbors take care of her safety.

Menstruation started when I was 16 years old. At first I don't know what to do. I didn't ask anyone about it too. It is really difficult for me at that time. Then later I ask my neighbors. They told me what things I shouldn't eat certain things like Sugar Cane, Ice cream). They told me to use pad. (May, A 20 years old girl with congenital deformities and blindness).

The researcher asked about how she feels when she doesn't have parents who can protect her. She answered that she met with a good people.

"I don't know but I think as a woman whether you're staying at house or going outside it is not safe, especially in this kind of place. However, fortunately, I met with good neighbors." (May, a 20 years old girl with congenital deformities and blindness).

The other girl who lived together with a step mother and her two sons in the same house which doesn't have any rooms nor doors also answered that she received some kind of protection and mentally support from her neighbors.

"Some of my neighbors told me that if those brothers try to do something, just shout and call them. They will come and help me." (Htwe, A high school student with Cerebral palsy)

Furthermore, the young women with physical disabilities also get the support from their friends too. Most of the participants answered that their friends never look down on them and they help them when she needed help. Moreover, if someone looks down on them or say something bad to them, their friends made responses to that kind of action for the sake of them. One of the participants said that while she has menstruation for the first time, her mother is so busy that she didn't know about her having menstruation. However, she received the information about menstruation and how to do the hygiene from her friends.

“My mom usually does not talking about those thing because she is very busy. Mostly I know those kinds of thing from my friends and TV. Actually, to use pad, I didn't know from my mom. I knew it from my friends.” (Wai, a high school student with Torticollis)

In conclusion, some of young women with physical disabilities also received the supports they need from the community members too. Although some family cannot support them mentally and physically, they get the support from the other way, the community members around them. These supports also have effect on their daily life. For example, the information about SRH, the general knowledge, and protection are also received from the community members. This is also helping them to survive in such a slum area which does not have much safety. However, the help and support from the community has limitation. For example, the NGOs and other organizations and groups cannot help to every people. They have limited resources for all the population in this area. Moreover, the organizations are giving support to the community according to their criteria and objectives of their programs. Therefore, not all people can access to the support if they are not matched with criteria. Moreover, the neighbors cannot always help them as they are also poor and low knowledge. Therefore, they cannot also give the information that the women with disabilities need.

4.5.3 Family's attitudes towards women with physical disabilities

The findings showed that the attitudes towards women with disabilities affected the knowledge, subjectivities and the notion of self of the women with physical disabilities. Therefore, the attitudes of other people have some kind of effects which influenced the life of women with physical disabilities.

4.5.3.1 Negative Family's attitude: Commit Bad Karma and Guilt

Firstly, family is the one of the most influential people upon women with physical disabilities. Their attitudes have some kind of power which changed into actions and practices while dealing with young women with physical disabilities. One of the key informants shared her opinion of she thought about her disability.

"I thought it is God's will. It is just my fate to have her. As according to Burmese people belief, I did bad things to her in the past life. That's why I have to pay for what I have done in previous life. I'm thinking deeply why I have her and I accept that it is just our fate as there is no heredity in our family to become a disabled person." (Ni, mother of the Cerebral palsy child)

She shared her feeling about her daughter and she couldn't believe that she got a daughter with physical disabilities because she repeatedly saying that in her family they do not have disability gene and she believe that it is usually happened because of the heredity. So, when she got this daughter, she said that she gave more attention than other children because she believed that she has to pay back for the sin she did in the previous life.

The study showed that the family think that it is because of their bad karma or it is because of their daughter did sinful act in the previous life. Moreover, they feel guilty towards themselves and their daughter. They feel like they have done something bad on the previous life and therefore, they have been punished in this life. However, they accepted as their fate and they try to do good things towards their daughters.

4.5.3.2 Feeling of shame and pity

Another participant shared her experiences that her sister was embarrassed because of her disability. She said that her appearance is different from other. Therefore, her sister feels ashamed to go out together with her. She was also told as an ugly person. Her sister was resisting for so long go out with her. She said that she wants to go out with her so she try her best to look good until her sister accept

her to take her out. She put “Thanaka” regularly and she wears beautiful close. She tried to be neat and tidy. Now, she said although she don’t usually go out, her sister is not seriously denying to take her out now.

“When I was in Grade 8, my sister never asked me to go out together with her. She told me that I’m so ugly so she doesn’t want to go out with me.” (Wai, a high school student with Torticollis).

The most common attitude of the family is feeling pity upon their daughters. Most of the key informants said that they feel pity or sorry whenever they saw the women with physical disabilities. When they are feeling pity and sorry, their action followed their feeling. They treat differently from other children or favor more. One mother explained how she treats her daughter different from other children. The family members always aware that they have daughter who have physical disabilities and they cannot treat them normally like other siblings. Sometimes the young women with physical disabilities has been treated as a special person sometimes they have been neglected. For example, one mother told that

“I love her more than other children of mine because she is disabled and I feel sorry for that. But I don’t like other people call her disabled. So I let them call her “child”. (Tin, mother of a teenager with Cerebral palsy).

In this sense, it is obvious that she treated her daughter as special person which is quite different from other siblings. She also said that she gives more attention than other daughters and sons because she feels sorry for her.

Another key informants said that she feel sorry towards her daughter for her physical disabilities. However, she said she couldn’t afford many support for her. Her husband also left the family since her daughter was so young. So she has to work for her family. Therefore, she cannot give so much attention on her and sometimes she said although she wants to give attention to her, she has been too busy that she cannot gives attention to her daughter.

“I feel sorry for her and pity than others. In my mind, I told myself that she is a disabled “(Kyi, mother of congenital deformities daughter)

4.6 Notion of self

4.6.1 “I’m different”: Notion of their own body impairment or disfigurement

Self is defined as a person's essential being that distinguishes them from others, especially considered as the object of introspection or reflexive action. Notion of self is defined as the whole set of attitudes, opinions, and cognitions that a person has of himself. Through the study the participants were answered about their body impairment, their notion of their body and their sexual self-image.

Mostly the participants think that they are not normal like other people. During the interview, most of the participants told the researcher that they are different from normal people and they answered what is normal. They noticed their body impairment and their disfigurement and portrayed themselves as different or not normal compare from other people who have legs, hands and no impairment. They think that they are different from other and it depends on how the community members treat them. Mostly the participants are described themselves as different because the other people told them that they are different and they were insulted by them because of their impairment. People called them “a girl with broken legs, a girl with a short leg, and a girl without hands, etc”. This kind of action portrays them as different from other people and these thinking embedded in their mind and it becomes their self- identity in the community as being different and being disabled.

One thing they noticed about themselves is they are different from other people.

“I think I’m different. Compare to the normal people, I’m different.” (Hla, cerebral palsy)

“My body is not like a normal body.” (Moe, Polio)

“Other people have both legs and hands and those are in good position. They have eyes which are not blind and have ears which can hear everything.” (May, a 20 years old girl)

“I feel depressed. As I’m different, people don’t want to talk with me much” (Htwe, person with cerebral palsy).

“If you have normal body you can walk properly and who can do whatever you want.” (Aye, a girl with physical impairment, cerebral palsy).

4.6.2 Unattractive, unsexy and ugly body

While they think that they are different, they do not think they are attractive like other people. They feel that their body is ugly, unattractive and they are not satisfied with their body at all. They see their body and their sexual image as follows:

“Although people look at me, I ignore their looks. However, I’m frustrated by my body appearance because other people look perfect and beautiful but my body is ugly”. (Pyone, congenital deformities)

“I like a beautiful smile and beautiful body. But for me I think I’m not attractive because I’m a disabled. I think beauty and disability has some kind of relation. Disabled person cannot be beautiful”. (Hnin, a girl who is paralyzed and a brain tumor)

Mostly the participants answer showed that they are compared themselves with other people especially when they talk about their sexual image. Most of the participants answered that they are not sure whether they are attractive or not or they have never think about attractiveness. Furthermore, most of them did not describe that they are attractive because of their appearance. The participants shared their sexual image as unattractive, ugly and not sexually attractive;

“I don’t know whether I’m attractive or not. Although I’m not satisfied with my body, I couldn’t do anything to change it .So I must accept my appearance. It is just my fate. But I do wish that I have a normal body which can do and work like normal people.” (Myo, polio).

“I don’t think I’m sexy.” (Wai, high school student)

“Let me compare with my sister. She has long hair. Sometimes she tied up her hair. She used mascara and she has beautiful body. She has sweet voice too. She is a little bit short but her body is really beautiful. Whenever she wears, it looks good on her. She has round face and everybody told her that she is pretty and cute. Whenever I sit beside her, people said my sister is cute and I’m so ugly”. (Mar, Polio)

4.7 Subjectivities

Subjectivity referred to an essential individuality, the consciousness of one's perceived states (Kleinman and Fitz Henry, 2007). In this study, the researcher intended to find the subjectivities of young women with physical disabilities. The researcher assumed that the subjectivities of these young women with disabilities may have influenced on their sexuality, sexual and reproductive health. Therefore, the researcher tried to understand their subjectivities through the in-depth interviews with young women with physical disabilities.

4.7.1 Feeling of incapacity

The study showed that the young women with physical disabilities have feeling of incapacity because of their body impairment or because of the influenced of the community members. On the other hand, as most of the people are familiar with the words “*Ma Than Swan*; Not strong but capable”, the participants explained that they feel encourage and they feel like they are capable person because of that word. However, during the in-depth interview, the participants explained why and how they feel incapable. In addition, they feel annoyed or irritated to have incapable body. In contrary, they do not like people look at them as incapable because of their impairment. However, they still feel that they cannot work the same like people without impairment.

“Sometimes I feel like when other people call me “Disabled” I think they also look down me tell me that I have no ability.” (Myo, Polio)

“I help to do households work at my house. Whenever I can't do well, I'm mad at myself. I feel really annoyed and irritated.” (Htwe, Cerebral palsy)

On the other hand, the participants are struggling not to depress. They tried to encourage themselves not to feel incapable. However, still notice that they have limited capacity. Furthermore, they believed that they should tolerate some kind of insult because they think that they do not have ability and power to react that kind of insult.

“People call me “Disabled” because I cannot work like other people and I cannot walk like others. I have difficulty in writing. Sometimes people dispraise me. They walk like the way I'm walking.” (Aye, Cerebral palsy)

“I am lack of ability to do something that I want to do.” (Hnin, paralysis due to accident)

“It means I couldn’t work the same amount of what others can do. Even I couldn’t talk back to what they insult on me. I don’t have any power to fight back them. That’s why I’m just trying my best to be quiet.” (Myo, Polio)

4.7.2 Lack of confident in engaging sexual relationship

While engaging for sexual relationship is the most difficult parts for young women with physical disabilities. Although they have some interest to opposite sex, they do not have much confident to have boyfriends. “Sexual subjectivity has been found to include five elements: sexual body-esteem, self-entitlement to sexual desire and pleasure, entitlement to sexual desire and pleasure from a partner, sexual self-efficacy and sexual self-reflection” (Boislard P and Zimmer-Gembeck, 2011). The findings indicate that the young women with physical disabilities have subjectivities as they should not express their sexuality, they suppress and ignore their body and their sexuality, and some are controlled by the sexual discourses on women with disabilities which are influenced on their thinking. The participants show their sexual subjectivities as less sexual confident or they controlled themselves as an asexual being. In addition, the women with disabilities have so much dependency on their family members, neighbors and friends as they accepted themselves as incapable.

Myo: A secondary school student who has polio

She is a secondary school student but now she left school because her grandmother said she is not good at studying and her health is not good. That’s why they took her out from studying. She answered that she does not think that someone will like her because of her impairment. Therefore, she thinks that she has to stay by herself. Moreover, she thinks that men will not like him for real and they will like her for fun. In addition she thinks that she cannot marry as she only have little chance to go out from her house and meet with other people.

“I don’t think there will be someone who likes me because I have bad legs and hands. I think I should stay by myself. I should stay with my grandmother because while dating with me my boyfriend will date with

another girl at the same time. He can be unfaithful to me. As I'm a disabled person, he will find another girlfriend. I don't think I can marry because I'm almost always staying inside the house. There's little chance to meet with others." (Myo, a secondary student with Polio)

Zin, a teenage girl with Cerebral Palsy

Another young woman with physical disabilities also explained that she never thought that she can marry because of her impairment. Therefore she would like to choose a single life and she explained that she is afraid of men as she just heard bad things about men.

'No I don't think I can marry because my legs are not good. Nobody will like me. I want to choose a single life. I don't want to marry because I think men are scary" (Zin, a teenage girl with Cerebral palsy)

Aye: a secondary school student with Cerebral palsy

Aye, a young woman who has Cerebral palsy since she was infant, explained how she think about relationship. She think that she can be supportive to someone she will love in the future. However, she believed that she could not get back the same support, kindness and understanding upon her disability. Therefore, although some boys seem to like her, she just told them not to like her because she is not good for them as she is a person with physical disabilities. Therefore, she said that she cannot marry nor have relationship.

In conclusion, most of the participants have some kind of feeling for the opposite sex. They think they can date. However, they think that they cannot find boyfriends and nobody will likes them. Furthermore, they do not want any criticism from other people because of dating. Therefore, mostly they answer that they will not date or they do not have any intention to have boyfriend.

4.7.3 Policing and controlling of the sexuality and body of young women with physical disabilities

The study showed that the young women in our study are controlled and regulated their body and sexuality according to the things they have learned from other people. The study showed that there are two ways that their body and sexuality have been controlled or surveillance. One way is policing by other people who stayed

around them and another way is they control themselves. This includes daily activities, including going outside of the house, a man to marry or date. For example;

“If I marry I will listen to my parent about who I have to choose”. (Aye, Cerebral Palsy)

One of the participants who is 15 years old explained that she never made any decision by herself about her own living activities but her grandmother decided everything for her.

“If I want to go out, I have to go with my grandma. My grandma said I’m still a child. That’s why I can’t go out without her. Even when I want to go out with friends, my friends need to take from my house and they have to tell the exact time to take me back to home. With my health issue or something, I’ve never decided by my own. Everything is decided by my grandmother.” (Myo, polio)

During the interview, according to her words and her explanation about her life, she has been too much controlled by her grandmother. Whenever, she talks something, she said that she needs to ask her grandmother first or if her grandmother allowed her to do she will do. For example, if she wants to go out, she needed permission from her grandmother and she can only go out with her grandmother. She cannot go out alone. She doesn’t have her own decision and also for her future partner, she said that she never thinks about having partners or marriage but if her grandmother will arrange for her she will marry.

Htwe, who is a high school student live together with her father and step mother and her two sons. While interviewing, she showed that she doesn’t like men to date. She repeatedly said that she doesn’t have intention to date. However, if her father arrange for her she will marry because she believed that parents will do a good thing for their children and her father will definitely choose the one who is suitable for her.

“I won’t date but if my father arrange for me I will marry because I think parents are always the most suitable person for their daughters. If I find myself, I’m not sure I can find a good one.” (Htwe, high school student with Cerebral Palsy).

On the other hand, the participants’ answers showed that they controlled their own body and sexuality as they are afraid of being criticized by the others or

according to the norms in the society. In addition, sometimes the control leads the young women with physical disabilities to be isolated from the outside world. Furthermore, it leads them to be dependent on the others and without other people they do not understand how they should take care of their health, education and their social life.

In summary, they all have some kind of controlled over their body and sexuality. Most of the participants also said that they do not make friends with boys because they afraid that other people will look down on them or their family members and teachers would scold them. Furthermore, while they isolated themselves from society, they do not receive the information relating to their sexual and reproductive health. As they are controlled their body and sexuality, the study showed that they do not understand to receive the sexual and reproductive health because they believed that it is not an issue for the young girls. Therefore, being control, surveillance and regulated own body sexuality has consequences.

“I don’t want to know about other people have interest on me because I’m afraid that if teachers and father will know about it, I will be scolded for sure. Even now they control me too much. They always said dos and don’ts. I hate to follow as what they said.” (Htwe, a 19 years old high school student).

“Since I become teenage, my mom said I shouldn’t have go alone. I have to stay stick with my parents so that I can be safe. I know that some people like my parents told me not to do makeup because they are worrying about me. They think that if I become beautiful I might face dangerous thing like rape. That’s why they protect me and I will listen to them about my relationship or marriage life too”. (Aye, a 14 years old secondary school student).

4.8 Experiences and practices of sexual and reproductive health

4.8.1 Cultural practices related to menstruation and white discharges

Mostly, young women with disabilities are learned their practices related to the menstruation from their family members and some are from neighbors. It is almost the same from one person to another.

Cultural practices have been done by the young women with physical disabilities during menstruation including the restriction of food. They avoid some food during menstruation because they believe that it can stop the menstruation. Some food like green tea leaves; sour food, mango, etc. are avoided during menstruation. They do not wash their hair during menstruation period because it can stop the menstruation process. Mostly, they don't use feminine hygiene to cover the smell. They use to clean their body and use "*Thanaka*" (Tree bark using for skin care) or some powder to cover the smell. When they have white discharges, they have not done anything as they do not understand what it is and they think that it is not important like menstruation or it is normal. They do not also have many practices for irregular or no menstruation as they think that it will become normal after some time like 2 or 3 months. However, if it will longer than that they told that they will go to the hospital for treatment. Another thing is they just go and buy medicine for irregular or no menstruation. Sometimes they use western medicine but mostly they use tradition medicine like mixture of ginger and jiggery or the herbal root powder.

The common problem during menstruation, irregular or no menstruation and white discharges is they do not understand fully what is really happened to their body. They believe that having menstruation are shameful and dirty. Menstruation is a polluted blood. Therefore, if they have menstruation they keep in a secret. While having health problem like irregular or no menstruation, they still keep quiet. They do not know that it might leads to more serious health problem. One of the participants said that she does not have menstruation until she is 17 and she was so small and her body development is stop such as her breast are not become developed and her body is still like children and she feel uncomfortable. For the irregular menstruation, they did not do anything although some participants said they do not have menstruation for 3 or 4 month. They said that although they did not do anything and it comes after 4 or 5

months. They do not understand about white discharges too. Therefore, when they have white discharges and feel itchy, they scrub or they put some perfume powder into the vagina, took the medicine that they do not notice and take shower again and again. However, the itching does not stop. Sometimes, they used perfume to stop the smell. Therefore, they might face with unbalance PH and they have high probability to have Reproductive Tract infection (RTI). The participants explained their practices as follows;

“I feel itchy so I use powder. My sister said if I used powder it won’t be itchy anymore.” (Htwe, a teenager with cerebral palsy)

“I usually have it but I didn’t do anything. If feel itchy, I scratch. My mom said I need to take shower then I won’t feel itchy”. (Aye)

“I have white discharge and I’m itchy. So, my grandma gives me traditional medicine not to have white discharge but I don’t know what kind of medicine it is”. (Myo, a teenager with polio)

4.8.2 Lack of understanding of the vulnerability and the ability to resist sexual violence and harassment

In the study area, most of the houses are very close and having no room or no doors. In addition, many of the extended family are living together in the same house which lead to social problems to many of the families in this area. Most of the young women with physical disabilities are from poor family and some of them are not staying with the parents and live together with other relatives. The study showed that the young women with disabilities do not understand their vulnerability of sexual harassment and sexual violence. The researcher asked whether they have been experienced sexual harassment. The participants answered that they did not have any sexual harassment and violence experienced. The researcher continued asking about how they understand sexual harassment and violence and how they can protect themselves. When the researcher asked these questions, the participants showed the expression that they have never think about it. Moreover, they do not understand very much about it. Another thing is they believed that they are mostly staying in the house and not going outside. Therefore, they believed that they will not experience that kind of things. According to the interview and observation, the study showed that the young

women with physical disabilities do not notice the vulnerability and therefore, they do not understand how to protect themselves. In fact, they do not know and do not have ability to resist the sexual harassment and sexual violence.

They have less ability to resist sexual harassment and sexual violence. The participants answered that they do not have experience about sexual harassment and sexual violence. However, they have experienced some people stalking them. One important thing is most of the participants answered that nobody will interest in them and they usually lived in the house. That's why they think that they would not experience sexual harassment and sexual violence. In addition, they do not know how to protect themselves or they do not know who to ask for help.

4.8.3 Insufficient knowledge about their own reproductive organ

In the study, the researcher asked questions about how much they understand about their body reproductive organ. However, almost every participant's answers showed that they do not fully understand about their body reproductive organ. Some participants answered that it was the first time they hear about reproductive organ from the researcher. The participants explained that while they have menstruation, their family members or their neighbors taught the practices for hygiene. However, nobody explained about the reproductive organ and how does it related to the menstruation. However, some participants know some things about reproductive organ because in the school they have some classes teaching about general knowledge. However, most of these classes teach about the HIV and AIDS. However, they do not explain clearly about the reproductive organ or menstruation and some participants said that although they know HIV/ AIDS, they do not know the route of transmission. They do not understand how the menstruation happened and they do not understand how their body reproductive organs are working. However, they noticed their body changes. Their answers were more related to the body changes. The participants shared their understanding about their body as follows;

“For the first time she had menstruation, she ask me that if leeches go into her vagina because it bleed.” (Zin, a 14 years old girl with cerebral palsy)

“There are changes in my body and see the development and have menstruation. I have menstruation and acne on my face. My breast becomes bigger”. (Ei, a high school student with congenital deformities).

4.8.4 Accessibility of sexual and reproductive health information and services

They have limited information resources or no information resources for sexual and reproductive health. Even the people around them like family members, neighbors or other community members, cannot give the right information or do not have much knowledge about sexual and reproductive health. Sometimes, they get information from their friends and some organizations or women group. However, they still do not get the information as nobody informs them that they will give sexual and reproductive health care. In addition, some participants told that their family members said they do not need to know that kind of information as they are too young. Although they get some information from the school or their neighbors, they do not understand clearly about sexual and reproductive health. Some participants have wrong information about sexual and reproductive health. One of the participants who are a university student explained where and what she got information about SRH.

“I attended the training in British Counsel about sex education and reproductive health. If we are so young we cannot marry nor have sexual relationship because organs are not fully developed. Our reproductive organs are fully developed when we are over 18 years old. And during menstruation, if we have sex we won’t conceive. I also learned about contraceptive and emergency contraceptive and condom. They taught us about how to protect ourselves from unwanted pregnancy”. (Pyone, an 18 year old university student with congenital deformities)

The other participants answered that they do not received or accessed to the sexual and reproductive health information.

“I have never heard of it. This is my first time I heard about menstruation, sexually transmitted diseases and other thing. I just heard it from you”. (May, 20 years old girl with congenital deformities and blindness).

One of the key informants answered her opinion about why young women with physical disabilities do not accessed to the sexual and reproductive health.

“Even the normal person has to try to get the information, for them they have to try more to get the SRH knowledge because they have weakness. Mostly they are living in the house and never go out. I think it is also limitation for getting the information. They should go out and seek the knowledge about sexual and reproductive health.” (Kyi, 18 years old university student who is a friend of one of the young women with physical disabilities)

In conclusion, inaccessible to the SRH information is not only because of the information gap between health care services and young women with physical disabilities but also the young women with physical disabilities do not know that it is an important information for the women. The discourse in the community also influence on the opinion about sexual and reproductive health as a dirty and shameful things to talk and the wrong information or limited information that is spreading in the community also prevent the young women to access the information.

4.9 Influence of discourse on sexuality and the notion of self and subjectivities of young women with physical disabilities

4.9.1 Resistant to discourse and positive notion of self and subjectivities related to sexuality and SRH practices

Case study of Pyone: an 18 years old University student with congenital deformities

Pyone is a university student and she is friendly. She is smart and she doesn't depress upon her body impairment although she said sometimes she frustrated about her body appearance. She lives together with her mother and her siblings. During the holidays she is working part time job in gourmet factory. She received sex education and sexual and reproductive health information from British Council training for youth.

As she is a university student and has training, she has much knowledge than other participants.

She has the highest education level among the participants. As she is a University student, she has broader environment and more network with other people. Her family is also supportive to her education. Moreover, mostly she can make decision of her life activities by her own. As she is well educated, she also received information and more knowledge than other participants. Therefore, she has positive notion of self and subjectivities towards her body and sexuality.

She said although she feels some kind of frustration for her impairment sometimes, she thinks she is like a normal person not a person with disabilities. Now, she is using a pseudo leg and she said that nobody noticed her impairment. Even some people noticed about her impairment, she said she doesn't feel shame upon her impairment. She said that she feels normal like other people and she doesn't think that she is unattractive. Furthermore, she said she has a boy who likes her and she said she like him too. Moreover, she believes that she can marry one day like other people too. Although they are not a couple yet, she said she shows her feeling and he shows his feeling too. Moreover, she said although some girls like him, he chose her even he knows that she has impairment. Therefore, she said she believed that she is attractive in some way.

Moreover, she received sex education and access sexual and reproductive health information as she has wide network while studying in the University. Therefore, she understands her body reproductive organ and she knows about how to take care of her sexual and reproductive health.

However, the sexual discourse has some power over her knowledge. She accepted that sex is possible within marriage and date on later age is better. Moreover, she doesn't aware of her vulnerability to the sexual violence and sexual harassment. She thinks that she is a person with disabilities and mostly staying inside the house. Therefore, she will not

experience sexual harassment or sexual violence as she is a person with disabilities.

In this study, the researcher interviewed 15 young women with physical disabilities. Out of 15 participants, only one participant who is a University student showed that she has more positive notion of self and subjectivities due to receiving more support from the family and community members, higher education and accessing to information and knowledge.

In this study, I found out that although some sexual discourse has been influenced on some parts, she has positive notion of self and subjectivities upon herself. She gets well support from her family mentally and physically including educational support. Therefore, she knows that she should receive information about SRH and she knows where to find SRH care services. Moreover, she has sexual confident over her sexuality. However, she said that she thinks sexuality is a shameful thing to talk. She has some individual discourse. She used the term “*Ma Kaung Thu: a person who has bad thing*” towards herself. She repeatedly said that she cannot have the same capacity like other people as she is a person with disabilities. Moreover, she has sexual discourse which is influenced on her mind. Therefore, she said that she doesn’t even want to talk about sexual and reproductive health although she received sex education from trainings. She said that she never want to discussed about her sexual and reproductive health to someone even to medical staff because she thinks that it is a shameful thing to talk and discussed. In addition, she said that she do the SRH practices according to her mother teaching but she doesn’t know whether they are harmful practices or regular practices. Furthermore, although she said she is capable to have relationship or dating, she thinks people with polio and cerebral palsy is asexual because she said they have an obvious body disfigurement. Therefore, she thinks they are asexual. Therefore, although she has higher education and good family support, some kind of her individual discourses has been prevented her from understanding fully about the disability and sexual and reproductive health including the vulnerability of sexual harassment and sexual violence.

4.9.2 Negative notion of self and subjectivities related to discourse and SRH practices

A case study of May, a 20 years old girl who have deformed legs and blind

May is a 20 years old girl living in the slum area of Hlaing Tharyar. She is the eldest daughter of among four siblings. Her two legs joint are extremely big since she was born. Therefore, she has difficulties in walking. Her father and mother divorced since she was young and later her father died and her mother married again and stays with her other family. Since her parents divorced nobody take care of her and her younger siblings. Her mother also lived with her new family and cannot take care of them. She has one older brother. However, he lives by himself in another township. Her younger brothers and sisters are so young. Therefore, she has to find money for her family and she couldn't study. She doesn't have any education. She sells food for the birds in the market. Her younger sister helps her to sell them. About 3 years ago, her vision started blur and now she becomes totally blind. Therefore, she cannot sell the food in the market by herself. Therefore, she prepares those foods to sell in the market and her sister sells them in the market.

The first time I met her, she is not afraid of the stranger and she can easily deal with the stranger as she is selling food in the market and therefore, she can easily deal with the people. However, she is frustrating about her disabilities. She said since she was young she has deformed legs and now she becomes blind. Blindness makes her more difficult to live and she has to depend on other people for her living. She repeatedly said that she is a disabled person. Moreover, she accepted that she is an incapable person and not normal like other people because of her impairment in her body. She also said that she is unattractive and nobody likes her. She continued that although somebody like her, it will not be real and it will be just for fun. She said she never dated before and she never think about dating. She added that she becomes disabled since she was born and become blind

since she was in her early teenage time, she doesn't have chance to meet with boys and she doesn't know that she can date or have relationship.

Moreover, she said she never learn about the practices for menstruation when she first had menstruation. She said she wasn't done anything until 2 or 3 months of started having menstruation. Then, after that she thinks she needed to ask her neighbors about menstruation because she didn't know what menstruation is and how she can clean herself. One of her neighbors explained her how to clean herself and what she should do during menstruation. However, she said she wants to know more. Therefore, she asked and listens to the radio. So, she got some information. But, she still don't know many things and do not understand her body reproductive organ and her sexuality and she doesn't know what kind of practices are harmful SRH practices and she doesn't know what white discharges are.. Moreover, she does not understand the vulnerability of sexual harassment and sexual violence.

In addition, she has negative notion of self and subjectivities because she thinks that she is unattractive, disabled, incapable and she said that she will always be a single and she can never have dating or relationship with boys.

In this study, not only May but also most of the young women with physical disabilities has some kind of problem which is related to sexual and reproductive health and they do not have confident of their sexuality and they have negative notion of self and subjectivities.

Firstly, most of the young women with physical disabilities in these studies showed that they feel different, abnormal and unattractive which makes them feel lack of confident in engaging in relationship. They feel different because of their impairment. Most of them said that they are not like “*Lu Kaung*”; a person who is good, as they have some kind of impairment. Some of the them say that they accepted that they are “*Ma Than ma Swan*”; Not strong and not capable. Furthermore, as they portrayed themselves as “*Ma Kaung Thu: a person who have bad thing*”, “*Ma Than Ma Swan*”, they think that they doesn't have capability like other people and they

unconsciously accepted themselves as abnormal people who are unattractive and who are not a sexually active people.

Because of the sexual discourse, they think that they think that dating is not for them and sexuality is a shameful thing. Therefore, they have been acting like an asexual person. Through the whole interview, these young women with physical disabilities showed that they have never think about having relationship and they do not think that they are sexual beings. Therefore, they have lack of confident in engaging in relationship or expressing their sexuality which makes them not to aware of their vulnerability of the sexual violence or sexual harassment. More than half of the participants answered that they do not think that they are vulnerable to sexual harassment or sexual violence because they are disabled and nobody will like them. Moreover, they are mostly living inside the house and most of the people don't notice them.

In addition, they do not received or lack of information about sex education, sexual and reproductive health. One thing is as they think themselves as asexual beings and they are different from others, they do not know that they also have the rights to access that kind of information. Another thing is other people including health care providers have limited knowledge about sexual and reproductive health care for person with disabilities due to the discourses in the community. The community members also think that sexuality is shameful things to talk and person with disabilities are not sexually active. Therefore, the young women with disabilities have difficulties in accessing the SRH information.

Furthermore, while they have difficulties in accessing SRH information, they do not understand their body reproductive organ and they do not understand their sexuality. Therefore, it has impact on their practices of regular and irregular menstruation. Mostly, the young women with disabilities claimed that they do not know whether they are practicing harmful practices or not. It is because even they ask their family or they ask their neighbors they do not receive enough information because most of the people are feeling shy to talk about that as they assumed that it is a dirty thing to talk about. Moreover, the research showed that the support from the family is also important in accessing the information and knowledge. If the family supports more to have contact with the society, the women with disabilities has more

chance to access the information. In addition, if the young women with disabilities received more support mentally and physically from the family, they have more positive notion of self and subjectivities.

In conclusion, in the community, the discourse has some kind of power towards the people knowledge of understanding their body and their sexuality. These discourses has effect towards the notion of self and subjectivities of women to see themselves as unattractive, abnormal, different from other and asexual. Therefore, while accessing to information about SRH, the young women with physical disabilities do not know to access the information and do not understand their sexuality. Then, they do not know whether they are doing the right SRH practices or harmful SRH practices. In addition, because of the low education and inaccessible to the SRH knowledge and information , the discourse influenced their concepts and behaviors more than the one who have higher education, accessible to the information and have well support from the family.

CHAPTER V

CONCLUSION, DISCUSSION AND RECOMMENDATIONS

5.1 Conclusion

This study explored how the discourses on the disability and sexuality has influenced on the notion of self and subjectivities of the young women with physical disabilities and how these notion of self and subjectivities has impact on their sexual and reproductive health. This study was taken in Hlaing Tharyar Township. There are 22 participants including 15 young women with physical disabilities and 7 community members.

Discourses have been explored through the interviews with both young women with physical disabilities and the community members. Qualitative research has been conducted with in-depth interviews and key informant interviews and also through documentary data. The data is analyzed using the concepts of Foucault and the critical interpretive medical anthropology.

The findings showed that the discourse are in everyday life has influenced on the notion of self and subjectivities of young women with physical disabilities. The state discourse has been emerged from the medical discourse of disability and sees the disability as a disease to be cured and a problem to be fixed. The word “*Ma Than Swan*; not strong but capable” is officially using nowadays which was used to call “*Ma Than Ma Swan*; not strong and not capable”. As the development programs from government and NGOs are working so hard for the inclusive development, they also try to change the language that used in the community for persons with disabilities. Although the use of term changed from “*Ma Than Ma Swan*” to “*Ma Than Swan*”, it still discourse on the body impairment and whenever people use that term people see the person with disabilities as an incapable and people with impairment.

Another discourse is using the language to call the person with disabilities according to their body impairment. The community members using “*Cut legs and Cut hands*’ if the person does not have hands and legs. Furthermore, people call the person

on the wheel chair, if they see the person using wheel chair. In addition, people see if someone has impairment and difficulties, they called "*Polio*". The discourse on the body impairment can be seen clearly in the community. Moreover, people believed that person with disabilities are pity and they cannot do anything by their own as they have impairment. In addition, people always divided as "*Normal people*" and disabled people are not normal. While they are using normal and not normal, the language depended on the body impairment and their body disfigurement. According to the medical point of view, normal person is someone who have all the body parts and flawless. Moreover, a person who doesn't have body disfigurement and their physical appearance doesn't have any significant impairment.

In addition, in this community, not only the community members but also the person with disabilities uses the word "*Lu Kaung and Ma Kaung Thu*". In this term, the people focus on the body impairment. If people do not have impairment or disfigurement, they called "*Lu Kaung: Good People*". "*Ma Kaung Thu: Bad people*" mentioned to someone with body impairment and disfigurement.

For the family members, most of the family in the study area is poor and lack of knowledge about disability, sexual and reproductive health. Their attitudes and behavior also influenced by the discourses. Mostly the family members believed that they have the child with disabilities because they did something wrong to their child in their previous life. So, they need to pay back to them in this life. On the other hand, some parents think that their child has done a lot of sin in their previous life. Therefore, they became person with disabilities in this life. However, these beliefs are not depending on the family education background or family economic status. Most of the family members in this interview have at least high school education background. However mostly they are poor or lower middle class people.

In addition, most of the family members are feeling pity on them. Some of the family members worry for them because they think that these girls have physical disabilities and they have less capability than other people. Therefore, the family members worry for the education and their future. However, most of the family members encouraged education for their daughters in order to consider for their future.

Furthermore, the discourse has influenced on the notion of body impairment and disfigurement, sexual image and their sexual confident and their

sexual subjectivities and the control over their body sexuality. Whether they have confident upon themselves is not depended on their age, however, it depends on their family support, education and knowledge they get from their community. The young women with physical disabilities who have education, who gets good family supporting physically or mentally and who have much more information from the community, have more confident, more positive self-notion and subjectivities. Although the discourse has been influenced on their opinion about sexuality, they have more positive thought. However, they are still portrayed themselves as asexual beings and afraid to have relationship or marriage. In the study, only two of the participants answered that they have flirting experiences. Most of them said they have some interest in opposite sex, however, they would not married or afraid to have relationship because they think nobody will like them.

As they have lack of confident and they believe that they are unattractive, this notion of self and subjectivities affected to their sexual and reproductive health issues. Firstly, the study showed that the young women with physical disabilities do not understand their body reproductive organ clearly regardless of their age and education. They do not understand it because they do not received enough information. On the other hand, they do not know that they need the information about sexual and reproductive health because they consider sexual and reproductive health issues is shameful thing to talk. In addition, they do not understand they need to get information and while they are asking information, people will look down on them. Mostly the young girl in the society do not understand because they feel embarrassing to ask and although they ask they do not received enough information. Therefore, the study showed that during menstruation, they know the basic practices about hygiene like what they should eat and they should not eat, how to use pad, how to throw them, and how to do hygiene not to smell. However, if they have irregular menstruation or white discharges, they do not know what to do. Sometimes they take the medicine that they do not know what it is. In addition, some participants said that they put perfume or powder into her vagina to stop the white discharges or relived from itching. Without knowing how to do during irregular menstruation and white discharges may lead to reproductive tract infection.

In addition, these young women with physical disabilities do not notice the vulnerability of sexual harassment and sexual violence. While the researcher asked them whether they understand what is sexual harassment and sexual violence, they do not show the understanding about it. Moreover, most of the participants said that they cannot experienced those kind of things as nobody interested in them and they are almost always living in the house and do not go out usually. However, in this study area, the rape cases are often happening although girls stay in the house. Therefore, the researcher asked about how they think about those cases, the young women with physical disabilities said they are not sure whether they are vulnerable or not.

In addition, more than half of the participants showed that they have negative notion of self and subjectivities except one participant. The only one participant who showed positive notion of self and subjectivities has higher education, her family also supports mentally and physically and she also received help and care from her friends. She also access to sexual and reproductive health information and also sex education. She also shared that she has a boy she likes and he also likes him. Moreover, she said although she is not a normal person like other, her disability is not significant as she can use pseudo leg and if she use it nobody notice that she is a person with disabilities. However she still have her won individual discourse which is influence on her as she is not a normal person and she feels like she is different from other. Therefore, she is still unaware that she has vulnerability to sexual harassment and violence. Moreover, she still has not clear or less knowledge about menstruation and white discharges. Her SRH practices are learning from her mother and the elder women from the community. However, she does not notice whether they are regular practices or harmful practices and she feel ashamed to ask about SRH to other people as she accept that talking about sexuality and related health issues are shameful thing.

On the other hand, the other fourteen participants have shown their negative notion of self and subjectivities as they are not normal, unattractive, sexually not active and too much policing and controlling from the other people. These girls also get less support from the family members. Therefore, the individual discourse has so much influenced on their notion of self and subjectivities. They have seen their self as unsexy, unattractive, disfigure, incapable and lack of sexual confident. The negative notion of self and subjectivities has leaded them unaware of their sexual and

reproductive health and unaware of their vulnerability to sexual harassment and sexual violence. It is because they believe that they are not attractive and they are disabled. Therefore, nobody will notice them to harm them. Moreover, they are always staying inside the house. Therefore, they have less chance to experience sexual harassment and sexual violence. In addition, they have influenced by the sexual discourse, therefore, they think that searching for SRH information is also shameful thing as it is related to sexuality. Moreover, they think that they are still too young to know about SRH as they think it is only for the married couple. Furthermore, they do not understand their own body reproductive organ and they do not know what are the regular practices and harmful practices as they have been thinking themselves as asexual or sexually not active and incapable person. Moreover, the confidence upon their body and their sexuality is not depended on their age, it depends on their family support, education and the knowledge they get from their community. It also depends on the seriousness of their disabilities and obviousness of their disabilities.

5.2 Discussion

In the discussion session, the researcher discussed about multiple marginalization, religious discourse upon disability and sexuality and the individual body of young women with disabilities as a body politic.

5.2.1 Multiple Marginalization on young women with physical disabilities

Person with disabilities are people who are marginalized. Women are also discriminated according to their gender and their role in the community. For the young women with physical disabilities, the marginalization become multiple being as a disabled, as a women, and as a teenager.

In the study of review of marginalization of people with disabilities in Lebanon, Syria and Jordan, 2009, it is stated about different marginalization for disability. According to Susans, J. Peters, poverty and lack of education created the continuing cycle of marginalization and vulnerability for the person with disabilities (Yeo, 2001, and Elwan, 1999). Peters also explained that concepts of deficiency

undelay poverty as an index of marginalization. The index of marginalization includes social and physical isolation, powerlessness and lack of voice, low social status and physical weakness.

In addition, Peters also explained that marginalization happened because of minority status which is arising in diverse and multicultural societies with a variety of ethnic groups, languages and customs” (Lewis & Lockheed, 2006:p48, cited in Peters, 2008) or other factors such as disability. The author also mentioned that among the minority populations, the rate of disability is higher than the general population due to higher rates of poverty, malnutrition, violence and lack of access to basic services.

Moreover, Peters, 2009, explained that culture practices and norms which linked to disability created a serious impact on marginalization. Culturally rooted attitudes concentrated on the severity of impairment are insignificant when compared to the social consequences of disablement.

Having disability but have no disability rights because of multiple marginalization. In the study of Hlaing Tharyar showed the multiple marginalization upon a young adolescent girl with physical disabilities who are living in the slum area of modern city of Myanmar, Yangon. The young adolescent girls who have physical disabilities have been experienced marginalized depending on their disability, their status as a woman, their age, their education level and their economic status. In CRPD, Article 6: Women with physical disabilities, it is stated that

1. “States parties recognize that women and girls with disabilities are subject to multiple discriminations and in this regard shall take measures to ensure the full and equal enjoyment by them of all their human rights and fundamental freedoms.”
2. “States Parties shall take all appropriate measures to ensure the full development advancement and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention”.

However, because of their poverty, their low education or lack of access to education, their gender role, their disability makes the young women with physical disabilities automatically excluded or marginalized from the equal life as a woman and as a person. The vulnerability as a teenager, woman and a person with disabilities is completely outcast them or becomes multiple marginalized group who are far away

from accessing the quality of life and equality. The poverty makes these young women difficult to access education and other basic human rights as a woman and as person. Therefore, they became uneducated or have low education which is again impact on their disability. It is like a vicious cycle in life of young women with physical disabilities because they have been marginalized because they are persons with disabilities. As they are person with disabilities they cannot easily received basic needs and rights then, they become more vulnerable and powerless at the same time. Therefore, they have been automatically excluded and marginalized from the non-disabled people. All in all, they young women with physical disabilities are marginalized by others and being marginalized makes them more and more excluded from the society.

5.2.2 Religious Discourse on person with disabilities

Bhensri Naemiratch and Lenore Manderson,2008 explained that disability is expressed in Central Thai and Issan as “*Pikarn*” which means physically handicapped or to have a physical defect in which the use of this term has negative meanings. It also stated that regardless of their own bodily status, ability and level of education all the participants are defined a person who is “*Pikarn*” as having an incomplete body which means not only the body but also their capacity to do something and their limited body functions. In addition, notions of physical form by the Buddhist influenced the construction of disabled bodies as imperfect.

In the Burmese society although the urban are is modernized and more developed than rural areas, the religious discourse related to body impairment are still embedded in people mind. Buddhism in Myanmar society sees the disability as a consequence of sin from the previous life or God’s will. Bhensri naemiratch and Lenore Manderson mentioned that “*Karma* is the understanding of cause and effect”. In Thai, it is known as “*Kam*” which is a central moral concept among Buddhists. In addition, the authors stated that it effects everyday actions by raising the notion of “doing good will get good” and “doing bad will get bad”. Furthermore, in the religion beliefs includes the indication of good and bad straddles material, social, interpersonal, and spiritual life, personal wealth, status and education which are all

examples of the growth of “*Bun*” or positive merit. On the contrary, physical and cognitive impairment are caused by negative merit or “*bap*”.

Addlakha explained that in India society according to the local beliefs, the person becomes disabled because they have been doing sin in their past.(Addlakha, 2009). As in Burmese society also Buddhists are the majority people, impairment or deformed bodies are because of bad karma of the person. Although, these people are good in this life, they must have done so many sin in their previous life and therefore, it is clear that the person with disabilities has been labelled as a bad person in their previous life. In the contrary, some of the people believed that they committed sin in the past life. Therefore, they get the child who was born with the impairment. Although, they have a little different point of view over disability, the same concepts are that they were bad and commit sin; therefore, they have to pay back their sin. It is also have the feeling guilty and feeling of pity at the same time.

Another thing is in Burmese society, they believed that person with disabilities are unlucky person not only for themselves but also for other people. In Buddhism, people believed that if a person did something bad in the past life, good fate becomes bad fate and good luck turn into bad luck in the present life. For example, people believed that a person becomes disabled person because he or she might have been cut out other people or animals body parts in their previous life. In another word, they use “*Ah Mingalar*”, it means person who is a disgraceful person and who bring bad luck. Long time ago, some people believed that if a person with disabilities come to the shop, they shop cannot sell well because the person with disabilities bring disgrace and unlucky thing. However, in modern days a lot of beliefs become dull but some people still believe in those things. Therefore, in the Burmese society, the constructions of the disability from the religious view are unlucky, bad person, disgraceful and a person who committed sin in their past life.

5.2.3 Myanmar young women with physical disabilities’ body as a body politic.

In the paper of Hull Disability Studies Seminar in 1996, it is said that the disability is the creation of disabling society which is not about the individual pathological body and being disabled by the society. It is also about the double

processed of discrimination and prejudice which restrict individuals with impairment (Barnes, 1992, and Shakespeare, 1994a, cited in Hull disability Studies Seminar, 1996). Moreover, the paper also explained that the impairment dominated approach to disability is distinguishing by the medical profession and professions associated with medicine and cure and rehabilitation in which they are prioritized and the emphasis on changing the individual. It is also stated that the body is seen as a composite of technical operations and functional capacities in which the experts is followed to alter the individual for the better (Crawford 1994:1352, cited in Hull disability Studies Seminar, 1996). Lock and Scheper-Huges stated that the relationships between individual and social bodies concern more than symbols and collective representations of the natural and cultural. It is also about power and control. Moreover, the authors stated that

“Cultures are disciplines that provide codes and social scripts for the domestication of the individual body in conformity to the needs of the social and political order and the use of physical torture by the modern state provides the most graphic illustration of the subordination of the individual body to the body politic” which is cited from Foucault, 1979.

In the study of Hlaing Thayar, it showed the similar findings that the individual young women with physical disabilities have impairment. However, the individual body has been looked as a disabled body and asexual body as the cultural, religious view and the medical perspectives has control or regulation over the people knowledge. However, in the research showed that one of the participants with higher education and a good family support is resistant to the discourse which is regulated the sexuality and the body. However, the rest of the participants portrayed themselves as abnormal and asexual by the controlled of the discourses in the community. Therefore, according to the Foucault 1980a, the anthropology of relations between the body and the body politic inevitably leads to a consideration of the regulation and the control not only of individuals but of the populations and therefore of sexuality, gender and reproduction are referred to as a “bio power”.

5.2.4 Limitation of the study

As the study issue is culturally sensitive issues in Myanmar, while searching for participants, it needs a clear and detail information. Most of the participants are age around 13-15. Therefore, two of the participants are not yet having menstruation. The target group itself is the limitation for the study as they are young, low education and lack of access to knowledge of the SRH.

In addition, the issues of the research about sexuality and SRH are also limitation because they are culturally and religiously sensitive issues.

5.3 Recommendations

5.3.1 General Recommendation

Now, the government tries to implement the existing policy about sexual and reproductive health, they should implement with the full understanding about women with physical disabilities and their life experiences in the community. The services related to the sexual and reproductive health need to be user- friendly. Moreover, the health care should provider should promote more advocacy about sexual and reproductive health in the community including the community leaders, local organizations leaders, health volunteer in the community, religious leaders, etc. In addition, the government and the society should cooperate to do advocacy to reduce the stigmatization and discrimination upon the disability and their sexuality. Furthermore, while making implementation program for sexual and reproductive health, they should implement in the form everyone can conveniently discuss and receive information. Lastly, the government, international organization and local organization should working together on the issues about sexual and reproductive health as one of the policy for the inclusive development community.

Provide awareness about disability, sex education and SRH

The awareness need to give not only to the community members but also to the health care providers and the staff from different kind of organizations to build up an inclusive development community. While getting enough knowledge about disability and SRH, the community members and health care providers can promote

more effective way to help the young women with physical disabilities to access the SRH care and information. The awareness also needs to provide to the women with physical disabilities to understand their own body, sexuality and disability. Then, the discourses influenced on their mind can be reduced and they will understand how and where to receive the SRH care and information.

Empowerment for young women with physical disabilities

As the discourse on disability prevents the young women with physical disabilities to feel incapable, they need to be empowered not only physically but also mentally. The government organization and non-government organizations working in that area, need to provide more program to empower them. According to this study, it showed that in most programs, men are the majority and women are not usually participating. Therefore, the government and the organizations in this area should plan a better program for empowering the young women with disabilities by fully understanding their nature, their difficulties and their life.

Policy for Disability Rights and SRH rights

Although the government has law and policy to protect the vulnerable groups, the policy is not much practicing in the community. As the awareness of policy and rights are still low in the community. Moreover, the current law and policy doesn't explain enough or still not strong to provide fully equal community for person with disabilities. Moreover, the awareness of SRH is still low in the community. Furthermore, most of the people do not know policy and rights for person with disabilities except from the some organization working for person with disabilities, therefore, government should provide clear information and awareness about their policy and law for the vulnerable groups. Moreover, the government should provide the strong and clear policy for SRH for person with disabilities and provide awareness to reduce negative attitudes and actions towards the SRH for person with disabilities.

5.3.2 Recommendations for further Research

This study is focused discourse on the young women with physical disabilities who are age between 13 and 20 regardless of their seriousness of the disabilities. For further research, conducting a qualitative study focus on how the

discourse is different from seriousness of the disabilities and how does it affect to their notion of self and subjectivities differently.

For another recommendation for further research, conducting a qualitative research about how the discourses affect the community members thinking, beliefs, attitudes towards person with disabilities and how does it has impact on the social support for the person with disabilities to access SRH care and information is strongly recommended.

In addition, the study on the how the notion of self and subjectivities shaped or decided whether to search for the health care and information or not is also recommended. As the current study show that sometimes the person with disabilities doesn't know or understand whether they need health care and information.

Furthermore, a comparative study upon accessibility of quality care and accessibility of information of SRH, the difficulties and barriers in accessing SRH information and services between the women with disabilities and women without disabilities need to be conducted to understand more about the SRH problems and to understand whether they access the require rights and equity in the community or not.

Finally, the study about policy for SRH of person with disabilities services need to be conducted. So the policy makers and the other organizations giving services to person with disabilities can conduct more effective programs for the development of the person with disabilities.

BIBLIOGRAPHY

- Abrams, T. (2014a). Heidegger, Subjectivity, Disability
- Addlakha, R. (2009). Gender, subjectivity and sexual identity: How young people with disabilities conceptualize the body, sex and marriage in urban India. Retrieved from <http://ideas.repec.org/p/ess/wpaper/id2075.html>.
- Amsterdam, V. N., Knoppers, A. & Jongmans, M. (2012). 'It's actually very normal that I'm different'. How physically disabled youth discursively construct and position their body/self. *Sport, Education and Society, First Article*, 1-19.
- Anderson, P., & Kitchin, R. (2000). Disability, space and sexuality: Access to family planning services. *Social Sciences & Medicine*, 51, 1163-1173.
- Baffoe, M. (2013). Stigma, discrimination and marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, 3(1).187-198.
- Barrett, A.K., O'Day, B., Roche, A. & Carlson, L. B. (2009). Intimate partner violence, health status and health care access among women with disabilities. *Women health's issues*, 19, 94-100.
- Basson, R. (1998). Sexual health of women with disabilities. *Canadian Medical Association Journal*, 159 (4), 359-362.
- Becker, H., Stuifbergen, A. & Tinkle, M. (1997). Reproductive health care experiences of women with physical disabilities: A qualitative study. *Archives of Physical Medicine and Rehabilitation*, 78, 26-33.
- Bowers, R. (2002). Stigma of Disability and Limb differences. *Inmotion*, 12 (4), 35-37.
- Browne, J. & Russel, S. (2005). My home, your workplace: people with physical disability negotiate their sexual health without crossing professional boundaries. *Disability and Society*, 20(4), 375-388.

- Brueggemann, J. B., White, F.L., Dunn, A.P., Heifferon, A.B. & Cheu, J. (2013). *Becoming Visible: Lessons in disability*. Cited in college composition and communication, Vol. 52, No. 3 (Feb., 2001), pp. 368-398
- Bywaters, P., Ali, Z., Fazil, Q., Wallace, M. L., & Singh, G. (2003). Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement. *Health and Social Care in the Community*, 11(6), 502–509.
- Cash, F. T.(2004). Body image: Past, present and future. *Elsevier*, 1, 1-5.
- Cook, J. R., Dickeens, M. B., & Fathalla, F. M. (2003). *Reproductive Health and Human Rights: Reproductive and sexual health*. New York,NY: Oxford University.
- Danaher, G., Schirato, T., & Webb, Jen. (2000). *Understanding Foucault*. New South Wales, Australia.
- Earle, S. (2003). Disability and Stigma: An unequal life. *Speech & Language Therapy in Practice*.pp21-22. Retrieved from <http://oro.open.ac.uk/12660/>.
- EFA. (2009). Concept Paper on Marginalization. United Nations Educational, Scientific and Cultural Organization, Paris.
- European Disability Forum. (2010). *EDF input to the general discussion of the CESC on sexual and reproductive rights*.
- Frohmader, C., & Ortoleva, S. (2013).The Sexual and Reproductive Rights of Women and Girls with Disabilities. *Issue paper, International conference on Human Rights*.
- Graham, J. L. (2005). Discourse analysis and the critical use of Foucault. Proceeding from '05 Annual Conference. Sydney, Australia
- Green, S., Davis, C., Karshmer, E.,Marsh, P. & Straight, B.(2005). Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry*, 75 (2), 197-215.
- Hardon, A. (1995). *Gender , Society and Development: A critical review of sexual and reproductive health*. Amsterdam,Netherlands: Royan Tropical Institute (KIT).

- Hunt, P. (ed.) 1966: *Stigma: The Experience of Disability*, London: Geoffrey Chapman.
- Japan International Cooperation Agency. (2002). Country profile on disability (ed). Myanmar: Thein, M. M.
- Jorgensen, M., & Phillips, L. (2002). Discourse Analysis as theory and method. SAGE publication. London.
- Kaplan, C. (2006). Special Issues in Contraception: Caring for Women With Disabilities. *American College of Nurse-Midwives Issued by Elsevier Inc*, 51(6), 1-7.
- Katsui, H. (2008). Identity of Disabled People: When do you want to be called "disabled people"? Retrieved from <http://disability-uganda.blogspot.com/2008/01/identity-of-disabled-people.html>.
- Kleinman, A., & Fitz-Henry, E. (2007). *Subjectivity: The experiential basic of Subjectivity; How individuals change in the context of societal transformation*. J. Biehl., B. Good., & A. Kleinman. (Eds.). California, LA: University of California.
- Kristensen, S.K (2013). Michel Foucault on Bio-power and Bio-politics. Master's Thesis.
- Lock, M. & Scheper-Hughes, N. (1990). A critical- interpretive approach in medical anthropology: Rituals and routines of discipline and dissent. T.M. Johnson & C.E. Sargent (Ed.), *Medical Anthropology: Contemporary theory and method* (pp. 47-72). New York, NY.
- Luborsky, R. M. (1994). The cultural adversity of physical disability: Erosion of full adult personhood. *Journal of aging studies*, 8(3), 239-253.
- McLaughlin, E. M., Bell, M. & Stringer, Y. D. (2004). Stigma and acceptance of persons with disabilities. *Group & Organization Management*, 29 (3), 302-333.
- Mona, R.L., Gardos, S.P & Brown, C. R. (1994). Sexual Self Views of Women with disabilities: The relationship among age-of-onset, nature of disability and sexual self-esteem. *Sexuality and Disability*, 12(4).
- Moyo, S. D. (2010). *Ensuring sexual and reproductive health rights of women with disabilities: A study of policies, actions and commitments in Uganda and*

- Zimbabwe*. (Prepared dissertation for development studies program). University of Reading, England.
- Murphy, F. R., Scheer, J., Murphy, Y. & Mack, R. (1988). Physical disability and social liminality: A study in the rituals of adversity. *Social Sciences & Medicine*, 26 (2), 235-242.
- National Coordinating Agency for Population & Development.(2009). Women with Disabilities Need Reproductive Health Services, Too. Kenya: NCAPD policy brief no. (3).
- Naemiratch,B. & Manderson,L. (2009). Pity and Pragmatism: Understanding of disability in Northeast Thailand. *Disability & Society*, 24(4), 475-488
- Nosek, A. M., Hughes, B. R., Swedlund, N., Taylor, B. H. & Swank, P.(2003).Self-esteem and women with disabilities. *Social Science & Medicine*, 56. 1737-1747.
- Peters,J.S., (2009). Review of marginalization of people with disabilities in Lebanon, Syria and Jordan. Education for all Global Monitoring Report.
- Power, P. (2007). The Philosophical Foundations of Foucaultian Discourse Analysis. *Critical Approaches to Discourse Analysis across Disciplines*, 1 (2), 18-34.
- Reinikainen, R. M. (2006). Everyday discourse on disability: A barrier to successful disability policy?. *Nordisk Sosialt Arbeid*, 26, 194-206.
- Roush, E. S., (1986). Health Professionals as Contributors to Attitudes toward Persons with Disabilities. *Journal of the American Physical Therapy Association*, 66, 1551-1554.
- Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Elsevier*, 1, 83-97.
- Salai, V. B. (2012). Understanding the challenges of disability in Myanmar. Retrieved from http://www.burmalibrary.org/docs13/Understanding_the_Challenges_of_Disability_in_Myanmar-red.pdf.
- Shakespeare, T. (2003). *Sexualities and Society*. J. Weeks., J. Holland. & M. Waites (Eds.).USA: Blackwell Inc.

- Shakespeare, T. (1996). Disability, Identity and Difference. Chapter 6 (in 'Exploring the Divide, C. Barnes and G. Mercer (Ed.), The Disability Press(pp. 94 – 113). University of Leeds: Leeds.
- Shakespeare, T. & Watson, N. (1996). "The body line controversy" a new direction for disability studies?.
- Sida. (2012). Disability Rights in Myanmar. Sida country Team.
- Teleporos, G., & McKaBe, P.M. (2002). Body image and physical disability-Personal perspectives. *Social Sciences & Medicine*, 54, 971-980.
- Thierry, M. J. (2006). The Importance of Preconception Care for Women with Disabilities. *Matern Child Health Journal*, 10, 175-176.
- Tremain, S. (2002). *Embodying Disability Theory*. M. Corker & T. Shakespeare (Ed.). New York, NY: Anchor.
- UN. (2006). International convention on the rights of persons with disabilities, New York.
- UN. Dialogue and Mutual understanding. *Fact Sheet: Youth with disabilities*. Retrieved from <http://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-with-disabilities.pdf>.
- UNFPA. & Ministry of Health, Myanmar. (1999). A reproductive health need assessment in Myanmar.
- UNFPA. (2003). *Sexual and Reproductive health of persons with disabilities*. ISBN# 978-0-89714-868-9.
- UNICEF. (2013). *Children and Young people with disabilities*. Fact Sheet. Retrieved from www.unicef.org/disabilities.
- UNICEF. n.a . Changing attitudes towards people with disabilities. Retrieved from http://www.unicef.org/disabilities/index_66543.html.
- Uyen, T. P. (2008). "Right love": An emergent and contested discourse on gender, sexuality and reproductive health in high school in Hanoi, contemporary Vietnam. (Master dissertation). Retrieved from Mahidol University.
- Westbrook, T. M., Legge, V., & Pennay, M. (1993). Attitudes towards disabilities in a multicultural society. *Social Sciences & Medicine*, 36(5), 615-623.
- Williams, D. P., Williams, R. A., Graff, C. J., Hanson, S., Stanton, A., Hafeman, C., Liebergen, A., Leuenberg, k., Setter, K. R., Ridder, L., Curry, H., Barnard,

M., & Sanders, S.(2002). Interrelationship among variables affecting well siblings and mothers in families of children with a chronic illness or disability. *Journal of Behavioral Medicine*, 25 (5), 411-424.

Women's Health West. (2013). *Family violence: Report on intensive case management for women with disabilities.*

APPENDICES

APPENDIX A

GUIDELINES FOR IN-DEPTH INTERVIEW

I. Preparation

1. Contact to the organization, The Leprosy Mission Myanmar.
2. Contact to the Field office of The Leprosy Mission Myanmar in Hlaing Tharyar
3. Introduction and explaining about the research and research's objectives to the staff in the field office and the volunteer from the field office.
4. Select participants by contacting the field office and the volunteer
5. Set the places, time and tools for interview.
6. Contact participants for asking them for informed consent orally and written consent.
7. Organize the in-depth interview with the permission for voice recording, taking photos during interviews.

II. Background information about women with physical disabilities

Personal (socio- demographic data) of the informant, these data will be asked indirectly during interview process:

- Age
- Educational Background
- Type of Physical Disabilities
- Age that the disability started develop
- Numbers of Family members who have disability. If yes, types of disability?
- Family Background

III. In- Depth Interview Guidelines

A. To understand the notion of self among young women with physical disabilities.

1. Impairment and disabled body

- a. How do you think about the physical body image of yours?
- b. How your body is different from ideal or normal body?
- c. What happen to your body in term of disability?

2. Sexual self-image

- a. What do you think about sexually attractive body?
- b. What do you think about your body?
- c. Do you consider your body as sexually attractive? Why or Why not?

B. To understand the subjectivities of young women with physical disabilities

1. Feeling of incapacity and sexual confident

- a. How do you feel about yourself in term of being yourself with your disability?
- b. How do you think about having relationship with opposite sex as a disabled person? Why or Why not?
- c. Do disabled people can have relationship or they can marry? Why or Why not?

2. Being control, surveillance, regulated own body and sexuality.

- a. What do you think about being a woman with physical disabilities?
- b. How people treat you when you are with your friends, doctors, neighbors and family?

- c. Can you make discussion or get advice relating to sexual and reproductive health? Why or Why not?
- d. What kind of information or advice do you receive from them in term of your sexual and reproductive health?
- e. Relating to sexual and reproductive health, do you have your own decision or people around you influences on your decision?

C. To explore sexual and reproductive health practices among young women with physical disabilities.

- 1. Do you know how to do hygiene during menstrual cycle?
- 2. How do you manage your hygiene during menstrual cycle?
- 3. How do you do when you have irregular or no menstruation?
- 4. Have you ever been touched or talked sexually that you don't want to? Do you know how to protect yourself against these acts?
- 5. Do people harass you verbally or physically? Do you know how to protect yourself against these acts? If yes, how?
- 6. Do you know what puberty is? Do you know why your body change is? (Eg, breast, reproductive organ and hair? How do you feel about these changes?
- 7. Do you know about sexual and reproductive health? Do you get any information from your family or some organization or from media? If yes, what kind of information that you get and do not get? Which information that you want to know but you do not know?
- 8. When (if) you have sexual and reproductive health problem, where do you go? Do you think you have health service which is user-friendly for you?

APPENDIX B

GUIDELINES FOR KEY INFORMANT INTERVIEW

I. Background information about community members and family members

Personal (socio- demographic data) of the informant, these data will be asked indirectly during interview process:

- Age
- Educational background
- Occupational background
- Years of working experiences

A. Explore the discourses

- a. What is disability? What does it mean to you?
- b. What the term that uses to call a disabled people? For you, what kind of term is easy to call and why?
- c. Do you think that impairment and disability is the same? Why and Why not?
- d. How do you think about the sexuality issues among women with disabilities?
- e. Do you think disabled people are sexually not active or asexual? Why or Why not?
- f. Do you think that disabled people also need sexual and reproductive health care? Why or Why not?

B. Explore social support and attitudes of family members towards young women with physical disabilities

- a. How do you feel about living with person with disabilities?
- b. What are you main concern about person with disabilities?

- c. What does disability mean to you?
- d. How do family members think about the women with physical disability?
- e. Do you think women with disabilities can live independently or they need to depend on others for their whole life? Why or Why not?
- f. What kind of social support do the women with physical disabilities need? Why?

APPENDIX C

GUIDELINES FOR DOCUMENTARY REVIEWS

- Document reviews collect materials from the magazines, journals, newspaper articles and pamphlets from the organizations for the person with disabilities, pictures and posters
- The messages in these materials while the researcher will collect and look for include disability, sexual and reproductive health of women with physical disabilities.

BIOGRAPHY

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