Subjugated knowledge of reproductive health and disability among disabled women

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Abstract

This article investigates how women with physical disabilities understand reproductive health and disability based on ethnographic research conducted in Ho Chi Minh City, Vietnam in 2019. Observations, photovoice, and in-depth interviews were adopted to collect data. 30 involved in the interviews included 20 women with physical disabilities, five key informants, and five health care providers. The findings used in this article were analysed from 20 in-depth interviews with women with physical disabilities. Lay understanding of reproductive health among women with physical disabilities in Vietnam was varied as categorised into four themes including (1) Self-characterised as infertile and asexual women, (2) Taking responsibility on childbearing, (3) Leaving a blank, and (4) Adapting and producing new knowledge. Drawing on the unveiled lived experiences of 6 case studies, their subjugated knowledge of these participants was illustrated. In this paper, the concept of subjugated knowledge by Garland-Thomson (2011) was adopted to interpret findings. 

Keywords: Subjugated knowledge, reproductive health, reproductive health knowledge, women with physical disabilities, disabled women, disability, healthcare, ethnographic research, qualitative research, Vietnam.
Introduction

Previous research in Vietnam has illustrated community understandings of reproductive health in relation to women with disabilities. These emphasise the belief that women with physical disabilities were infertile and/or should not give birth (Nguyen et al. 2017; Nguyen et al. 2020; D et al. 2011; Nguyen 2021). At the same time, people in the community assumed that having a physical disability would substantially limit reproductive function and parenting ability (Nguyen et al. 2020; Nguyen 2021). This impacted women with disabilities in seeking reproductive health information (Nguyen et al. 2017; Bui 2020) as family members or community members avoided sharing reproductive health information with them because of the sensitivity of the topics (Nguyen et al. 2017; Bui 2020; Khut, Lê, and Nguyễn 2012). This avoidance led to disabled people receiving limited sexual and reproductive health knowledge (Nguyen et al. 2017; Khut, Lê, and Nguyễn 2012; Bui 2020).

Subjugated knowledge is a concept which refers to the language deficiencies and attributions of abnormality that devalues the contributions of disabled people (Garland-Thomson 2011). Subjugated knowledge is one of the key elements of misfit theory (Garland-Thomson 2011) which is adopted in this research to explain and interpret our findings. When applied to this paper, it refers to both lacking of information (when it compares to the WHO’s definition) and understandings, or holding non-normative knowledges, by the study participants regarding reproductive health and the lack of priority attributed to the need for disabled people to have such knowledge; indeed, this is illustrated by the active silences around reproduction that disabled women encounter in Vietnam. From our empirical findings, the reproductive health knowledge of the participants is variable, as some participants have a better understanding than others, and some have very little understanding regarding reproductive health.

In the findings section of this article, we first discuss the subjugated knowledge about reproductive health and disability among the study participants. Drawing on Garland-Thomson’s (2011) misfit theory, we focus on the unveiling lived experiences of six case studies (Dinh, Kim, Thu, Ngoc Nhu, and Thanh) to examine how their knowledge has been shaped. The reason for choosing these case studies is because their stories illustrated well the varying levels of reproductive health knowledge held by the participants. Following this section is a discussion section where we interpret our empirical findings through the misfit lens of Garland-Thomson (2011). A conclusion is presented in the end of this paper.

Methods

Study design and setting

Qualitative data used in this paper was extracted from the ethnographic research of the first author. The primary data collection was based in Ho Chi Minh City, Vietnam’s largest city. It is a dynamic city that is a destination for migrants from provinces throughout Vietnam for study and work. In Ho Chi Minh City (HCMC), there are many organizations of/for people with disabilities such as Disability Research Capability and Development, Ho Chi Minh City Disabled Youth Association, Orientation Vocational for Disabled Youth Club, Women with Disabilities Club, Saigon People with Disabilities Group, etc. These groups are popular among people with disabilities because they provide opportunities to engage in social activities.

Data collection

Within the context of this research, interviews were used to examine participants’ experiences when accessing reproductive health care of women with physical disabilities. Informed consent was acquired. Interviews were conducted in a quiet room, and audio recorded. The interview took approximately one hour for each person. The interview guide explored women’s access to reproductive health information and services. Broadly, the first author asked women about their experiences to access related information, health care services,
contraception, any assistance, or barriers they have encountered, and their solutions for managing barriers. Interviews allowed us to explore participant’s perspectives and experiences in-depth. Thus, they enabled us to address the factors that shaped the participants' knowledge and impacted their experiences. Interviewees also were asked some questions regarding each their social demographic details including age, career, education, religion, income, number of children, and the nature of their disabilities. At the end of the interview, the first author asked for contact details for following up later on to confirm some details. All contact details were digitally stored on a password protected computer.

This research also included observations and photovoice methods for data collections. However, within this paper, we only used data from the in-depth interviews. Thus, we did not mention details other methods in this paper. Below, we present sample size and recruitments for in-depth interviews.

**Sample size and recruitment**

At first, we sought to recruit approximately 20 women with physical disabilities, although the final sample size was determined using the concept of data saturation. According to this, the data collection process would stop when there would be little or no new information emerged (Rapley 2014, p. 60). All study participants met the following inclusion criteria: aged 18 years or above; identified as a woman; lived/worked/studied in HCMC, Vietnam; and live with a physical impairment (including congenital or acquired disabilities).

Participants were recruited through two disability-specific organisations: The Women with Disability Club (WDC), and the Saigon People with Disability Group. The first author is a member of Saigon People with Disability Group (SPDG), and has closed links with the leaders of both groups (she has known them personally for many years). She was previously chairperson of the Student Disability Club in Ho Chi Minh City, and she has also been involved in inclusive disability activities for many years. This means that she was well-connected to, and trusted by, the wider community of women with disabilities.

She arranged with the group leaders to distribute the study information sheet to potential participants. Anyone who was interested in this research was invited to contact her via email, Facebook, Zalo. Zalo is an app that users sign up by using a phone number, or via her phone number, all of which were given in the information sheet. Snowball sampling was used to recruit subsequent participants. This recruitment method is extensively used in researching vulnerable groups and was effective in locating members of vulnerable groups where the research topic was sensitive (Faugier and Sargeant 1996). She asked participants to invite their friends who met the inclusion criteria to participate in this study. Potential participants might be interested in this study if their friends invited them, because some Vietnamese people with disabilities were very introverted or reclusive. By that way, we had 20 women with physical disabilities participating in this research. Below is social demographic characteristics of women with disabilities.

The 20 study participants had a range of physical disabilities; seventeen women lived with physical disabilities which resulted from polio syndrome, two women experienced disability as a side effect of injections in their early childhood, and one woman had experienced spinal cord injury due to a serious motorbike accident. Almost all study participants used assistive technologies. However, there was one participant who was paralysed in both legs and did not use any support aids due to her narrow living space. She always stayed at home as she found it very hard to go out without a companion.

Participants were relatively diverse in terms of their sociodemographic characteristics. All were aged 30 to 53 years old; ten married participants had disabled partners, while five married women had non-disabled partners. Most of the disabled partners had severe disabilities and also used some forms of support such as crutches, leg braces or wheelchairs. Most of the married participants with disabled partners lived independently, and sometimes their family members supported them with postnatal care, infant care and childcare. Three single women with physical disabilities were also included in the study, to examine how their perceptions of reproductive health might differ from those of married women with disabilities. Most participants described themselves as having no religion, while others were Buddhist (nine participants), followed by Catholic (four participants), and Cao Dai (two participants). There was diversity in terms of careers. The
largest group were women working in companies (ten people), government (one person) or self-business (four people). This study included four women who were unemployed/housewife, and one woman who sold lottery tickets.

Participants varied in their literacy levels. The group as a whole was highly educated with most women having graduated from vocational school or university. Six participants had lower education levels and had not finished secondary school, while one participant had no formal education but learned how to read and write from her friend. The incomes of women in this study were closely associated with their education levels, so that the higher their education levels, the higher incomes they earned. While the 2019 annual GDP per capita in Vietnam was $USD2,715 (The World Bank 2019), most women (sixteen people) in this study had incomes higher than GDP per capita in Vietnam. There were only four participants who had lower incomes than this. However, this study was conducted in Ho Chi Minh City where the Gross Regional Domestic Product (GRDP, an indicator of average wage) in 2020 was about $USD6,328 (VnEconomy 2020). In comparison to the GRDP of Ho Chi Minh City, most incomes of women in my study were lower than GRDP, while only four women had higher incomes. These characteristics impact on the seeking health care information of these women.

Ethics approval

This project has received ethics approval from the Human Research Ethics Committee at Monash University, Clayton, Melbourne, Australia (Project ID: 18096).

Data analysis

Thematic analysis was used for analysing data in this project. This method was to identify, analyse, and report themes within the data. Thematic analysis involved the search across a number of interviews (data set) to find repeated meaning patterns and define themes. This process moved constantly back and forth across the whole data set (Braun and Clark 2006). We followed six stages for thematic analysis as described by Braun and Clark (2006). NVIVO software, and Excel were used to support the analysis process. All the transcriptions were in Vietnamese, and only selected quotes were translated into English. The first author created initial themes and coding book. She then discussed these themes with the second authors. The other authors worked on revising themes and checking quotes. We all discussed, revised, and finalized those themes.

Results

Previous studies have illustrated that Vietnamese women in general have been shown to have high levels of knowledge regarding reproductive health and reproductive technologies (Gammeltoft 1999), whereas minority (non-disabled) people (McKinn et al. 2019) and teenagers (Nguyen and Bengtson 2012; Khuat 2003) lack reproductive health knowledge, which increased their likelihood of suffering from reproductive tract infections (Binh, Gardner, and Elias 2002; Whittaker 2002; Khuat 2003; McKinn et al. 2019).

In this paper, one element that shaped participants’ experiences of reproductive health was related to their knowledge levels. When asked to define reproductive health, each study participant listed at least one of the different aspects of reproductive health, covering a diverse range of topics, such as childbearing, mother and child health, sexual health, sexually transmitted diseases, physical health, mental health, contraception, conception, menstruation and hygiene, and pregnancy. For example, Loan (37-year-old) defined it in the following way: “Reproductive health includes pregnancy check-ups, birthing, and postnatal care”, and Hanh (32-year-old) said “I think reproductive health is about pregnancy. It concerns the process from pregnancy to giving birth”.

Both of these participants identified reproductive health as associated with the actual processes of reproducing, yet they did not capture the holistic elements that characterise the WHO’s definitions. These statements...
reflect that their reproductive health understandings were narrow because their understandings only focussed on pregnancy and the antenatal/postnatal care. To further understand the different levels of reproductive health knowledge from the participants, we draw upon the six case studies to examine how their reproductive health knowledge has been shaped. While Dinh self-characterised herself as an infertile and asexual woman, women in the study commonly defined reproductive health as childbearing, and the care before – during – after pregnancy (prenatal/postnatal care). Additionally, other aspects of reproductive health such as mother and child health, menstruation, and hygiene were offered by other participants. Two women, Thu and Ngoc, said they did not know how to define reproductive health, although they did discuss how social stigma had shaped their own understanding and experiences. Other participants identified diseases associated with the reproductive system.

Synthesizing reproductive health elements from my study participants’ knowledge, we categorised their definitions and knowledge surrounding reproductive health into four main themes (see Figure 1 below). The first theme is ‘self-characterised as infertile and asexual women’. This theme focuses on how the education within the family influenced disabled women, in turn, identifying themselves as infertile and asexual people. The second theme, ‘taking responsibility on childbearing’, highlights how the limits of this definition in turn affects women’s access to reproductive health education within their families. Some of these women noted the importance of ‘mental and physical well-being in order to produce a baby’. This theme also emphasises their current concerns in relation to reproductive health. The third theme is ‘leaving a blank’. This theme reveals the experiences of misfitting between their bodies and the internal/external environments which resulted in a self-perceived ‘lack’ of reproductive health knowledge. In this context, the term ‘lack of knowledge’ refers to the narrow understandings of reproductive health of the participants in relation to the WHO’s definition. The last theme is ‘adapting and producing new knowledge’. This theme explores how study participants utilised different means to gain knowledge, often defying social expectations to do so. This theme also reflects the women’s misconceptions about the relationship between sexual health and reproductive health. In the first three themes, we explore the subjugated knowledge of the study participants about reproductive health and disability. By highlighting these case studies, we explain how their knowledge has been shaped. These experiences reflect women’s perception of themselves and reproductive healthcare. Below, we first provide a detailed illustration of the case studies, with a focus on the study participants’ knowledge and understanding of reproductive health. We then analyse these case studies to explore how subjugated knowledge is produced among disabled women as a result of misfitting.

Figure 1: Reproductive health subjugated knowledge of women with physical disabilities

Self-characterised as infertile and asexual women

Vietnamese people assume that women with physical disabilities are unable to perform traditional gender roles regarding reproduction due to their disabilities (Mestechkina, Son, and Shin 2014; Nguyen 2021). The discrimination within the family toward people with disabilities often resulted in the participant women keeping silent at home. A few women in this research shared that they had attempted to challenge this discrimination from inside their families. In their families, disabled women were believed to be asexual, infertile, or have difficulty with becoming pregnant. Kim spoke about her experience in her family, stating that:

I know that I am a woman with a disability. I acknowledge that it is very hard for me to have a baby because my mother often told me about that. Other people in my family said that too. I knew my situation, but I could not predict how hard it would be (Kim, 34 years old, married, vocational school, office worker).

Kim’s statement illustrates the barriers caused by perceptions within her family but also within the general public perceptions. This produces misunderstandings of disabled women’s ability regarding their reproductive potentials. Consequently, women with disabilities underestimate their abilities and thus become more vulnerable (Garland-Thomson 2011).

The study women experienced greater restrictions regarding reproductive health education within their
families relating to cultural mandates. This aspect is well illustrated by case studies of Dinh. Below, she shared their experiences of being defined as an asexual and infertile woman because of her disability which in turn, shaped her subjugated knowledge about reproduction and disability.

*Dinh’s case study*

Dinh is a 38-year-old married woman and is running her own business from home. She has a spinal cord injury after being involved in a serious motorbike accident when she was around 20-years-old. She is now a permanent wheelchair user. She was very honest with her experiences of discrimination within her family and said that: “They are my family, but they do not understand me as well as my disability. So, I never ask them anything and I will never ask for it”. She shared that:

You know, prior to my wedding, my older sister told me: “Oh my god, you would never be able to have sex, so how dare you get married”. Do you believe that? She is my older sister, but she said that to me and repeated that a lot. She always said something that implied “Oh my god, you would never have any feeling when you have sex, so you do not have to get married”. Due to her disability, her family members defined her as an asexual-infertile-woman. When Dinh heard that, she was very sad. It was not just her older sister saying such things, but also some of her other family members. They discussed whether she could become pregnant or how she could have sex. In her family’s opinion, Dinh should not get married or have sex because of her disability. Her family members believed that Dinh was an asexual person. Her parents’ belief reflected the common assumption that “you are disabled, so you are asexual” (Nguyen et al. 2017; Nguyen et al. 2020; D et al. 2011; Nguyen 2021). Dinh did not mind explaining further but kept silent. The negative attitudes from her family members could have resulted in Dinh doubting her ability and devaluing herself. However, tried to overcome this stigma by getting married to a non-disabled man. In this way she stopped the gossip of other people around her marital life as a disabled woman.

However, she continued facing another barrier, which we refer to as the “infertile - misfit”. It was assumed that she was infertile because of her spinal cord injury. She said, “My parents and family—in—law strongly believed that we have not had any children yet, because of my disability”. They took it for granted that a person with spinal cord injury is infertile”. Facing this barrier produced a subjugated knowledge about reproductive health as they devalued their daughter’s ability (Garland-Thomson 2011). In this situation, Dinh also started believing that she was infertile, because she has not had any pregnancy yet after five years of marriage. One day, one of her friends who lives with a spinal cord injury announced she was pregnant. This announcement encouraged Dinh to overcome her self-discrimination and find out the cause of infertility between herself and her husband. She and her husband went to see an infertility doctor. The doctor consulted found that her body is “normal” and her husband is infertile. After the consultation with her doctor, she now understood that her spinal cord injury is not the cause of their infertility. They are now seeking treatment for her husband’s problem. In this case, although Dinh’s subjugated knowledge was produced at some points in her life, Dinh found new knowledge of reproductive health and disability through her social networks of other disabled peers. In other words, the ability to engage in social networks creates opportunities for people with disabilities and contributes to improving their self-knowledge including knowledge regarding their reproductive health.

In Dinh’s account, social-cultural norms around disability have influenced her parents’ perception of reproductive health and disability. Their misunderstanding has transferred to their children and created disadvantages and discrimination for disabled women. Although Dinh’s story showed her abilities to challenge social-cultural norms, she was less confident to change her parents’ perception as she showed no strategy to deal with it.

**Taking responsibility on childbearing**

This theme discusses disabled women who understood their responsibilities in childbearing. More specifically, these disabled women defined their understanding of reproductive health in terms of childbearing and the
maintenance of well-being for childbearing. Therefore, we categorise this theme into two subthemes as presented details below.

Reproductive health is understood as childbearing

Vietnamese culture and social norms regarding education about sexual and reproductive health challenge young people who are unmarried and single. Conventionally, people believe that providing education about reproductive health to young people means “v dagen cho hu chy” (literally translated as signalling a way for the deer to run) (Bui 2020, p. 796). That is to say, this education may encourage their young children to have premarital sex (Nguyen 2021; Bui 2020; Khut, Le, and Nguyen 2012). With respect to this belief, a good “fit” for young people to learn about sexual and reproductive health is after they are married. Therefore, most parents avoid having a conversation on the sexual and reproductive health topic, or they try to use metaphors when they want to talk to their children about such topics. Despite efforts to restrict information within the family, non-disabled people and those who have higher incomes try to overcome this barrier by using digital tools, social networks, and other resources around them.

In relation to people with disabilities and those who have no or lower incomes, they lack access to social networks, digital resources and other means of education due to the cultural norms around disability, the limitations of the built environment, and economic factors which restrict their opportunities. In turn, their experiences reflect different levels of knowledge about themselves and reproductive health. Moreover, reproductive health in Vietnamese is often translated as “sc kho sinh sn”, in which the synonym of “sinh sn” (reproduction) is “sinh d” (birth) in dialect. Therefore, when talking about “sinh sn”, participants refer directly to birthing and pregnancy. These participants, therefore, think the word “childbearing” encompasses reproductive health. For example, Tran shared her thought below:

It is about pregnancy and birthing. For example, how to become pregnant, and how to give birth (Tran, 36 years old, married, high school, gift shop owner).

Tran was unmarried and single when she lived with her parents. At that time, Tran’s parents took it for granted that Tran did not need to learn about reproductive health. Thus, she did not learn any from her parents yet. Similarly, Kim’s account below is an example of the limited reproductive health education within their families.

Kim’s case study

Growing up in a poor village, unfortunately, Kim got poliomyelitis (polio), but she is able to walk without any support. In her migration to Ho Chi Minh City, she graduated from a vocational school and used to work as an accountant for the organization Disability, Capacity, Research and Development (DRD). This is a nonprofit organization of people with disabilities for people with disabilities. She then married a disabled man and the couple have a five-year-old son. During the time working for DRD, she had more chances to learn about sexual and reproductive health through training courses held by DRD. However, her understanding of reproductive health was simplistic. She said:

When I think of the word “reproduction”, I think of the word “childbearing” as well as how I can have a baby (Kim, 34 years old, married, vocational school, office worker).

Kim shared that in her childhood, her mother told her that she had to take good care of her body. She said her mother always said, “You have to take care of yourself for giving birth when you are older”. By saying that, Kim’s mother was referring to taking care of the genital areas and was warning her to be careful when making friends with men. Kim said that her mother did not explain any further “how to take care of my body”.

Kim’s account implies cultural mandates and gender expectations of being a mother. In the Vietnamese context, the domestic traditional gender roles expect married women, who are with and without disabilities, to be able to become pregnant, to give birth, to take care of children (Mestechkina, Son, and Shin 2014), and to take care of the elderly (Nguyen 2021). These traditional roles still exist in modern Vietnam (Mestechkina,
Son, and Shin 2014; Nguyen 2021). Additionally, unmarried and single people are not encouraged to search or learn about sexual and reproductive health (Khut, Lê, and Nguyễn 2012; Bui 2020). From Kim’s mother’s point of view, Kim’s situation was inappropriate to learn about reproductive health because she was unmarried and single at that moment. Therefore, Kim’s mother did not have a direct conversation with Kim about reproductive health. She avoided talking to Kim about genitals Kim’s mother educated and expected Kim to maintain her body for giving birth to a child later in life, but Kim was restricted to seek out further information on this topic. Kim’s desire contradicted the social norms in relation to reproductive health. Consequently, Kim received little reproductive health information from her mother.

Kim’s mother warning about making friends with men implied saying no to having premarital sex because premarital sex is forbidden and socially seen as a taboo in Vietnam (Ghuman et al. 2006; Do et al. 2017; Khut, Lê, and Nguyễn 2012; Bui 2020). If a girl has premarital sex, she will be labelled “gái hằng” (meaning bad girl) and seen as bringing shame to the family (Do et al. 2017; Bui 2020). Kim’s understanding is shaped by the limitations in relation to reproductive health education within her family. Her knowledge is determined by what she gleaned from her mother; therefore, she defines reproductive health only in terms of childbearing.

Kim’s story shows the limitations of reproductive health education within her family. This contributes to her lack of knowledge about disability and reproductive health, which in turn influences her future decision-making. Stigma and discrimination towards people with disabilities still exist among the families of some of the women in this study. Due to the cultural norms and the perception of family members about reproductive health and disability, women in this study received no or little reproductive health knowledge.

Reproductive health is good physical and mental health to produce a healthy child

Another subtheme that emerged from the interviews was the understanding of reproductive health as good physical and mental health for childbearing. Some study women are expecting or have children and were concerned about how to produce a healthy baby. Therefore, their understanding was developed based on their current concerns in life. Other study women defined reproductive health simply in terms of menstruation and hygiene.

The well-being of both males and females

Disabilities caused by polio or injuries will not transfer from mothers to children (Department of Health 2014). With respect to this fact, some study women were more concerned about their physical and mental health. They did not care much about their disabilities but were concerned about how to maintain their well-being. In this sense, their current concerns met with gender cultural expectations. Some study women suggested that both men and women must have good health and well-being when they want to produce a baby, and this is especially important for a woman. To prepare for this process, they mentioned the importance of healthy eating habits. They believed that if couples did not have good health, they would not be able to produce a healthy baby. For example, Thi stated:

“When you ask about reproductive health, I think straight away about women’s health. I mean the physical health of the mother to see if she is able to give birth. It also includes eating healthy food. To have a baby, we also need a healthy man. I mean without a man; we cannot produce children (laugh). We do not only eat healthy food but also need to make sure that we do not have any stress. You know, if we are stressed, we cannot have healthy babies. The very important thing is to make sure about the quality of women’s egg and men’s sperm, make sure the egg is good and the sperm is strong… I am more concerned about women’s health. This is very important because a healthy mother conceives a healthy baby (Thi, 34 years old, married, Bachelor’s degree, sales admin).”

In such statements, study women were repeating common health promotion messages that encourage women to prepare for childbearing through health examinations and eating healthy food. The emphasis on food is not only about nutritional value - in Vietnamese culture, correct balances between the hot and cold, wet and dry humoral qualities of foods is considered essential to maintaining strength and health (Gammeltoft
Similarly, Que shared her concerns to eat healthily:

I think reproductive health is about women’s health only. For example, if I want to have a baby, I need to check my health first to make sure that I am well. If I have any illness, I must have treatment prior to becoming pregnant. If I am pregnant, I need to know about eating healthy food during pregnancy and know how to take care of the baby (Que, 36 years old, married, high school, freelance craftsperson).

Some participants, like Que, defined reproductive health on the basis of their current concerns. If like Que they are trying to have a baby, they would say that reproductive health is the care before, during, and after pregnancy. Hoai is an example. She and her husband were seeking help for producing a baby. She stated that she read a lot of information related to pregnancy on the internet. Although she said, “I think this is a very hard question for me (laugh)”, she gave an example to clarify her reproductive health thinking. She shared:

I think if I am invited to reproductive health training courses, I will expect that I will learn about how to take care of my health prior to pregnancy, during pregnancy, how to take care of my baby, about eating healthy food. It is like if I want to have a baby, how I prepare for it. Prior to pregnancy, I will eat food that may help to conceive quickly. If I am pregnant, I will eat food that provides nutrition for the baby and me. And after giving birth, I will eat food that can help me to recover better and produce more breast milk for the baby. It is not only about eating healthy food but also is about caring in three stages (Hoai, 35 years old, married, Bachelor’s degree, accountant).

These statements reflect the study participants’ knowledge about themselves and reproductive health which are shaped by their experiences with health promotion messages and learning from the internet. They understood that they are women and (potential) mothers. Therefore, they focus on maintaining a well body for childbearing. Their reproductive health understanding implies the important roles of health promotion and the internet in disseminating reproductive health information for people.

Maternal and child health

Other women emphasised maternal and child health when defining reproductive health. This was particularly the case if women were concerned about their health as mothers and that of their babies. From this perspective, they would talk about how to maintain a mother and child’s well-being, how to immunise, or how to prevent illness. For example, My, a mother of a five-year-old son, was really concerned about her health and her son’s health. She indicated that reproductive health is all about maintaining good health generally for herself and her son.

It is all issues about how to maintain good health for the mother and the baby, and something like disease prevention (My, 38 years old, married, high school, office worker).

My’s thinking is quite different from those of other women described above. While other study women understood reproductive health as childbearing, My only focused on maternal and child health. My acknowledged that, “I know my reproductive health understanding is insufficient”. She shared that she neither participated in any reproductive health training course nor received any learning from her mother. Even when she went to see a doctor for her pregnancy check-ups, she “did not raise any question to the doctor because I do not know what to ask”. Therefore, My equated reproductive health with her current concern about healthcare for her son and herself.

Menstruation and hygiene

Another woman, Le, equated reproductive health with menstruation and hygiene. Le stated that she only learned about reproductive health when she first experienced menstruation. Her mother taught her about hygiene. Le said:
I think reproductive health is menstruation and hygiene during the (blood/vaginal) discharge. That is the only thing I know. Because when I was little, I was educated like that (Le, 44 years old, married, Vocational school, office worker).

Like many of the women of this study, Le had restricted access to reproductive health information. Le only remembered learning about menstruation and hygiene from her mother when she was a teenager. This is surprising given that Le is married and currently working as an accountant and hence we might expect her to provide a more sophisticated understanding.

**Leaving a blank**

This theme is well illustrated by case studies of Thu and Ngoc who said they had no idea about reproductive health. These women had experienced isolation and segregation, leading to dependency. Dependency refers to the situations of people with severe physical disabilities who need a companion to support their daily life (Garland-Thomson 2011). Segregation is caused by the loss of mobility and being cut-off from normal social networks and activities (Garland-Thomson 2011). In other words, if people with disabilities have no support, they may not be able to get out of their houses and integrate into society. In this sense, they are excluded from social activities and may face isolation within their houses.

Moreover, beliefs that people with disabilities are dependent, asexual, and incompetent continue (Nario-Redmond 2010). With respect to these beliefs, some parents of people with disabilities tend to keep their children at home (Nguyen 2021; Ginsburg and Rapp 2013). In addition, this affects disabled people’s sense of identity as they come to view themselves as dependent on others (Nguyen 2021; Garland-Thomson 2011; Burholt et al. 2017) further reinforcing their social exclusion and segregation (Ravaud and Stiker 2001). In such cases as described below, women were either made dependent upon carers or perceived themselves as a dependent. These power relations restricted their abilities to live independent lives, affecting their access to information or autonomy (Garland-Thomson 2011).

**Thu’s case study**

On a hot day in Ho Chi Minh City, the first author received a phone call from an unrecognised phone number. It was Thu. She made this call while she was selling lottery tickets. She said she would like to participate in our research as her friend introduced this research statement to her. During the phone call, we tried to organize a place for the interview. She did not want to interview at her home because her mother is so ‘annoying’. She would like to go to a coffee shop after she finished her work. An agreement has been made. By saying the word ‘annoying’, Thu implied that her mother was a dominator and gave us a hint about her mother.

Prior to the appointment, Thu called the first author and asked to come over to her house because she was very tired due to the heat of the weather. When the first author came to her house, it was almost inaccessible. The house is too high with many steps in the front door. When her mother built the house, she failed to account for the fact that her daughter needs a ramp. It could be because current popular housing designs do not include ramps. This reflects that lack of affordances provided for people with disabilities when non-disabled people designed and built houses or public places. Many people with disabilities report that they cannot access their apartments and other public spheres because the builders did not make ramps for them (Nguyen, Liamputtong, and Horey 2019; Nguyen 2021). Similarly, Thu’s mother ignored Thu’s situation, because she did not want the house visible to everyone in the community. If there is a ramp, her house would stand out and catch the attention of others signalling that her child is disabled, bringing shame and stigma to the family (Gammeltoft 2014). In this sense, Thu’s mother wants to hide Thu inside the house and does not want other people to know of Thu’s existence.

This lack of physical accommodation to her disability renders Thu dependent. Thu would like to go out and find a job. But to do so her mother has set up a temporary foldable ramp for Thu to get in and out of the house by her “xe lc” (a manual swing wheelchair). Despite the effort to create this affordance, Thu cannot
use the ramp independently. Thu said, “My brother assists me in and out the house because I cannot do it by myself”. Therefore, she depends on her brother's support every day.

Once the first author (An) got inside the house, Thu invited this interviewer to her room with the door shut. We had a conversation inside her room. However, during our conversation, her mother kept knocking on the door and asking the first author what and why we were doing this. The first author kept calm, stopped the conversation with Thu, and explained what we were doing. She then asked the first author to provide the private information such as phone number, address, and workplace. She also asked the first author to give her evidence. The first author gave her a name card and a research statement which provided all the needed information to her. We took it for granted that Thu has her right to privacy because Thu is 53 years old, but her mother wants to control everything related to Thu. Seemingly, her mother thought that the first author is a potential cheater or a bad person who was going to do something bad to Thu. She did not trust me. The first author ignored her because Thu was the person we needed to talk to.

Thu’s mother exerted power over Thu every day. When we went back to our conversation. Thu revealed that “My mother is always like that with all my friends”. Thu complained that her mother is over-controlling. Although she feels uncomfortable, she cannot do anything but listen to her mother’s commands. Thu’s obstacles within the home are associated with her vulnerability, which leads her to dependency and isolation. Thu’s mother has restrained Thu from accessing the external world, particularly from making friends and accessing information, let alone learning about reproductive health. Thu has little and autonomy to make decisions over her life.

Due to her mother’s power, Thu hides at home. She left school in grade 6 as nobody was able to assist her to school. She does not go out with friends and does not have many friends either. She shared honestly that when she first called me, her friend encouraged her a lot. When we tried to ask a question by giving her a clue such as “what do you think about reproduction?”, Thu said, “I have no idea about that. I do not know what it is”.

Moreover, Thu stated that although she does not know much about reproductive health, she does not want to go for a lesson or participate in a training course. It is because her mother would ask her “when, what, where, how and why” if Thu asks her permission to go out. Thu always stated that “My mother is so annoying” in this way, which leads to Thu’s giving up on learning opportunities. Thu’s case study illustrated that the restrictions she faces within the family and her dependency has resulted in the limitation of her learning about various aspects of life, including reproductive health.

Ngoc’s case study

Ngoc is an unmarried and single woman who also left school in grade 7 (13-year-old) because no one was able to help her to go to school. Ngoc’s legs are weak due to a side-effect of an injection when she was 4 months old. She is unable to stand up by herself. She uses her arms as her legs and moves around the house. Ngoc is currently living with her aunt in a tiny house which is located on a small street in Ho Chi Minh City. Her mother passed away when she was a teenager. Her father then remarried another woman. Nhu introduced Ngoc to us and encouraged her to participate in this research.

Ngoc came from a poor family background. The limited finances and her disability were the main barriers to her remaining at school. In her childhood, her mother was very sick while her father was always busy earning income. She is also the only child so no one could assist her to get to school, so in turn, she left school when she was 13-years-old. Since then, she always remains at home. As a result, she also never received any health or reproductive health education normally taught at grade 9 (15 years old) (HOC247 2021). Ngoc is experiencing financial hardship due to her unemployment and receives a small social allowance. According to Decree 28/2012/ND-CP (2012), the disability allowance for those who live in the cities is 570,000 VND/month (approximately USD$251 USD is equivalent to 23,342 VND at the time of writing.). This is the only income that Ngoc receives. With respect to this allowance, she can’t afford her daily life expense and remains financially dependent on her aunt’s income.
One day, we received a phone call from Ngoc. The first author already had Ngoc’s phone number on the contact list because Nhu passed it to us. Before talking to Ngoc, Nhu told us that “Ngoc is very sensitive and less confident. She does not want to talk to strangers”. Due to the first author’s reputation among people with disabilities networks, Ngoc accepted us and called us for a conversation. During the first call, she agreed to have an interview. She suggested that we meet at her house. She then sent us her address, and we made the time for the interviewing.

A few days later, prior to the interview day, she called us again and said that she would like to withdraw from the research. We asked her why she would like to do that. She said: “I have been thinking about this topic since the day I called you. I think that I do not know anything about this. I am worried that my answer may not be good for your research or that I will not know how to answer your questions”. We said: “It is ok as every story counts. You can say anything you know. For the things you do not know, you can say that you do not know. Do not worry about that”. She then was happy to see us for an interview.

On the interview day, the first author came to her house at 2pm. She was waiting for us at the front door. To be honest, when the first author saw her house, the author was shocked and felt very bad (but tried to smile). We could not imagine that two people could live in this tiny space. From my perspective, this house is equivalent to a hut in a slum. We estimate that the living area is about 1.2m in width and 2.5m long. This house includes a mezzanine floor. On the ground floor, she puts a desk on the left side, a cooking area is in the middle of the house, and the toilet (including the bathroom) is on the right side. They sleep on the mezzanine floor. They go up there by the wooden stairs. We looked at the stairs. It is very dangerous as it is very easy to slip. The first author asked her:

Interviewer: How do you manage your life? How do you go upstairs? Ngoc: I always stay at home. In the morning, my aunt gets up, goes to the market, and buys groceries. Then she drops them off for me and goes to work. I cook meals, then do some house chores such as washing, cleaning, then playing with my dog. My aunt will come back home for lunch. After lunch, I do the dishes and she goes back to work. Interviewer: So how do you manage the stairs? Ngoc: It is easy! I climb up and down, step by step. Interviewer: Wow! I cannot do it. So how do you manage cooking? Ngoc: As you see, my aunt designed this area and put everything low as I can reach.

By her aunt’s design, Ngoc is fitting quite well in her house. To people without disabilities, they may feel uncomfortable to live in such a tiny house and feel unsafe to go upstairs as the stair is very steep. But Ngoc has adapted to this tiny living area. Within Ngoc’s house, there is a reasonable comfortable zone for her, because of the way she uses her arms to move around the house and does things without any obstacles. When she fits such an environment, she feels comfortable, safe, and confident (Garland-Thomson 2011). She is at home, she can do everything by herself such as cooking, showering, washing clothes, and cleaning. Inside her house, the way she organises makes her day-to-day life easier.

However, despite her confidence to move around at home, her disability poses an enormous barrier whenever she must leave her house. As she mentioned, she is always at home and rarely goes out. We asked her: “Why don’t you want to go out?”. She said: “As you can see because of my disability, I cannot go out by myself. If I go, I need a personal assistant and a wheelchair. But you see my house like this, where can I put my wheelchair? Nowhere. Many charitable organizations suggested giving me a wheelchair for free, but I rejected them all because I cannot keep it in my house. I need it but I cannot keep it. And an assistant is a big issue. Who can help me? My aunt is working every day. My dad does not live in this city”. We felt very sad for her. We then asked “Please forgive me if my next question makes you uncomfortable. Do you feel being isolated or lonely?”. She said: “No, I got used to it. I was very sad and felt lonely a long time ago after my mother passed away. For now, I am ok with my life. I accepted my situation and live with it because I have no choice”.

Ngoc’s narrative illustrates the role of non-government organizations (NGOs) in Ho Chi Minh City in trying to create more affordances for people with disabilities. Ngoc stated that she got many invitations from NGOs to come to their offices and get the wheelchair. These invitations reflect the contributions of NGOs in the
disability movement in Vietnam. Ngoc appreciated these NGOs’ activities. However, she did not receive the wheelchairs for herself due to her tiny house. Sometimes, she received the wheelchairs and gave them to other people with disabilities who were in need. These people were recommended by her aunt.

Her disability and the material world create prominent disadvantages for her (Garland-Thomson 2011). These disadvantages are greater when she interacts with the motorbike taxi and the built environment. Ngoc understands that it is very hard for her to go out by herself. She explained that if she would like to go somewhere by herself, she needs to book a motorbike taxi. She does not have enough money to book a taxi because taxis are always more expensive than motorbike taxis. When the motorbike taxi driver comes, she asks him to carry her to the back seat of the motorbike first or she will try to climb up to the motorbike taxi if the driver is unwilling to help. Then, at the destination, she asks the driver to take her down and put her in the wheelchair, or she will try to get down and climb on a wheelchair if the driver does not help. As she currently does not have a wheelchair due to her tiny house, Ngoc needs to arrange a wheelchair which is to be ready at her destination. The further problem is that wheelchairs are not always available at any place in Ho Chi Minh City. If she can arrange a wheelchair at her destination, she continues to face inaccessible built environments such as steps at the buildings. Faced with these barriers, she remains at home instead of going out. Consequently, Ngoc depends on her aunt to go shopping for her every day. This is also one of the reasons why Ngoc does not have a job. Although Nhu has been trying to take Ngoc out of her house by introducing many jobs and social events for Ngoc, Ngoc rejected them all. As she says above, she accepts her situation as fate. Many women with physical disabilities in the Northern of Vietnam, view their disabilities as fate, which in turn decreased their confidences of access to healthcare services (Nguyen 2021). From Ngoc’s point of view, in some ways, she blames herself as she has a physical disability.

While she did not receive reproductive health education within her family, she has fewer opportunities to learn from relevant training courses. Due to her severe disability, she has been struggling with the external environment as she mentioned above. Therefore, when we asked about reproductive health, Ngoc replied:

I do not know (how to define reproductive health). I will answer if I know what it is. For this question, I do not know because I am still single (and unmarried). I have not given birth yet. Although I used to take care of my cousin when she had a baby, I still do not know what reproductive health is. I feel this is a very hard question. Skip it please! (Ngoc, 36 years old, single, secondary school, housewife).

Ngoc’s lack of access to the world outside her home space is reflected in her lack of access to information, which resulted her in limited knowledge about reproductive health and her ability. Although Ngoc has full rights in decision-making related to her body, she decided to remain at home instead of battling the constant logistic, material and financial challenges posed to integrate into society. Consequently, Ngoc is limited in her opportunities to develop reproductive health knowledge.

As these accounts of Thu and Ngoc illustrated, enforced dependency, carer control, daily routines, and reluctance and the material and financial challenges to leave the house can all affect whether women have the ability to obtain relevant information. Such information is likely to be beyond the sphere of their everyday life and circumstances.

Adapting and producing new knowledge

Many participants in this study responded creatively to acquire more knowledge about themselves and reproductive health. While women such as Dinh, Kim, Thu, and Ngoc challenged the restrictions within their families, which resulted them in having a very limited understanding of such topics, other participants used assistive technologies and other resources to overcome a range of limitations they encountered. This group of women understood reproductive health in terms of sexual health which they defined as sexual positions and sexually transmitted infections. Nhu and Thanh’s stories below are examples of their resourcefulness to learn more about themselves and their reproductive health.

Nhu’s case study
Nhu suffered from polio in her childhood which resulted her in using crutches permanently for her mobility. She obtained a Bachelor’s degree in Biology and has a good job with a high income. She is an unmarried and single woman. With respect to her marital status, she was not allowed to seek out reproductive health information due to the cultural norms (Khut, Lê, and Nguyệt 2012; Bui 2020). However, she is an active woman with an extensive network among the community of people with disabilities. Nhu acknowledges that the world has been physically designed and constructed in a way that favour the majority of non-disabled people. She notices that she faces barriers when entering public buildings where there are high steps at the entrances, no elevators, and a lack of ramps. By using her crutches, she has created a good fit between her body and the built environments such as her school, her university, her workplace, and other places where she tries to access. In addition, when Nhu enters these environments with her crutches, she becomes visible, and commonly encounters negative attitudes. However, she ignores the way people look at her, but focuses on her goals. She consciously overcomes stigma and discrimination and has more confidence than many of her peers with disabilities. Nhu participated in reproductive health training courses and workshops related to disability and confidently defined reproductive health. She said:

Reproductive health includes sexual health, birthing, sexually transmitted diseases. It is related to gynaecological health. For sexual health, I mean sexual positions of both men and women, and make sure they do not have any sexually transmitted diseases because if one of them is infected with the disease, he/she will be contagious and spread it to his/her partner. And the sexual position is very important because if we do not have the right position, we will get ill (Nhu, 40 years old, single, Bachelor’s degree, office worker).

Nhu’s definition is broader than the definitions of Kim and Tran above, although she has a misperception about the importance of sexual positioning to health. But what is significant is that she has created opportunities to learn more about reproductive health.

Thanh’s case study

Thanh suffered from a side-effect of an injection in her childhood. She uses crutches due to weakness in both legs. She is a single mother to a two-year-old daughter. In Vietnamese culture, a single mother breaks social norms on out-of-wedlock childbearing. Hence, she faces negative attitudes from family and people in the community. As such Thanh faces a fourth level of discrimination as a single mother. In this sense, Thanh faces this social barrier in the external world, regardless of the fact that her situation is accepted within her family. Thanh’s family is supportive and is happy to welcome Thanh’s daughter. Thanh also revealed that “my mother encouraged me to have a baby out-of-wedlock. She did not care who was the father of my baby”. The encouragement of Thanh’s mother and her support created a comfortable zone for Thanh within the family. With respect to this support, Thanh is more confident in her rights to make decisions concerning her body and reproductive health.

In contrast, outside of her home, Thanh challenges many obstacles when entering the world made for “ordinary” bodies (Garland-Thomson 2011, p. 596). Thanh uses her crutches to overcome her mobility difficulties. She completed a Bachelor’s degree and currently has a good job as an office worker. She became an athlete and a team member in the Disabled People’s National Sports Team. Joining this team, she has had more opportunities to develop a large network and participate actively in society. Like Nhu, Thanh had participated in some sexual and reproductive health training courses and workshops, which provided her with basic sexual and reproductive health knowledge. Similar to Nhu, Thanh shared that for her, reproductive health is an umbrella term that covers sexual health, sexually transmitted infections, and birthing, including contraception and conception. She said:

Reproductive health includes sexual health, birthing, contraception, and conception. I have learned about sexually transmitted diseases. I had a chance to watch a video about sexually transmitted infections, so I knew what they are... reproductive health is also about contraception and conception (Thanh, 37 years old).
The higher education levels and higher economic status of both Nhu and Thanh allow them greater opportunities to find means to fit into society as a person with a disability, and understand the environment they live in. This helps them to act to overcome various barriers and create more opportunities for their lives. They integrate consciously through social activities such as training courses and sports teams.

In Nhu’s account, she highlights the importance of sexual positions for health, and could not explain in detail other elements. For women with physical disabilities, making decisions on sexual positions depends on their physical abilities and how these abilities align with those of their partners (Nguyen, Horey, and Liamputtong 2019). Therefore, her emphasis upon sexual positions reflects her particular concerns as a disabled woman for her well-being, something other abled-bodied people may not consider essential to reproductive health (except in the context of sexual variety and techniques).

Disabled women in this study had diverse understandings of what constitutes reproductive health and disability. Their understanding is shaped by social, cultural, and economic factors complicated by the obdurate realities their disabilities pose to their mobility and social standing in the community. Some women with higher education levels were able to negotiate this more easily and this was reflected in their greater knowledge of reproductive health than that of women with lower education levels. Many answers revealed women’s exposure to some health promotion messaging with regards to maternal and child health. In general, due to the restrictions for education within the family and school, most study women had limited understandings. The family background appeared to influence the reproductive health understandings of women. In this study, some women, who had a poor family background such as growing up in a lower-income family or whose father or mother had passed away, had less reproductive health understanding than other women, who grew up in a higher income family and had parents.

Discussion on subjugated knowledge of women with physical disabilities

As illustrated above, the study women interacted with the social-physical environments that created the degrees of fitting or misfitting. Their embodiment shaped their understanding of disability and reproductive health. The complexity of their lived reality has been examined through six case studies of Dinh, Kim, Thu, Ngoc, Nhu, and Thanh. Below, we firstly discuss the enactment of misfitting in their daily lives by drawing on Thu and Ngoc’s lives. We highlight the narratives of Thu and Ngoc because these cases illustrate the dynamic interactions between bodies and the material environment. We then focus my discussion on how the subjugated knowledge has been shaped among disabled women.

The enactment of misfitting in Thu and Ngoc’s everyday lives

Garland-Thomson (2011) foregrounds the notion of materiality to capture the enactment of disability as embodiments when interacting with the physical environment. People with and without disabilities inhabit and share in normative world-building, whereby the physical and institutional environment is designed around non-disabled people (Garland-Thomson 2011). Therefore, this kind of material environment offers few resources or affordances (Mitchell and Snyder 2016) for disabled people.

This aspect is well illustrated by the case studies of Thu and Ngoc who both faced physical barriers to accessing the world outside their homes. For Thu the design of her house is inaccessible for her. Similarly, Ngoc faced numerous obstacles whenever she would like to go out. Although Ngoc adapted quite well within her house due to the well-designed by her aunt, the external physical environment that challenged her daily life. In response to these barriers, Ngoc decided to remain at home. Additionally, negative social attitudes and stigma from other people in the community toward disabled people was encountered by all my informants such as the motorbike taxi drivers who were unwilling to assist disabled people to get on and off the motorbike taxis. The insights from both Thu and Ngoc’s cases reflect the difficulties for social activists to challenge the current policies and build an inclusive world for a broad range of human variations.

Within a society that still views disabled women as asexual, infertile, and incapable in taking care of themselves or giving care to their kids (D et al. 2011; Nguyen et al. 2020; Nguyen et al. 2017; Shildrick 2007;
disabled people face a series of challenges in seeking reproductive health information. As illustrated by case studies of Dinh, Kim, Thu, and Ngoc women were only able to gain ‘limited’ understanding of reproductive health. Their positions as disabled people have resulted in them having only partial knowledge.

Almost all the study women did not receive a reproductive health education within their families because they were single and unmarried when they lived with their parents. Even when wanting to carry a pregnancy, Kim understood that she may find it hard to give birth later in life due to her disability, but she had few opportunities to seek further information on this topic. For Thu and Ngoc, remaining at home limited their access to any information. Due to her disability, Dinh was considered infertile and asexual. Although the fact that her disability does not lead to female infertility (Department of Health 2014), her parents asserted that Dinh was infertile. Only after she found out from a peer that reproduction might be possible did she seek medical advice only to find out she was fertile.

This paper shows how social-cultural norms around sexual and reproductive health are one of the main barriers that increased the restrictions for disabled women accessing reproductive health knowledge.

Conclusions

While their levels of information varied, most women with disabilities defined reproductive health in limited terms. For some women, key informants, and health providers, reproductive health remains a silent topic of which little is ever spoken due to the cultural norms around disability and reproductive health. In some regards, this reflects the general lay public’s understandings of reproductive health matters in Vietnam; however, as seen in the case studies, for the women with physical disabilities in this study, knowledge is dependent upon their access to schooling, mobility, jobs, and access to information sources. It is also limited by the degree of control and power they have over their own lives. For all, their understandings fall far short of the WHO ideal holistic definitions of reproductive health.

These findings are comparable to earlier research of the first author in this area when she interviewed twenty participants with physical disabilities (ten males and ten females). The findings from that study revealed that people with physical disabilities lacked knowledge about sexual and reproductive health (Nguyen et al. 2017). Their access to healthcare information was limited, and so too was their knowledge of sexual and reproductive health ((Nguyen et al. 2017; Tran, Vu, and Vu 2017). Years later, in this study, there has been a little progress made in reproductive health knowledge among women with physical disabilities due to some positive changes in implementing the Disability law. With respect to this law, the built environment in some places has been modified to be more accessible for disabled people. This facilitated some disabled women to participate in several sexual and reproductive health training courses held by some NGOs.

The limited knowledge of the study women about reproductive health is matched with the comments of key informants and healthcare providers’ views. Cultural and economic elements are the main factors that contributed to a lower level of access to relevant information and rights of the study women. Moreover, the economic factor is closely linked with the limited knowledge of the study women about reproductive health. The majority of disabled people live in poverty (Vo 2018; CCIHP and ARROW 2019; GSO 2016), they need to spend their time earning money. Therefore, they lack opportunities to participate in any reproductive health training courses due to time poverty.

The cultural aspect of misfit theory (Garland-Thomson 2011) was developed in Western countries where people may have greater accessibility to education. This research has contributed to this theory by extending the cultural elements to accessibility in the Asian context and related to a specific sensitive topic – reproductive health.

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