

Maternity Care Experiences of Women with Disability: A Phenomenological Study

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Abstract: Women with disability are those women with impairment which can be either physical, sensory, cognitive or mental which can affect everyday life activities. Pregnant women with disability, for instance, experience challenges during the course of pregnancy. Their voices of being a mother are heard on different perspective. This study aimed to explore the maternity care experiences of women with disability. The objective of the study was to explore the women with disability lived experiences on pregnancy, their challenges and the possible barriers and facilitator where the women faced during pregnancy. A qualitative phenomenological study was used to conduct this study by using semi-structured, in-depth individual interviews, observation and recorded voices were transcribed into codes and key themes. A guide questions for interview was designed for the purpose of this research. 16 pregnant women with disability were selected as the participants of the study through purposive sampling technique. With the two-part interview, the women with disability interview were conducted during the last trimester to delivery and followed by verification and interpreting the texts and recorded voices on the personal interview. Findings revealed that women with disability encountered positive and negative maternity care experiences.

Keyword: Disability, maternity care, phenomenological, pregnancy, qualitative study.

I. INTRODUCTION

With the risk facing the women during pregnancy, having disability gives additional challenges for them. These challenges are linked to accessing health services due to their physical, sensory, cognitive or mental problems. These provides behavioral differences from the normal women without disability during pregnancy. Difficulties for women with disability include overstimulating environment, feeling of secludedness, lack of information and anxiety during communication and appointment to the health care setting.

People with disability face all forms of discrimination and exclusion from several aspects of life such as social, cultural and political. For WHO, women with disability are being acknowledged as they encounter different and additional disadvantages due to their condition which result to the possibility of experiencing exclusion than those without disability. Lee at;al (2015) cited that the exclusion which the women with disability experiences compromises more life outcomes for themselves including the attainment of health and reproductive health. maternal and child care. Although most pregnant women with disabilities can have a normal labor and delivery experiences without problems including their children, they should have a good planning in preparation for their condition since they have impairment. Yet, the capacity of providing maternal services to pregnant women to delivery are provided by the government. As stated in the Republic Health Law, the government guarantees to universal access of women to maternal care. This provision agrees that the state should undertake its duty in providing maternal and child care.

The UNFPA (2012) suggested that the agencies and service providers had little awareness on the sexual and reproductive health experiences of women with disability, and limited capacity to respond to their needs. On the other hand, there is a dearth on the information about the number of women with disability in the Philippines specifically on pregnant women.

Malouf et.al., (2014) mentioned that limited research exists describing maternity care and issues experienced by women with disability. Since there is no large scale studies that have been carried out relating to maternity care experiences of women with disability, as a result, it is important for the healthcare provider to recognize that women with disability must be respected and cared as they have tendency of hesitancy in seeking care due to anticipating unwanted reactions from others.

In addition, the aim of the study was to examine the maternity care experiences of women with disability during their pregnancy. Their lived experiences are important part of this study. A phenomenological qualitative research was used to substantially described their lived experiences which provide a foundation of the concept. In order the study to be rigorous, it is essential to obtain descriptions of the maternity care from whom deeply experienced.

II. BODY OF ARTICLE

METHODS:

This part describes the qualitative phenomenological methodology used in this study to explore the lived experiences of women with disability in maternal care. A phenomenological research design provides individual description of their existing experiences in relation to the phenomenon, in this case, pregnant women with disability experiences with respect to maternity care. This method contextualizes experiences of the participants through personal description of the experiences, their statements and its meaning. Phenomenological study explores the essence of experiences of individuals with firsthand account. Davidsen (2012) described phenomenological research being used to generate a theoretical account which allows the researchers to elicit the effect and significance of experiences that the individual may have undergone.

The researcher utilized a qualitative phenomenological design. An in-depth semi structured interviews, interview transcript; tape-recorded data were used to extract from the participants the maternity care experiences. Following the interviews, the data being collected were analyzed and the recorded data were transcribed. The researcher make used of a more thorough read into the transcribed data and identify the key phases or sentences related to the study participants experiences in order to produce a meaningful unit. Creswell (2007) elucidated that formulating meanings from those key phrases or sentences allows common themes to surface.

For this study, a purposive sampling was used because the participants represented individuals who experienced maternity care being pregnant women with disability in rural health setting in Bolinao, Pangasinan. This composed of 16 (sixteen) participants who are pregnant and recently postpartum women with disability and agreed to participate as they have the direct knowledge on the phenomenon. This was conducted from October 2017 to December 2017. The researcher utilized thematic analysis on data as its meaningful unit was then organized into key themes.

STATEMENT OF THE PROBLEM

This phenomenological study was guided by the following central research: What perspective do these study participants have regarding maternity care experiences of being pregnant women with disability. The research sub questions for the study were: (a) What challenges have participants encountered being pregnant women with disability in accessing maternity care? (b) How do participants deal with challenges? (c) What are the barriers and facilitator do have these participants in maternity care despite being women with disability?

RESULTS AND DISCUSSION

These were the descriptions from the 10 pregnant women with disability. These participants provided delineations on the maternity care experiences they had yet shared common perceptions when it comes to pregnancy to delivery. Their challenges were unique and distinct as they handled it differently.

This part presents the results after a candid conversation was made within the duration of the study. After analyzing the data, the following themes and subthemes emerged from this research study as listed in Table 1.

TABLE 1. Themes and Subthemes Identified In the Analysis of Interviews with Pregnant Women with Disability about Their Experience in Maternity Care

Major Themes	Sub Themes
Lack of Sensitivity	Discriminatory Attitudes Lack of knowledge in providing maternity needs for women with disability
Mobility Problems	Distance to maternal care center
Lack of Infrastructure	Structural barriers Not disability friendly resources
Need Strong Social Support	Dependence Negative perception about disability

Lack of Sensitivity

The first theme emerge from this study was lack of sensitivity. The women with disability substantially limit their everyday living. They deserved sensitiveness and respect when accessing maternal health services. It is a responsibility of the health service provider to prove their concerned and commitment for the vulnerable group. Like pregnant women with disability which must be safeguarded to protect from any untoward situation. They should not be judged by the caregiver, nurses or midwives. Owing to their physical or sensory disabilities, a social worker in the community is important concern to the disabled.

Study participants were candid about their maternity care experiences despite the anxiety they felt to access the maternal care. Despite the challenges adhered, they must continue their prenatal examination and maternal follow up checkup. Delivery of the baby to motherhood (parenting) gives the most stress for them. With this, two subthemes arise which are (a) discriminatory attitudes and (b) Lack of knowledge in providing maternity needs for women with disability.

One woman with physical disability said:

“When I went to the health center in my barangay for prenatal checkup, I heard one of the nurse whispered to her colleague “whose your patient, the disabled? It can be true, although they didn’t know I hear it, it feels like disappointing. It’s some kind of frustrating. Their thinking provoked me to never return to the center and transfer to the center.”

One participant with physical impairment said:

“I am conscious of being treated by the health provider in different manner. I cannot do anything because of my condition but to please with the available maternity care which sometimes I encountered a disrespectful social worker. Their attitude of insensitivity shows how they are being professional but most of the time the nursing staff is good.”

One participant with sensory impairment said:

“I feel that I was treated with lack of respect sometimes. The feeling that I should receive all the information that I need during pregnancy where not totally given due to my condition. Because of my impairment, I understand that being treated normally during my pregnancy was not forthcoming. I am eccentric and no one should judge me. Also, I felt that the social worker was reluctant to help me due to my condition.”

The discriminatory attitude was the socially complicated challenges for the pregnant women with disabilities. The real experience of difficulty was the prejudice of commentary. It agrees with Nangosi (2014) of New Vision which explained that women with physical disabilities are usually more disadvantaged who have different life experiences due to several attributes associated with female. Often times, prejudice and discrimination hinder women with physical disabilities in accessing reproductive health services. They encounter attitudinal barriers as they seek healthcare services in various health facilities.

However, on the subtheme of lack of knowledge in providing maternity needs for women with disability. The study participants perceived inadequate knowledge to manage their condition during pregnancy. Other participant believed that they have similar thinking on them.

One participant said:

“Most of the time, the nurses explained to me about the nutritious food to eat since I was anemic before become pregnant. It’s good to know about their concern. But one time during my check up, it’s actually inappropriate that the nurse advice to do exercise. Considering my condition, I’m not saying she is a rude one but maybe didn’t think how I can properly do that. But I appreciate what the nurse is trying to imply.”

Similarly, another participant said:

“I don’t know if the nurses are trying to help me. It feels like she was hesitant to assist me. I didn’t look scary. I cannot blame myself I have had this impairment. A lot of things happened when I took delivery in the hospital. Maybe because its private and I need to pay all the costs.”

The negative experienced by the participants in dealing with the healthcare professionals does not differ with other studies as they reported that their healthcare providers are often ill-equipped to effectively handle pregnancies and usually lack the know-how on handling their condition. (Curtis,1997; Blackford&Richardson,2000).

Mobility Problems

Mobility of the pregnant women is a critical factor most especially to women with disability. It enable the woman with disability to access the health care center easily. It is convenient on the part of the pregnant mother to have maternal care services available. But due to lack of healthcare infrastructure, people living in the rural areas tend to limit their access and experience sufficient healthcare services.

Even though the healthcare center can provide all the maternal services which the women needs, this barrier is a factor to be considered. This arise the subthemes of (a) distance to maternal care center.

One participant said:

“I experienced lower access to maternal services. One time, when I was late going to the center because I am waiting for my husband, I went to the center which was almost done. I am pleased that the nurse assisted me and informed me about some appointments. Proximity of my house especially the barrios were really a problem and take times to reach the place.”

Another participant said:

“For me, it’s a burden of cost to travel to the maternity center. I try to wake up early just to meet the time of scheduled appointment. This long travel time incurred additional effort and stress for me.”

Further, one participant said:

“Travel time to my destination which is the maternity center was unpredictable. When I reach the highway to way for the jeepney, it was difficult and aside from the non-disability friendly transportation like buses. Tricycle is the one I prefer the most as it’s easy to ride with and the driver can wait for a while. How I wish the LGU Local Government Unit will construct additional health center in order to avail health services easily and near to my place.”

Physical condition is the major hindrances of accessing the maternal health services efficiently. Since they have disabilities travel time and distance are essential factor to immediate care response in case of emergencies. In contrast, the distance has no impact on the significant increase in risk of stillbirths from the either to maternity services to their residence (Parker, Dickinson, Morton-Jones 2000).

Lack of Infrastructure

Certainly, the pregnant women with disability should receive the most concern as sometimes it was not followed. Women with disability are belongs to the vulnerable group in terms of maternity care. Murray & Bacchus (2005) suggested that at times these women with disabilities are subject to prejudgment from the health providers in a negative way. The researcher interviews indeed show how the need for appropriate healthcare infrastructure of the rural health setting should be acted upon by the government concerned.

Although the lack of infrastructure does not mean that going to the rural maternity center was unsafe. It's just it gives a few confidence to the place and assistance is much more needed to the women with disability. This made the (a) structural barriers and (b) not disability friendly facility the subthemes of this research study. A real lack of infrastructure means real lack of confidence.

One woman with physical disability said:

"One of the difficulties I encountered is the lack of grill in the lane of entrance. Although it is not so steep but I think the grills will be helpful for the entrance and exit of those patients especially those with disability."

One participant said:

"But, not all maternity centers which I've been admitted was no structural barriers usually they have. Actually, the help of my family to go there was enough although I would say that some needs additional barrels/grills for handling and repair of the rough lane."

Another participant said:

"Unavailable signage inside the facility should be visible and clear so that I will know the way and what to do."

The nature of the healthcare infrastructure designed for the pregnant women with disability should be made accessible. Within the duration of interview, most of the women account for the on duty nurses and significant others will assist them in going in. Despite the fact that like senior citizen, women with disability are part of the prioritized lane.

The not disability friendly healthcare facility was reported by most participants under study. Obviously, the need of the normal pregnant women was largely different from what with disability had. Deficiency on the resources should be addressed for a smooth service delivery as possible. Other participant said they did not want to complaint but they expect the care and respect remained.

"I feel like my disability was largely ignored due to lack of infrastructure in the facility...I'm suffering from visual impairment and suitable toilets separate for the disabled persons should be available. Using their toilets consumed more time...I remember one day, there are lots of female who want to use the bathroom, maybe if I don't have this condition they will not let me."

... (participant with visual impairment)

"As I noticed, the facility needs sufficient wheelchair...one is not enough. There should always be a wheelchair since in case of emergency or with disability transferring of patient will be easier and will remain safe. The first time I went to the facility and dismayed about their services, I didn't come back again."

... (participant with physical impairment)

"There are many persons who can assist me when climbing the stairs but it's supposed that the delivery beds should be disability friendly including the examination tables. I often felt discouraged about the services I had received during my delivery. Seeking skilled care can be beneficial but the infrastructure takes us some risk."

... (participant with physical impairment)

On the article of Phil Rabinowitz, he explained that the physical features can present serious problems for people, typically due to the needs of not considering those physical features. Inadequate consideration can also be extended to the ways with disabilities can be treated when they seek employment, education and services. Indeed, the laws protect the women with disabilities and to some extent guaranteed them to access the state maternal and healthcare services.

Need strong social support

Women with disability specifically those pregnant needs a strong social support as it has a tremendous impact on person's participation to everyday lives. This social support plays an important role to participate them in social and personal lives. Social support theories as cited by Bastani (2001) explained that relationships are not necessarily sources of social support unless the people perceive them as available and suitable sources of support for their needs. Yet, Akbarian (2007)

enumerated that the social support has psychological benefits for the people with disability such as effective coping methods, enhanced self-esteem, personal skills, better social life and empowered people social development.

Most of the study participant's family, relatives and the health professionals who supported them facilitate to access the maternity services of the healthcare facility. Their communication and concern feel them psychologically secured. Other participant said without family members that can accompanied them in the maternity center, they cannot attend their appointment.

"I feel secured whenever my husband will bring me in the healthcare facility. He assisted me to do everything. When I was in bleeding, even though it bothers me but I knew someone was there for me."

... (participant with physical impairment)

"With the availability of social workers on the facility, I still wanted their support for us. Aside from their services provided, they contribute to the staffing needs of the healthcare facility."

... (participant with physical impairment)

"The health professionals when comes along, they are good when I need them. They are there whenever I need them and provide unsolicited advices."

... (participant with visual impairment)

The subtheme of negative perceptions about disability considers how they need to have strong support to be secured. They need to have a better support to deal with their social lives and facilitate the needed maternal care for them. Other participant said their strong support come from their family.

"I know people arounds me judge me in the negative way. But, it doesn't stop me from doing what I deserved. I knew I have a lot of challenges so I have to be strong and my family was there."

... (participant with physical impairment)

"My disability was a barrier to what I want but life is so short. I cannot change it, just continue and everything will follow. The important thing is I am not alone."

... (participant with hearing impairment)

"I feel being part of the society. I have my own right. Others have their own rights too. It allows me to receive the necessary care despite what may others think about me."

... (participant with visual impairment)

The social space where the women with disabilities belong is significant. It consist of the people either family-related or not that should be aware of the social support needed by them. Designing effective intervention for the pregnant women with disability is proper and necessary. As suggested by Roberts (1988) that social support does contribute to the promotion and maintenance of health while Swanson (1989) found that social support promoted adaptation to physical disability by actually buffering the effects of environmental stressors.

III. CONCLUSION

The result of this study shows women with disability experience a range of challenges in realizing their rights to maternal care. The women have positive and negative experience in their pregnancy to delivery period in accessing maternal services. They experience not to a full enjoyment of some privileges. A strong disability support was needed to increase their autonomy and not feel a burden of care.

The findings on maternity care experiences of women with disability have clinical and research implications. The participants are aware on the barriers and facilitators of care in having disability. Healthcare providers should have the knowledge in the care of pregnant women with disability. The need for an enhanced patient-centered training should be implemented to deliver a personalized level of care and provide adequate safety and concern supporting the women with disability. A provision of disability friendly healthcare facility is needed and should be implemented.

REFERENCES

- [1] Akbarian MS. Disability with approach of social welfare. *J Student Mohaghegh*. 2007;1(2):47–55.
- [2] Bastani S. (2001). *Middle class community in Tehran: social networks, social support and marital relationships*. University of Toronto.
- [3] Blackford, K.A., Richardson, H.,(2000). Grieve S. Prenatal education for mothers with disabilities. *Journal of Advanced Nursing*. 32(4):898–904.
- [4] Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks: CA: Sage Publications.
- [5] Davidsen, A. S. (2012). Phenomenological approaches in psychology and health sciences. *Qualitative Research in Psychology*, 10(3), 318–339.
- [6] Lee, K., Devine, A., Marco, M.J., Zayas, J., Atkinson, L., Vaughan, C., (2015). Sexual and reproductive health services for women with disability: a qualitative study with service providers in the Philippines. *BMC Women's Health* 15:87. Retrieved from <https://doi.org/10.1186/s12905-015-0244-8>.
- [7] Malouf R, Redshaw M, Kurinczuk JJ, Gray R (2014) Systematic review of health care interventions to improve outcomes for women with disability and their family during pregnancy, birth and postnatal period. *BMC Pregnancy Childbirth* 14:58. doi: 10.1186/1471-2393-14-58.
- [8] Murray SF, Bacchus LJ (2005). *Factors Contributing to Patient Safety Incidents and Adverse Maternal Health Outcomes for Five Minority Groups of Women in the United Kingdom: A scoping of current knowledge*. London: National Patient Safety Agency.
- [9] Nangosi, D. (2014). Address challenges faced by women with disabilities. Retrieved from https://www.newvision.co.ug/new_vision/news/1309433/address-challenges-faced-women-disabilities
- [10] PARE. *Qualitative Study on the Realization of Reproductive Rights and Protection from Violence for Women and Girls with Disabilities in the Philippines*. Manila: UNFPA. 2012.
- [11] Parker L, Dickinson H, Morton-Jones T. 2000. Proximity to maternity services and still birth risk. *Arch Dis Child Fetal Neonatal Ed*; 82: F167- F168.
- [12] Rabinowitz, P.(n.d.). Ensuring access for people with disability. Retrieved from <https://ctb.ku.edu/en/table-of-contents/implement/physical-social-environment/housing-accessibility-disabilities/main>.
- [13] Roberts, S.J. (1988). Social support and help seeking: Review of the literature. *Advanced Nursing Science*. 10, 1-11.
- [14] Swanson, B., Cronin-Stubbs, D., & Sheldon, J. (1989). The impact of psychosocial factors on adapting to physical disability: A review of the research literature. *Rehabilitation Nursing*. 14, 64-68.
- [15] Thomas, C., Curtis, P.,(1997). Having a baby: Some disabled women's reproductive experiences. *Midwifery*. 13(4):202.
- [16] WHO, UNFPA.(2009). *Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note*. Switzerland.