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Pitout JDD, Church DL, Gregson DB, Chow BL, McCracken M, Mulvey M, Laupland KB (2007). Molecular epidemiology of CTXM-producing *Escherichia coli* in the Calgary Health Region: emergence of CTX-M-15-producing isolates. *Antimicrob. Agents Chemother.* 51: 1281-1286.

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Full Length Research Paper

The eating experiences of patients hospitalized in a muscular dystrophy ward in Japan: A phenomenological study

Emiko Ishida

Graduate School of Medicine, Division of Health Science, Osaka University, 1-7 Yamadaoka, Suita, Osaka, 565-0871, Japan.

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The aim of this study was to explore the life experiences of patients hospitalized in a muscular dystrophy ward in Japan, with particular focus on their eating experiences. Participant observation and unstructured interviews were conducted, and data analyzed by employing Merleau-Ponty's phenomenology. Nine patients agreed to participate in this study, although only five were included in the analysis. The overarching theme of patients' eating experiences was "cultivating new eating habits," which patients nurtured according to their surrounding environment and in response to the increasing medical support and their progressive functional decline. The new eating habits were organized into five sub-themes: "moving my body at my own will," "eating independently," "learning to accept the percutaneous endoscopic gastrostomy tube," "an alternative to having meals" and "using tube feeding." These new eating habits engendered in patients a "richer," multisensory perception of eating, one where they do not merely rely on taste.

Key words: Muscular dystrophy ward, patients, eating experiences, phenomenology.

INTRODUCTION

Muscular dystrophies are a clinically, genetically, and biochemically heterogeneous group of disorders that share distinct clinical-pathological features on muscle biopsies (Emery, 2002). Different muscle groups are affected depending on the type of muscular dystrophy, with Duchenne muscular dystrophy being the most common; this is an X-linked recessive neuromuscular disorder, occurring in childhood (Dubowitz, 2004).

Most previous studies on muscular dystrophy have been on the pathophysiological and genetic mechanisms behind this disease (Nätterlund and Ahlström, 2001). On the other hand, because the progression of muscular weakness characteristic of the disease causes numerous problems in the everyday lives of those who suffer from it (Ahlström and Gunnarsson, 1996), some researchers

have investigated the many types of support offered to muscular dystrophy patients. In recent years, the survival rates of young men with Duchenne muscular dystrophy have increased due to the development of mechanical ventilators and other medical technology. This has led to research on the quality of life of patients supported by this technology (Kohler et al., 2005; Narayanaswami et al., 2000). Furthermore, research on patients' own experiences, as opposed to those of the parents, is becoming more common. To investigate patients' experiences directly, researchers have employed a number of methods, including phenomenological methods (Nätterlund and Ahlström, 1999; Pehler and Craft-Rosenberg, 2009), inductive content analysis (Boström and Ahlström, 2005; Nätterlund et al., 2001), ethnographic case studies (Gibson

et al., 2007, 2009), and Ricoeur's theory of interpretation (Dreyer et al., 2009).

In Japan, muscular dystrophy wards are the typical method of care for patients with the disease, which the government first implemented in 1964 with a single long-term care facility. This has since grown to 2,500 beds in 27 areas across Japan. Recently, advances in life sustaining and assistive technologies such as mechanical ventilators have increased the life expectancy of these patients. In 2007, around 2,066 patients were living in muscular dystrophy wards; 56.7% of these patients were on artificial ventilator support (Tatara and Jino, 2008).

Most muscular dystrophy research in Japan has focused on the development of therapies and life-prolonging treatments. In addition, research groups consisting of staff from muscular dystrophy wards have begun investigating the problems characteristic of patients living in those wards, such as psychological problems, particularly in young patients (Masuda, 1993; Okumura, 1997), control of complications, and issues specific to severely impaired patients (Omoto et al., 2010). However, because of the widespread use of mechanical ventilators, some researchers have recently begun to explore ways to improve the prolonged hospitalized life of patients with muscular dystrophy by focusing on patients' life purposes and quality of life (Kawai et al., 2005; Konagaya et al., 2006). Nevertheless, these studies were conducted from the biomedical and technical perspectives; in contrast, few studies have considered how patients live in these wards, despite all of the necessary supports. More recently, several researchers conducted studies on patients' views of living with muscular dystrophy in Japan (Tsuji no, 2005; Ito, 2008, 2010; Ishida, 2012).

In this study, focused was on describing the life experiences (particularly those related to eating) of hospitalized patients in a muscular dystrophy ward, because in the initial fieldwork phase of this study, some of the participants confirmed that one of their particular pleasures was eating. Furthermore, many participants talked about their memories of eating experiences and often seemed to be particularly lively during mealtimes at the ward. Therefore, it was thought that the experience of eating might be an important aspect of their hospitalized lives.

In Japan, previous research on the eating behavior of muscular dystrophy patients has often centered on reducing the risk of pneumonia by aspiration and suffocation because of their dysphagia (Fujihara, 2010; Yoshiga et al., 2010). These studies led to the creation and publication of a recipe book for muscular dystrophy patients (Nutritional and Physical Sectional Committee, 2007). Above all, previous studies have taken a particularly medical perspective in studying the eating behavior of muscular dystrophy patients, focusing mainly on ways to help them eat as their motor functions decline. However, few researchers have considered eating experiences

experiences from the patients' perspectives, such as how they eat their meals daily. Similarly, no attempt has been made to describe the experiences of patients who must be fed by a tube because of their severe muscular impairment.

Thus, the purpose of this study is to describe the life experiences of those patients who have lived in a muscular dystrophy ward since their childhood, focusing on their eating experiences and also to get valuable suggestions for nursing practice. Providing nurses with deeper philosophical insight into the meaning of eating for muscular dystrophy patients would lead to enhancing patient care in a situation where technical nursing skills based on medical knowledge are more emphasized. To describe these experiences and fully understand their meaning for patients, it would be necessary to focus particularly on individual patients' own perspectives in the context of how they try to eat their meals daily in the ward, rather than by developing a general theory created by analyzing the experiences of a large sample of patients. This is on a phenomenological approach was decided.

METHODOLOGY

In this study, the eating experiences of patients in a muscular dystrophy ward were described by employing the concepts of Merleau-Ponty's phenomenological approach. As discussed, in previous studies that took a medical perspective in examining patients in muscular dystrophy wards, patients reported feeling that they had lost their ability to live by themselves because of the increasing muscular weakness and related symptoms of the disease, and thus they often experienced considerable anxiety. In the present study, a number of patients observed and interviewed were observed, and while they reported feeling anxious at times, most did not remain so. The French philosopher Merleau-Ponty (1945, 1962), inspired by Husserl, claimed, "Phenomenology . . . does not expect to arrive at an understanding of man and the world from any starting point other than that of their 'facticity'". However, nurses in muscular dystrophy wards tend to view patients as static beings, often taking a perspective wholly focused on the scientific and medical aspects of patient care; this is because their primary responsibilities are providing medical care, particularly with recent advances in medical technology. In other words, nurses do not attempt to see patients' "facticity." That is to say, by focusing solely on treating patients, nurses are difficult to clearly see patients' "facticity". For this reason, Merleau-Ponty's approach to phenomenology was suitable for exploring muscular dystrophy patients' experiences.

Merleau-Ponty (1945, 1962) also claimed, "All my knowledge of the world, even my scientific knowledge is gained from my own particular point of view, or from some experience of the world without which the symbols of science would be meaningless". That is, he insisted that our primary experience of the world is not from a positivist, scientific viewpoint, but instead from a singular, personal point of view centered on our actual experience of the world. From this perspective, patients were viewed not as static beings as seen from the medical perspective, but as dynamic entities formed of their own subjective points of view.

Furthermore, although these patients were confined to the world of the muscular dystrophy ward, they were still surrounded by many people, events, and ideas - much the same as in the outside world, and were in constant interaction with such ever-changing phenomena

and were in constant interaction with them. Merleau-Ponty (1945, 1962) claimed that, “the phenomenological world is not pure being, but the sense which is revealed where the paths of my various experiences intersect, and also where my own and other people’s intersect and engage each other like gears”. That is, people’s “lived experience” is constituted of their interactions with other people and phenomena. Therefore, it is found that in order to fully understand patients’ eating experiences, focus must not merely be on their anxiety and struggles, but include all of their life experiences in all of the surrounding contexts of their lives namely, what each patient’s experience of eating means within his or her individual context.

Thus, in the present study, each patient was viewed as a singular entity with his or her own life and unique context, rather than the more stable, generalized view of patients as people suffering from anxiety and struggling to live in a muscular dystrophy ward. In this way, each patient’s actual lived experience could be described.

Settings and participants

Data were collected at the muscular dystrophy ward of a 300-bed medical center belonging to the National Hospital Organization, located within a rural area in Japan. A nurse manager volunteered to make initial contact with participants in the muscular dystrophy ward, except for patients with severe impairments, before data collection began. After receiving approval for this study from the ethics committee of the hospital, the study was conducted between October, 2011 and September, 2012. Direct recruitment of ten participants was done from the ward and one patient in them was rejected. The inclusion criteria were being hospitalized in the muscular dystrophy ward and being over 18 years of age. In addition, they had to be able to speak Japanese and understand the interview questions and research purpose.

Nine patients, ranging from their teens to their fifties, agreed to participate in this study. This age range allowed for considerable variation in experiences and demographics. One participant passed away during the course of the study. All were men. One participant was receiving invasive ventilation 24 h per day through a tracheotomy, while another was receiving noninvasive positive pressure ventilation (NIPPV), also 24 h per day. Four were receiving NIPPV either only when lying down after lunch and dinner or only at night. Four participants were using a percutaneous endoscopic gastrostomy (PEG) tube. One participant was fed solely by the tube, while two participants ate only their lunch by mouth. The last participant only used the PEG tube while taking his medication.

For this study, the interview data and field notes of five participants was used, Participants A, B, C, D, and E, but focus was mainly on two: Participants A and B because they were most willing to talk about what eating meant to them in light of their declining motor functions and their experiences of using the PEG tube. Unfortunately, the other three participants (C, D, and E) did not speak much about eating, and thus only a limited amount of data could be collected from them; however, their experiences could be analyzed to complement the structure of the two participants’ experiences. Furthermore, the data of the other four participants, not analyzed in this study, could be analyzed in the same way. Finally, for the subsequent analysis, information from the field notes on a nurse in the ward was also included. One of the attending nurses and a mother of one participants appeared.

Data collection and analysis

Data collection methods during the fieldwork phase of this study included unstructured interviews and observation of the participants in the ward, recorded via field notes. In line with Merleau-Ponty’s aim (1945, 1962), “to return to the world of actual experience which

is prior to the objective world”, no structured methodology related to the medical or general perspectives was employed in collecting the data for this study. Because unstructured free dialogues are more appropriate for drawing out patients’ detailed and in-depth experiences. In the unstructured interviews, data from daily conversations with participants at their bedsides was recorded; often posing questions about what was observed. These interviews were audiotaped when given permission.

For the participant observation, attention was paid to their day-to-day activities by observing them at their bedsides. Furthermore, staff members were observed throughout the day as they cared for their patients, performing activities such as suction, moving patients to their power wheel chairs, and conducting physical and occupational therapy, while also paying attention to how staff conversed with patients. their daily life routine was described and made sure to keep observations from patients’ perspectives, which would allow to view the patients not as static beings, but as “a subject destined to the world” (Merleau-Ponty, 1945; 1962).

In analyzing the data, Merleau-Ponty’s argument (1945, 1962) of “...a figure on a background...”; that is, “The perceptual ‘something’ is always in the middle of something else, it always forms part of a ‘field’” was referred to. In other words, there was need to consider the overall structure of each patient’s experiences; therefore, focus was on the modalities of patients’ experiences, such as their “unique mode of existing” and their “unique manner of behavior towards others and the environment.” Furthermore, a recorded of each patient’s manner of speaking, such as when they were hesitant, faltering, or uncertain (e.g., using words such as “like,” “so,” or “seem”), rather than on the actual content of their experiences, was taken. By doing so, it was imagined that an abstract of some universal eating experience of patients in a muscular dystrophy ward could be taken. The following steps were taken to analyze the data.

1. First, the field notes and transcribed interviews were read in their entirety a number of times to obtain an overall picture of each patient’s experience.
2. Then, all of the statements in the field notes and interviews related to eating, within their contexts was identified and described from each patient’s perspective.
3. After reading the field notes and transcriptions several times, the overall structure of each patient’s experience was conceptualized.
4. Through repeated analysis of the content, an extract of the themes of the eating experiences was done. Each theme was then scrutinized and refined to reflect a universal theme of life in the ward.
5. Finally, how each eating experience theme fit within the structure of each patient’s overall experience in the ward was described.

For the past five years, there has been a study group on phenomenology for clinical practice, which consisted of nursing researchers, philosophers of phenomenology, anthropologists, clinical nurses, and so on. Various phenomenological methodologies have been studied and the aforementioned experts provided information on their guidance and oversight to be sure that the findings of this study well-reflect the eating experiences of participants. Furthermore, the study group helped to enhance the validity of the affirmations made by this analysis. In addition, a nursing researcher who specialized in phenomenological research supervised the whole analysis process. Before submitting this article for publication, the results were explained to the participants and all participants’ permission to publish the findings was received. Furthermore, it was confirmed that the analysis results fully represented their ideas.

RESULTS

The main theme of patients’ eating experiences that

extracted was “cultivating new eating habits.” Patients nurtured these habits according to their surrounding environments and in response to increasing medical support and their own progressive functional decline. The new eating habits were organized according to the following five themes that emerged from the data analysis: “moving my body at my own will,” “eating independently,” “learning to accept the PEG tube,” “an alternative to having meals” and “using tube feeding.” Using Merleau-Ponty’s philosophy, I thought a great deal about how to describe the experiences of each patient and how I might identify a universal theme from each description in the analysis.

Themes extracted from eating experiences

Moving my body at my own will

One of participant A’s eating habits was attempting to move his mouth and body at will. Participant A is a man in his 30s, who was admitted to the ward in his second year of elementary school. When he was 16 years old, he required a sudden tracheotomy and started using an artificial ventilator. More recently, he has become almost entirely bedridden, save for his bath, which he takes two times per week; he also goes outside once or twice per year. He started using a PEG tube two years ago. Currently, he eats only his lunch by mouth. Although he said, “I enjoy eating,” and looked forward to eating his lunch every day, he still found it difficult to move his mouth. One day, the lunch menu had curry, which was popular with both patients and staff. Participant A also seemed to eat more than usual, so we engaged in the following conversation after he had finished his lunch.

Interviewer (I): How was it today? Wasn’t it good?

Participant A (A): Yes, it was quite good today. It’s fun! My body doesn’t feel so tired.

I: Does your body feel tired when you find it difficult to eat?

A: I can’t really move at will. It takes unnecessary strength to move some parts of my body.

I: Do you feel tired when the menu has your favorite food?

A: I can move the food in my mouth and chew it as I like [therefore, the menu was not related to his feeling tired].

At the beginning of our conversation, he mentioned the taste of the curry only briefly, and then said, “It’s fun!” in reference to that day’s lunch, because he could chew it. In this conversation, he mainly expressed how fatigue affected his motor functions, and thus his ability to eat. In this regard, the act of eating, for him, appeared to mean the ability to move his mouth at will to chew his food - rather than merely the taste. The following day, I asked him, “Usually it’s [the food] delicious, isn’t it?” referencing his impression of the previous day’s lunch.

A: The feeling of fun that I get from eating might be similar to the good feelings that other people get from exercising or moving their body. I just feel happy that I can move my body according to my will.

I: Do you mean that you care more about your ability to move your body or mouth than the act of eating itself, and that the act of eating is more like an instrument for you to achieve movements of your body parts?

A: It might be. Somewhere inside, I still feel the desire to move according to my own will.

The first sentence about the feeling of fun indicated that he had no experience of the “good” feeling of exercising or moving his body because he added uncertainty to this statement by saying, “might be similar...” In addition, the phrases “exercising or moving their body” and “move my body” were likely recalled because of his feeling of “fun” from eating, indicating that motor experiences are what he associated most with eating. However, he often expressed these experiences by using a variety of terms (for example, “fun,” “good,” or “happy”), and while these terms are similar, their use suggests that his eating experiences are characterized by a wide range of feelings, thus, the act of “moving the mouth” might have had the same meaning for him as exercising or body movement had for others.

While talking about his desire to move, he remained uncertain, saying, “it might be...” and “somewhere inside.” In this regard, it seems that in his daily life, he eats without any particular awareness of his desire to move. Furthermore, the words “somewhere inside” also suggest that his desire to “move” is no goal for the future, but a fixed quality of his self, weak enough to remain forever below his awareness. In other words, he will continue to eat according to this desire to move at his own will. In addition, he told me the reason why that he often tried to eat even when he found it difficult to move his mouth.

A: Well, maybe. I think that all sports players have a tough time. It’s not exactly how players probably feel, but the feeling might be similar to how they must feel when they know that they can’t play a game without practicing for a long time. Maybe it’s similar, in a way, to how players feel happy when they play well in a game and their team wins.

He explained his reason for trying to eat, even when it was difficult to move his mouth, using sports players as an example. He claimed that despite the difficulty he had in chewing his food, he was happy when he was able to do it properly, much like how sports players felt after winning a game. Furthermore, his use of the phrase, “their team wins” suggests that he might consider his act of eating with assistance as somewhat of a team effort. That is, although Participant A had trouble in moving his mouth, he fought his disease along with the staff members of the ward by putting his entire body into the act of eating.

Eating independently

Another eating habit that Participant A had cultivated in the ward was to find a way to make it feel as if he ate independently, even though he was constantly assisted throughout his meals by an attending nurse. I frequently observed how Participant A was positioned on the bed for lunch, as well as how he was assisted by an attending nurse. The scene described was repeated daily.

Attending nurse 1 pushed the lunch cart to Participant A, after she had finished her morning care routine for the four patients in the same room as him and had started their feeding tubes for their lunches. Participant A, who had been in the right lateral decubitus position since that morning, was placed supine for his lunch. He said to the nurse, "Lift my head," and she lifted it a little. Then he said, "Glasses," after which she removed them, and "Legs," causing her to lift them up and place a pillow under them. This process of positioning him for lunch, always consisting of a combination of his voice and the nurse's actions, was repeated daily. After positioning him, attending nurse 1 sat down beside the bed on a stool and told him the lunch menu: "Today we have wontan noodles, yogurt, and the usual..." When she showed it to him, opening the cover (of the food container), he turned to look at it. nurse 1 then asked him, "Do you want to eat the wontan?" She then put some noodles in his mouth, just enough to comfortably fill his mouth. He then shut his eyes and chewed slowly, rolling the noodles in his mouth. Nurse 1 put her hand on his cheek and stroked it gently to help him chew and waited for another opportunity to put some food in his mouth with the chopsticks.

After I had observed this meal scene several times, I engaged Participant A in the following exchange.

I: You eat lunch with assistance, but you're not so conscious of it, are you?

A: Yes, that's true. I feel like I'm just eating food by myself. When my mouth moves, all of my focus is on it. The assistant is like an assistant robot. Of course, they try to talk to me, but I don't really listen to them.

The phrases "I feel like ..." and "The assistant is like..." indicate that he understood that he was not eating by himself, and that he does not actually consider her an assistant robot. Furthermore, although he said, "I don't really listen to them," he still answered the nurse's question when she asked him if something had been lodged in his throat. Thus, he clearly does listen to the nurse assisting him in eating. However, it seems that he still considered eating to be an independent experience. This was evident from other conversations I had with him; for example, he said, "I have been receiving assistance, but from my point of view, I am eating independently." These notions of eating "independently" were further developed as follows.

When eating, Participant A's main concern was the food, its taste, and his ability to chew. As I observed every morning at his bedside, I noticed that when the nurse began assisting him with his meal, she was considerably slower than when she was performing her relatively fast-paced morning duties, which involved activities like mouth care, toilet support, and so forth. At this slower pace, without thinking, the nurse helped him move his mouth, brought food to it. Given this attention to the mouth and the slow, unthinking performance of the nurse, Participant A was likely fully engaged in this sense of eating independently.

Participant C, a man in his 20s, also considered it important to eat independently. He typically spent most of the day in his power wheel chair and ate all three of his meals in the dining room, saying, "I can't stand it [asking for assistance with my meal]" and "I do not want to give up [eating by myself]." He eats his meals daily using a converted spoon, a system that he had arranged with his occupational therapist; this was done to respect his strong feelings about eating on his own, although a meal assistant would always watch him and help when he needed it. One day, the mother of another patient, who had come to assist with her son's eating in the dining room, said, upon seeing Participant C eating in front of her, "Whenever I saw everyone trying so hard to eat on their own, I came back home thinking that I have to do my best." Thus, the participants' desire to eat independently was influenced not only by their strong wills, but also by the many kinds of support surrounding them such as nurses, occupational therapists, other staff, converted spoons, and even mothers of other patients, who did not support directly but rather in spirit.

Learning to accept the PEG tube

For Participant B, an important eating habit that he had needed to form was being fed through a PEG tube. He related to me his experiences of "not having given up drinking" and "no longer having to eat or drink," both of which appeared to influence his decision to take the PEG tube. Participant B is a man in his 50s, who has spent about 40 years in the ward since he was hospitalized while in the sixth grade of elementary school. He was once very active in the ward, but recently has become bedridden; he now requires a 24 h NIPPV, and gets his three daily meals through a feeding tube. More recently, doctors have begun to encourage early operations, when the dysphagia is not as severe. Patients who are given PEG tubes early still typically eat using their mouths at least once a day, as Participant A did. However, gastrostomies - the making of an opening into the stomach often present serious problems for patients. Participant B said, "Medical care has progressed so much, and sometimes I have resisted it....The same thing happened with this gastrostomy. I was told to hurry up

(and get it), but I hadn't yet given up drinking (fluids)." At the time of the study, Participant B was being fed through a PEG tube for all three meals a day. His feelings about it were as follows.

Participant B (B): In my case, eating itself was hard. Eventually, I could only drink nutritional supplements. But there was one time when the medicine (accidentally) entered my trachea, and I thought I was about to die. So when it was decided that I would be getting a PEG tube, I felt secure and happy, because I would no longer have to eat or drink. When eating became hard and I began drinking nutritional supplements, I had to drink around 200 ml of those supplements, plus water and milk. I started getting pain in my stomach, because it would bloat. I gave it up when they told me that nasogastric feeding could be used if I could no longer drink nutritional supplements. Recently, more and more patients are being encouraged to get a PEG tube before their condition gets as bad as mine. I waited until the last moment to get one.

When Participant B was encouraged to take the PEG tube, he said, "...I had not yet given up drinking." However, after experiencing the pain, suffering, and fear associated with attempting to eat, drinking heavy nutritional supplements, and nasogastric feeding, he began to accept the use of the PEG tube by degrees. The phrases, "eventually" and "so when..." showed that he had already understood why he needed to change his eating habits before he had even accepted the PEG tube.

When he decided to undergo the gastrostomy procedure, he felt "secure and happy." The word "secure" suggests that he was thinking of his past experiences of considerable pain and suffering from other eating methods; however, the word "happy," along with the statement, "...I would no longer have to eat or drink," suggests that he was also thinking of the future. Thus, he may have come to his decision to take a PEG tube by reconciling the vast number of experiences associated with eating from his past and future. After getting the tube, he compared his experience of the PEG tube with past eating experiences, and found that it was a positive experience.

In summary, Participant B related his experiences of "not having given up drinking" and "no longer having to eat or drink," both of which appeared to influence his decision to take the PEG tube. By holding on to these ambiguous and somewhat conflicting ideas, he was able to experience a number of procedures and eating arrangements, which ultimately led him to accepting the PEG tube. The experiences of Participant D suggest that patients who took a PEG tube in the ward based their decision on not only their own subjective experiences, but also the experiences of other patients. Participant D is a man in his 20s, who was admitted to the ward six years before the study period; he began using a PEG tube a few years ago, around the time doctors began to encourage

its early use. He said about his decision, "I asked (my doctor) to give it (the PEG tube) to me. When I began to find it hard to drink much fluid, I saw other patients (like Participant B) who had already gotten the feeding tube, and thought that it might be easier for me. The PEG tube is much better now, because I know how painful it is to have a bloated stomach (from nutritional supplements)." That is, Participant D accepted the PEG tube not only because of his experiences with painful bloating, but also because he had observed other patients using the feeding tube.

Alternative to having a meal

Participant B cultivated a variety of new eating habits in response to the feeling that his tube feeding gave rise to new sensations in his stomach. For example, many of the bedridden patients in the muscular dystrophy ward watch TV cooking programs while they are being tube-fed at lunchtime. Participant B described his experience of watching cooking programs on TV during lunchtime as follows.

B: I wanted to watch TV cooking programs, something that I did not watch a lot of before (getting the PEG tube). People often tell me that they feel sorry for me, because even if I watch them, I cannot eat anything. However, this makes me want to watch these shows even more. It seems to produce gastric juice in my stomach even without me having an actual meal.

In addition, Participant B wrote the following in his blog: "tube feeding tastes good." I decided to ask him about it again.

B: How can I say it, it might be a sensuous kind of thing. My stomach might be the signal.

I: Is it tasty?

B: It might be different from tasty; it's more like my stomach is filling up.

I: It would be nice if you could taste how good it is, and not just that it makes you full.

B: Again, how can I say it, it feels like stomach acid is produced when the formula enters my stomach.

I: You also said that this gastric acid comes out when you watch TV programs, but it's the same feeling as when the enteral formula enters the stomach, or someone is eating right next to you?

B: I feel it the strongest when [the enteral formula] enters my stomach.

I: So you're fine with it. But even if you tell me that you don't care about it, I wouldn't feel so good eating right next to you.

B: I don't care about that at all, and in fact, I would rather see it.

I: So would you want me to eat right next to you?

B: If it looks tasty. I would like to see you enjoy your meal.

Participant B explained that he watched cooking

programs because they made him feel as if his stomach was producing acid. In other words, he considered watching cooking programs as an alternative to having a meal, as evidenced by the production of extra stomach acid. In addition, the other alternatives included the enteral formula entering his stomach and seeing another person enjoy his or her meal. When I asked him about the “taste” of the enteral formula, which he had written about in his blog, he always prefaced his explanations with “it might be...” and “how can I say....” This uncertainty suggested that he considered the “sense” of the formula entering his stomach to be different from the conventional sense of something tasting good. However, he did not deny that it was not in some way tasty, suggesting that he felt some satisfaction from the tube feeding. His description of the experience of receiving the formula through the tube “my stomach is filling up,” and “stomach acid is produced” indicate that he experienced sensations in his stomach that were entirely different from taste. As Merleau-Ponty (1945, 1962) pointed out, “The senses intercommunicate by opening on to the structure of the thing”; thus, for Participant B, the sensations of food tasting good intercommunicated with a number of other bodily sensations, giving rise to new “senses” in his stomach. This is further supported by his mentioning, “I feel hungry, but I don’t want to eat,” in a number of our other conversations.

Participant D was the only one of his roommates, all of whom were roughly the same age as him, who took the PEG tube. For him, talking about food and watching cooking programs with his roommates had become his alternative to having a meal. One day, he began talking about food with one of his roommates who had just finished eating his lunch in the dining room and had come back to their room. While he was being fed through the PEG tube, Participant D asked, “Did you finish eating lunch? What did you eat for lunch?” In addition, when they rested on the bed after lunch, they both watched the same cooking programs and enjoyed talking about it with each other, exclaiming “Oh! Look!”, “Oh, that looks tasty!”, and “Yes!” In this way, their room was full of energy during the lunchtime break. Therefore, Participant D might have gotten some satisfaction by asking about the lunch menu, as well as watching the same cooking programs and talking about those programs with his roommates.

As seen, patients with muscular dystrophy who used a PEG tube related a number of alternatives to having a meal, including experiencing the unique, pleasant sensations in the stomach associated with tube feeding and bonding with roommates over lunchtime activities. Furthermore, they received some satisfaction from these alternatives, which eventually developed into eating habits for these patients.

Using the feeding tube

It was found that patients not only utilized the PEG tube

passively, that is, for purely medical reasons but they also used it actively to enhance their quality of life in the ward. For instance, because Participant B spent 24 h a day lying on his hospital bed, his PC was one of the most important ways for him to connect to the outside world. He used the mouse by putting it on his abdomen and, through trial and error, determined the maximum amount of time he was physically able to use his computer. By not lying on his side and keeping himself in the supine position, he was able to extend the amount of time he could use the computer.

I: How did you figure out the best ways to use your computer without having to change the position of your body?

B: At first, I used the air mat. Then, I found two body positions that allowed me to extend my legs on both sides by putting my legs down and using big pillows. These two styles are fixed. I put a pillow behind my waist when I feel pain in my back. However, for me to do this, it is important to keep my weight constant. I feel pain in my tailbone when I start to lose weight. So, I increase the amount of formula from the feeding tube when my weight decreases and decrease the amount when my weight increases. My ideal variations in weight are within 1 kg. In this way, tube feeding is useful for me.

Participant B found it important to control his weight by adjusting the amount of formula he received from the feeding tube, so that he could maintain the supine position and use his PC as much as possible every day. His methods of finding the best body position and weight control were developed through trial and error, as well as through asking for help from the staff and doctors. However, his frequent use of “I” indicated that he was the primary subject; furthermore, he did not refer at all to the staff or doctors in the quotation. I believe that this was because the staff and doctor were merely a part of his eating habits, and thus easy to ignore (see Participant A’s description of eating independently). Nevertheless, he was only able to mention and fulfill the process because he was surrounded by staff that both heard and respected him.

Another instance of active use of the PEG tube was related to me by Participant E, a man in his 40s. Although he could eat food using his mouth, he also used the PEG tube, which he took at around the same time that he underwent a bile stone operation, to take medicine for potassium deficiency. He said of this that, “It (the medicine) is active carbon, or charcoal. I take it through the PEG tube between meals. It can sometimes get lodged in your throat when you take it by mouth. It is difficult even for healthy people to take, (therefore, the PEG tube is convenient).” In other words, he used the PEG tube to relieve his pain.

DISCUSSION

In this study, the eating experiences of a number of

patients living in a muscular dystrophy ward was described, and these experiences analyzed from the perspective of the phenomenology of Merleau-Ponty. Typically, previous studies have described the lives of patients living in such wards for long periods only in terms of the anxiety and struggle they have undergone (Tsuji, 2005; Ito, 2008; 2010). In this study, while Participant A reported on how difficult it was for him to move his mouth due to the progressive decline and the act of eating for Participant A was also a chance to move his mouth and body, he felt happy when he was able to firmly chew his food. Furthermore, Participant B suffered from pain and fear before accepting a PEG tube, both he and Participant D reported feelings of satisfaction from tube feeding.

Previous researchers took a primarily medical perspective of the eating behavior of patients with muscular dystrophy, focusing on ways to improve their ability to eat as their motor functions decline (Fujihara, 2010; Kawai et al., 2005; Konagaya et al., 2006; Yoshiga et al., 2010). Participant A became fully engaged in this sense of eating independently by giving his full attention to his mouth and because of the slow, unthinking performance of the nurse. When Participant B used tube feeding to maintain his weight so that he could maximize his use of the PC, he considered staff members and the doctor who aided him as merely part of his eating habits. That is, the participants observed considered their eating behaviors to be independent activities, despite the daily role that attending nurses and doctors had in them.

Regarding tube feeding, a number of researchers have focused on the decision-making process associated with giving an elderly person a PEG, often demonstrating its particular difficulty (Brotherton and Abbott, 2009; Brotherton et al., 2007; Fairrow et al., 2004; Sukanuma et al., 2009). Participant A decided to use the PEG tube only after two years of consideration, and Participant B had not yet given up drinking when it was recommended to him. However, this study showed that the decision-making process of taking a PEG tube involves reconciling an enormous amount of previous experience with the future expectations associated with eating, including resolving ambiguous feelings such as “not giving up drinking yet” and “no longer having to eat or drink.” Furthermore, after getting the PEG tube, participants in this study reported that they had formed new habits that brought them a similar amount of satisfaction as eating once had, such as pouring the formula into their feeding tubes, watching cooking programs, and observing other people’s eating experiences. Engaging in such habits also appeared to give patients feelings of being full and that stomach acid was being produced, instead of merely giving them an experience of something as tasting good. The feeding tubes, in all, appeared to allow patients to live better lives.

In summary, this study showed that patients with muscular dystrophy had “cultivated habits” (Merleau-

Ponty, 1945, 1962) of eating according to their surrounding environment and in response to the increasing medical support and their progressive functional decline, instead of clinging to their past habits. With these new eating habits, their eating experiences came to be based on a “richer” perception of eating, one where food was viewed beyond merely its tasting good. It is thus important for nurses caring for patients with muscular dystrophy to understand what eating means to each patient; this would subsequently improve general medical care for these patients.

Recently, with the advance of medical technology, nurses in muscular dystrophy wards in Japan who have been playing a key role in providing sophisticated daily medical care to these patients as part of health care teams are apt to put more emphasis on preventing serious complications such as pneumonia and suffocation, rather than improving patients’ satisfaction with eating. In addition, because of a general lack of qualified nurses working in these wards, nurses working with patients with muscular dystrophy are often heavily burdened by busy daily practice, and thus they cannot generally afford to give much thought to patients’ desires for eating. Because patients with muscular dystrophy often have considerable difficulty eating, owing to the progression of their disorder, it cannot be denied that nurses should focus on preventing accidents.

However, it is hoped that this article can show that cultivating new attitudes and habits about eating will minimize the negative aspects of eating for patients with muscular dystrophy, such as its overall difficulty, the fear associated with it because of patients’ progressive functional decline, and patients’ resistance to tube feeding. By minimizing these negative aspects, meal times can become a more enjoyable and richer experience for patients with muscular dystrophy. Accordingly, by attending to patients’ behavior, habits and desires related to eating, nurses can not only reduce the risk of pneumonia, but also understand and collaborate with the patients on how to make eating more meaningful, particularly for patients who find it difficult to eat or who have tube feeding. By giving thorough attention, nurses can think about and practice how best to help patients enjoy eating. Furthermore, this will ensure that nurses are in a better position to give good advice to young patients with muscular dystrophy who have a negative outlook on eating. It is thought that such nursing practice would not only prevent further eating problems, but also improve quality of life for patients in muscular dystrophy wards.

This study had some limitations. First, these data may have placed a disproportionate emphasis on the experiences of patients who have a relatively positive outlook on living in a muscular dystrophy ward. Furthermore, this study highlights the importance of describing the context of each patient’s experiences. Therefore, five patients’ experiences (mainly two) out of the nine participants

observed was described and discussed.

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Full Length Research Paper

Awareness and barriers to utilization of maternal health care services among reproductive women in Amassoma community, Bayelsa State

Onasoga A. Olayinka^{1*}, Osaji Teresa Achi¹, Alade O. Amos¹ and Egbuniwe Michel Chiedu²

¹Faculty of Nursing, Niger Delta University, Wilberforce Island, Bayelsa State, Nigeria.

²Nnamdi Azikiwe University Teaching Hospital, Nnewi, Anambra State, Nigeria.

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Nigeria is on the verge of not meeting the fifth millennium development goals of improving maternal health due to a high maternal mortality rate which is estimated to be 630 women per 100,000 live births and lack of utilization of maternal health care services is a major contributing factor. Hence, the study was designed to explore awareness and barriers to the utilization of maternal health care services among reproductive women (15 to 45 years) in Amassoma community, Bayelsa State, Nigeria. The study population consists of women of reproductive age (15 to 45 years). A purposive sampling technique was used to select the sample size of 192. Data were collected using a questionnaire and descriptive and inferential statistics were used to analyze the data generated. The study revealed that the majority of the respondents [182 (94.8%)] have heard of maternal health services but only few actually knew the main services rendered at maternal health care services. Regression coefficient showed significant association between educational status and utilization of maternal health care services (MHCS) among the respondents ($\beta = 0.47, p = 0.000$); parity and utilization of MHCS ($\beta = -0.14, p = 0.016$); and age and utilization of MHCS ($\beta = -0.19, p = 0.001$). The major variables associated with barriers to utilization of maternal health services among respondents were poor knowledge of the existing services, previous bad obstetric history; attitude of the health care provider, availability, accessibility and husband's acceptance of the maternal healthcare services. It is recommended that Government should subsidize maternal health services in order to make it affordable, acceptable and available to women. Also nurses should encourage women of reproductive age to utilize maternal health by providing a welcoming and supportive attitude at all contacts.

Key words: Awareness, barrier, utilization, maternal health care services, reproductive age, women.

INTRODUCTION

High maternal morbidity and mortality rate is a huge public health problem in the developing countries of the world, including Nigeria. The maternal mortality rate in Nigeria is 630 deaths per thousand live births and Nigeria

ranks 10th position in the world record of health indicators of maternal mortality which is far behind our neighboring developing country, Ghana and Benin with 350 deaths per 1000 live birth each; with marked variation

in maternal mortality ratio between the six geo-political zones and between urban and rural areas (CIA World Fact book, 2012).

With an estimated 52,000 annual deaths, Nigeria accounts for about 10% of all maternal deaths, globally, and has the second highest mortality rate in the world, after India. It is also reported that, for every woman that dies from pregnancy-related causes, 20 to 30 more will develop short- and long-term damage to their reproductive organs resulting in disabilities such as obstetric fistula, pelvic inflammatory disease, a ruptured uterus, etc (World Health Organization (WHO), 2007; Shiffman and Okonofua, 2007).

Despite the existence of national programs for improving maternal and child health in Nigeria, maternal mortality and morbidity continue to be high and studies suggested that the majority of maternal deaths can be prevented or reduced if women had access to, or visited maternal health services during pregnancy, childbirth and the first month after delivery (Dayaratna, 2000; WHO, 2004; Federal Ministry of Health, 2005). However, many women in developing countries do not have access to maternal healthcare services and it is reported that the use of such services remain low in Sub-Saharan Africa including Nigeria (Babalola and Fatusi, 2009); where only 58% of women have attended at least one antenatal clinic during pregnancy, 39% of births are attended to by a skilled professional, 35% of deliveries take place in a health facility and 43.7% receive postnatal care (NDHS, 2003; WHO et al., 2012).

Darmstadt et al. (2005) are of the opinion that accessibility of health services has been shown to be an important determinant of utilization of health services in developing countries. In most rural areas in Africa, one in three women lives more than five kilometers from the nearest health facility (World Bank, 2002). The scarcity of vehicles, especially in remote areas, and poor road conditions can make it extremely difficult for women to reach even relatively nearby facilities. Walking is the primary mode of transportation, even for women in labor (World Bank, 2002). Addai (2000) stated that women in higher socioeconomic groups tend to exhibit patterns of more frequent use of maternal health services than women in the lower socioeconomic groups, factors such as education appear to be important mediator. Another important factor in the utilization of maternity care services, especially in Africa, is the cultural background of the woman. The cultural perspective on the use of maternal health services suggests that medical need is determined not only by the presence of physical disease but also by cultural perception of illness (Addai, 2000). In most African rural communities, maternal health services co-exist with indigenous health care services; therefore, women must choose between the options (Addai, 2000). The use of modern health services in such a context is often influenced by individual perceptions of the efficacy of

modern health services and the religious beliefs of individual women (World Bank, 2002).

World Health Organization (WHO) contends that the immediate cause of maternal deaths is the absence, inadequacy or underutilization of the healthcare system (WHO, 2004, 2007). Maternal health care services are underutilized particularly among those who are in the greatest need despite the fact that they are available in most of the hospitals in Nigeria, though each hospital operates according to its own rules, regulations, policy and conditions of services depending on the available resources.

Mothers are expected to seek maternal health care before, during and after delivery in the hospital, but it was observed that a low number of women came to the hospital to fully utilize these services in the study setting despite the beneficial impact. This study was planned to explore awareness and barriers to utilization of these services among reproductive women in Amassoma community in Bayelsa State

METHODOLOGY

A descriptive research design was used and the study setting was Amassoma community, Bayelsa State, Nigeria. Amassoma community is one of the largest communities in Southern Ijaw Local Government Area of Bayelsa State. The target population were all reproductive women who were either pregnant at the time of interview or had delivered within the last two years. Purposive sampling technique was used to select 192 reproductive women from the target population. The instrument for data collection was a self-developed questionnaire divided into sections relevant to the objectives of the study. Informed consent of the respondents was sought and the purpose of the study was explained to the respondents. Information provided by the respondents was treated with confidentiality and respondents' anonymity was maintained. The necessary translation of the contents of the questionnaire was given to the women for proper understanding. The data obtained was analyzed using statistical package for social sciences (SPSS) for windows 19.0. Both descriptive and inferential statistics were used to analyze the data collected and level of significance was set at 5% (0.05) such that significant associations were established when $p < 0.05$.

RESULTS

Table 1 shows that the majority of the respondents 112 (58.3%) were between the ages of 20 to 30 years, followed by 31 to 40 years 60 (31.3%), and 41 to 50 years constituted only 20 (10.4%). 174 (90.6%) were Christians and 18 (9.4%) were Muslims. The majority of the respondents 128 (66.7%) had tertiary education, followed by 42 (21.9%) who had secondary education, while 22 (11.4%) had primary education. Most of the respondents 70 (36.5%) were civil servants and artisans, while 44 (22.9%) were students and only 8 (4.2%) were full time housewives. The majority of the respondents 82

Table 1. Demographic characteristic of the respondents.

Variable	Other parameter	Frequency	Percentage
Age group (Years)	20 - 30	112	58.3
	31 - 40	60	31.3
	41 - 50	20	10.4
Religion	Christian	174	90.6
	Islam	18	9.4
Educational status	Primary	22	11.4
	Secondary	42	21.9
	Tertiary	128	66.7
Occupation	Civil servant	70	36.5
	Artisan	70	36.5
	Housewife	8	4.2
	Student	44	22.9
Average income per month	Below N20,000	82	42.7
	N20,000- N40,000	44	22.9
	N41,000-N60,000	8	4.2
	Above N60,000	58	30.2
Parity	Primigravida	33	17.2
	Primiparous	74	38.5
	Multiparous	85	44.3
Marital status	Single	12	6.3
	Married	180	93.7

(42.7%) had a monthly average income of below N20,000, followed by 58 (30.2%) who earned above N60,000 monthly, 44 (22.9%) earned N20,000 to N40,000, while the remaining 8 (4.2%) earned N41,000 to N60,000 monthly. Most of the respondents 85 (44.3%) were multiparous women, followed by primiparous which constituted 74 (38.5%), and only 33 (17.2%) were primigravida. The majority of the respondents 180 (93.7%) were married and 4 (6.3%) were single. Respondents.

Table 2 shows that the majority of the respondents 182 (94.8%) have heard of maternal health care services while 10 (5%) have not. Out of the 182 (94.8%) who have heard about maternal health care services, 106 (55.2%) of them first learned about it from the hospital, 35 (18.2%) from friends and family, 22 (11.6%) from mass media, 14 (7.3%) from school while other sources contributed only 5 (2.6%). Out of the 182 (94.8%) who claimed to know the services rendered at maternal health care centers, only 2 (10.4%) agreed that preconception care is part of the services while 88 (45.8%) included postnatal care and 75 (12.5%) included family planning; only 50 (28%) included

immunization as part of the services. However all the respondents 182 (94.8%) are of the opinion that antenatal care and delivery are part of the services rendered in maternal health care.

Table 3 shows that the majority of the respondents stated that lack of knowledge about the existing services 187 (97.4%), availability of facilities/equipment 185 (96.4%), previous history of complication during pregnancy labour or post delivery 175 (91.1%), schedule of maternal health care clinic 166 (86.6%), affordability of maternal health care services 164 (85.4%), attitude of the health care provider 162 (84.4%), previous experience of the services rendered 158 (82.4%), accessibility to maternal health care services 149 (77.6%) and the husband's acceptance of the maternal healthcare services 139 (72.4%), were the major barriers affecting utilization of maternal health care services. Cultural acceptance 66 (34.4%) and language barrier 68 (35.4%) were identified as the least factors affecting the utilization of maternal health care services, respectively.

Table 4 shows that the higher the B value, the greater

Table 2. Awareness of maternal health services.

Question		Frequency	Percentage
Have you heard of maternal health care services before	No	10	5.2
	Yes	182	94.8
What is your initial source of information	Hospital	106	55.2
	School	14	7.3
	Mass media	22	11.6
	Friends and family	35	18.2
	Others	5	2.6
Do you know what services are rendered at maternal health care centers	No	10	5.2
	Yes	182	94.8
**Which of these services rendered in maternal health care services	Preconception care	2	8.3
	Antenatal care	182	94.8
	Delivery care	182	94.8
	Postnatal care	88	26.0
	Family planning	75	12.5
	Immunization	50	5.2

**respondent tick more than one option as applicable

Table 3. Barrier to utilization of maternal health care services.

Barrier	Frequency	Percentage
Attitude of the health care provider	162	84.4
Availability of facilities/equipment	185	96.4
Lack of knowledge about the existing services	187	97.4
Language barrier	68	35.4
Schedule of maternal health care clinic	166	86.6
Accessibility to maternal health care services	149	77.6
Previous experience of the services rendered	158	82.3
Previous history of complication during pregnancy, labour or post delivery	175	91.1
Affordability of maternal health care services	164	85.4
Cultural acceptance	66	34.4
Husband's acceptance of the services rendered	139	72.4

*Respondents listed more than one barrier

the contribution of the predictor variables. This shows that educational status is an important factor that influences utilization of maternal health care services

(MHCS) among the respondents under study. Since the association is positive, it shows that higher the level of education, the more likely they will utilize maternal health care services. The finding also revealed that age and parity are key factors in utilization of maternal health care services (MHCS) among the respondents. Since the association is negative, it shows that higher the age and

parity, the less likely they will utilize maternal health care services.

DISCUSSION

Majority of the respondents 182 (94.8%) have heard of maternal health services but only few actually knew the main services rendered at maternal health services. This implies that despite high awareness of maternal health

services, there is lack of in-depth knowledge of some services rendered such as preconception care and postnatal care. This may have influenced their utilization because for these women to utilize the maternal health services, they must be knowledgeable about the existing services.

The study revealed that only 2 (8.3%) mentioned preconception care as part of services rendered. This is not surprising, since many women in Nigeria do not see preconception care as necessary. According to WHO (2012), there is growing evidence that extending the maternal, newborn and child health to include prenatal care which is a woman's health before she becomes pregnant can increase the well-being of women and improve subsequent pregnancy and child health outcomes.

Only 88 (26.0%) of the respondents mentioned postnatal care as part of services rendered. Postnatal care is regarded as one of the most important maternal healthcare services which is crucial for monitoring and treating complications in the first six weeks after delivery. Postnatal services are primarily comprised of physical examination, immunization, health education and family planning services (Safe Motherhood, 2002; NPC, 2004; United Nations, 2002). According to Safe Motherhood (2002), the majority of women in developing countries receive almost no postpartum care after delivery; only about 5% of women receive postnatal care in the Sub-Saharan Africa.

The study revealed that previous history of a complication during pregnancy, delivery or post-delivery influences utilization of maternal health care services. This is in line with the finding of Kebebe et al. (2012) that women with perceived risk and previous experience of pregnancy related complications are highly likely to attend African National Congress (ANC). The attitude of the health care provider and previous experience of the mothers about the care received, also influence utilization of maternal health services. This is not surprising since negative attitudes by health care providers elicit negative outcome in the utilization of maternal health care services and on the other hand, positive behaviours of health care providers to women will bring about positive outcome. Various studies have shown that there is a relationship between attitude of health care providers and mother's choice of where to receive antenatal, delivery and postnatal care (D'Ambruso, 2005; Natukunda, 2007; Onasoga, Opiah, Osaji and Iwolisi, 2012). The attitude of health care providers towards women is a major influence on women's decision whether to use or not to use a particular type of maternal health care service.

The husband's acceptance of the maternal healthcare services is also one of the main factor identified and according to WHO (2004), women's decision making power is extremely limited in many parts of Africa, particularly in matters of reproduction and sexuality. In this regard, decisions about maternal care are often made by

husbands or other family members. The finding of this study agreed with Ladipo (2008) and WHO (2010) that affordability and accessibility are also important determinant of utilization of health services in developing countries.

The study also revealed that level of education is a significant predictor to utilization of maternal health care services. This is in line with Wong et al. (2004) that the higher the educational level and experience, the more likely the utilization of health care. In other words educated women are more likely to use maternal health care services than women with no formal education (Addai, 2000; Mekonnen and Asnaketch, 2002). Age of the mother also has a significant negative association on utilization of maternal health care services. Studies have shown that younger mothers are more likely to deliver in health facilities than their older counterparts. Furthermore, the study also revealed a significant negative association between parity and utilization of maternal health care services. This corroborates the finding of Kebebe et al. (2012) that women in a larger household are less likely to deliver at health facilities. However no significant association was found between occupation and marital status of respondents and their utilization of maternal health care services.

Conclusion

The study was designed to determine awareness and barriers to utilization of maternal health care services among reproductive women in Bayelsa Local government Area, Bayelsa state. Literature showed that utilization of health services is a complex behavioral phenomenon, related to the availability, acceptability, quality and affordability of services, social structure, health beliefs and characteristics of the users. In this study, most of the women (94.8%) were aware of maternal health services in general but lack comprehensive knowledge of services provided. The study has shown that age, education, and parity have significant impact on mother's utilization of maternal health care. The major variables associated with barriers to utilization of maternal health services were lack of knowledge about the existing services, previous bad obstetric history; attitude of the health care provider, availability, accessibility and husband's acceptance of the maternal healthcare services.

IMPLICATION OF THE STUDY TO NURSING PROFESSION

It is imperative for the Nurse-Midwives to understand the barriers that hinder women from utilizing maternal health care services as this provides evidence to address women's problems and ensure effective utilization of available

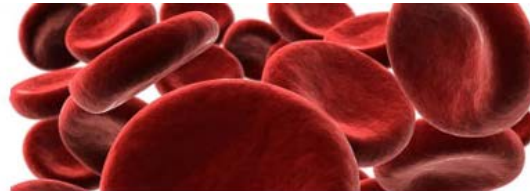
maternal health services. Therefore, nurses-midwives should encourage and build up a trusting relationship with the woman and her family in order to ensure maximum use of these services as well as liaise with policy makers in order to eradicate these barriers.

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