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Children with Duchenne Muscular Dystrophy: Challenges, Coping and Caring

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Abstract- This study investigated the life experiences of parents and family members caring for a child with Duchene muscular dystrophy through a Case Study Approach. Specifically, it answered the following questions: 1) How are the lives of parents and family members caring for the child with muscular dystrophy? and Based on the findings of the study what program could be develop for children and families of a child with Duchene muscular dystrophy? The researcher utilized the case study research design to explore the life experiences of parents and family members in caring for children afflicted with Duchene muscular dystrophy. Case study is concerned with studying the phenomenon in context to generate insight on how phenomenon actually occurs within a given situation. Two families were chosen as interviewees; composed of parents (father and mother) and family members (grandparent and uncle) who are caring for a child afflicted with Duchene muscular dystrophy. Furthermore, the location of this study is at Urdaneta City, Pangasinan. Duchene muscular dystrophy is a rare disease, and in this place the researcher has identified two families as participants of the study. In building a complex, holistic picture of the life experiences of parents and family members caring for a child with DMD various sources are highly complementary and good case study used many sources such as interviews, participant observation, and field notes to gather evidences. But before formal investigation, participants were invited through a formal letter received by them personally. Based on the stated problem, it was concluded that family experiences in caring for their DMD child started when family members noticed remarkable abnormalities in the child's developmental milestones; such as-unusual walking, tip-toeing, frequent falling, difficulty in climbing stairs, rising from the floor with hand support (Gower Maneuver), difficulty maneuvering while riding a bicycle, and unusual pronounced calf muscle. These convinced them that there was problem about their child's health and that there was a need for them to seek medical assistance. Furthermore, both families experienced emotional challenges in caring for their DMD children. At the start, there was a reaction of disbelief, rejection, guilt feeling, hopefulness, apprehension, distress, uncertainties, confusion, fear and disappointment. Economic challenges of the family in case #1; were with the parents becoming workaholic is evident while in case #2 there was a lack of financial resources. When it comes to the physical challenges, both families experienced tiredness. Lastly, disappointment and disheartedness were the social challenges which both families experienced. Despite all of these challenges, parents and family members caring for these DMD children use emotional coping mechanisms of harmonious relationships within themselves. Their ultimate resort is spirituality. By putting their trust in God, this made them accept that their being in that situation is God's will; they now have a positive outlook in life. Lastly, based on the findings of the study a program was developed to improve the life experiences of children and families with Duchene muscular dystrophy

I. INTRODUCTION

Children are valued for they bring joy, happiness and fulfillment to parents as well as to families. Parenting is a challenging role of ensuring children's health and safety; hence, having a chronically ill child in the family has an impact on the welfare of each member of the family.

Furthermore, a child with an illness is affected in the physical, psychological and social functioning while persons in the immediate context such as parents, family members and caregivers are also affected emotionally, mentally, psychologically, financially and mentally. A child's illness has both direct and indirect effects on family members, and their relationships. It is not unusual for an individual's family member to feel anger, denial, self- blame, fear, shock, confusion and helplessness since they are faced with changing day-to-day routines, plans for the future, feelings and meanings about self, others and life.

Muscular dystrophy is a rare type of illness affecting mostly males but in rare cases it can affect females. Duchene muscular dystrophy (DMD) is the most common type which affects a male newborn. According to US Census Bureau (2009) the prevalence of DMD occurs one in every 3500 birth (2.9 per 10,000) male births and in the Philippines there are 14,373 extrapolated incidences in every 86,241,697 extrapolated population statistics (Statistics by Country for Duchene Muscular Dystrophy, 2004). A survey conducted by the Japan International Cooperation Agency (2002) based on the National Statistics Office 1995 available population survey data found that in the Philippines there are 919,292 total number of people with disability and 15 percent are affected with physical disability, 65 percent are male while 35 percent are female. Moreover, 80,000 of persons with disability are from Region 1 where the participants of the study are located.

The diagnosis of DMD presents many challenges to families, parents particularly mothers who have the added burden of knowing that they may be the carriers of the mutation responsible for the disorder. As the disease progresses, both sides of the family develop an attitude of blaming and will react with doubt, denial, anger, anguish, anxiety as well as feeling guilt. As such, DMD has a great impact on the family in terms of their daily stressor and adjustment particularly when muscle weakness begins to interfere with the child's activities of daily living. In addition the disease involves time-consuming care, awareness and readiness on the terminal nature of DMD, availability of financial and medical resources.

Similarly, Furlong (2010) stated that parents want the best for their children for them to grow up, grow old and enjoy their lives, but when a catastrophic diagnosis is made no one knows what is going to happen, and the plan they had has to change.

Chronic diseases are illnesses that are prolonged, do not resolve spontaneously and are rarely cured completely (Stanton, 2007). Correspondingly, muscular dystrophy is a group of degenerative genetic diseases that weaken the body's skeletal muscles, particularly the muscles that control movement and with no known treatment. For families living with a child with muscular dystrophy, care giving is a full-time job.

Symptoms onset is in early childhood usually between ages 3 and 5. As the disease progresses, fatigue and body weakness are present and later on the child need to use assistive devices (wheelchairs, walkers, devices to assist breathing). In most cases, the affected individual may need permanent assistance from a home caregiver and will be confined to a wheelchair or electric scooter. Worst, the heart and muscle are affected which can be fatal and the child would increasingly need assisted breathing (Muscular Dystrophy in Children: A Guide for Families, 2010).

Furthermore, Furlong (2010) suggests that caregivers need to take all resources available when caring for the child because it is a never-ending process of accommodation and re-accommodation as the disease progresses. Upon diagnosis, family caregivers need to make sure that the home is a safe and healthy place for the affected child such as if child wheelchair fit underneath the dining table so they can join the family at mealtime; if the child still walking, make sure that there are no obstacles in the home that may lead to fall and construct a bathroom sink that the child can access to maintain independence in grooming as long as possible.

Hence, planning ahead is important as there are many cost insurance issues and waiting list of equipment that a child may eventually need. It is important to prepare child to grow up, grow old and be independent, regardless of a diagnosis. Child need to be encouraged to speak up if need assistance, do a task themselves if able and function in this world to the best of their abilities just as their siblings and peers do. Because of the progressive nature of muscular dystrophy, particularly Duchene muscular dystrophy, the illness has definite impact on the life of child, parents, caregivers and families (Furlong, 2010)

The Philippines' general public is now open and indulgent about disabilities. Many individuals, companies, civic or welfare organizations give money or inkind donations to persons with disabilities but they are still deprived with equal access opportunities. Hence, it is extremely important to assess the life experiences of parents and family members caring for a child with Duchene muscular dystrophy so that the professionals can deliver evidence-based quality health care.

II. METHODOLOGY

- Research Design

Generally, research is understood as systematic, controlled, empirical and critical investigation of hypothetic statements on supposed relationships among phenomenon. According to Bruce (2006) research process should be understood as one of ongoing planning, searching, discovery, reflection, synthesis, revision, and learning.

Correspondingly, Yin (2009) defined case study as an empirical inquiry that investigates a contemporary phenomenon in-depth and its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident. The researcher utilized the case study research design to explore the life experiences of parents and family members in caring for children afflicted with Duchene muscular dystrophy. Case study is concerned with studying the phenomenon in context to generate insight on how phenomenon actually occurs within a given situation.

The research at hand is also an illustrative or descriptive case study in the sense that the researcher collects pieces of evidence about the family's life experiences in caring for children with Duchene muscular dystrophy to exemplify similarities, differences and to understand the phenomenon. Amisted (1984) stated and mentioned by Mann (2006), illustrative case studies typically utilize one or two instances of events to show what a situation is like; it serves primarily to make the unfamiliar familiar and to give readers a common language about the topic in question.

Specifically, it sought to address the meaning, implication and significance of the different conscious experiences, thoughts and observations on the life experiences of caring parents and families that seem rational for the development of a health program to facilitate gaining knowledge, skills as well as improvement of families' caring experiences. As such, a proposed health program would be properly endorsed to the Pangasinan Provincial Health Office for study, review and possible implementation.

- Research Approach

The researcher used the case study research method to illustrate the contemporary real-life experiences of parents and family members in caring for a child afflicted with Duchene muscular dystrophy. Stake's (1998) approach to case study was based on a social constructivist paradigm. Social Constructivist recognizes the importance of experience and collective interactions to shape human perspective and behavior. Meanwhile, Yin (2009) approach is based on a post positivist paradigm. Post positivist emphasizes the meaning of human experience through inquiry or by observing human behavior as data.

Specifically, this study used the illustrative or descriptive case study. The illustrative or descriptive case study exemplifies the life experiences of parents and family members in caring for children with Duchene muscular dystrophy by elucidating the commonalities, divergence and significance of situation to understand values of experiences. As declared by Mann (2006), illustrative or descriptive case study utilizes one or two instances to show what situation is like to help interpret data when it is believed that the researcher knows little about the subject. This approach was based on the actual observations of events to enable the researcher to evaluate the context to understand the subject.

- Case Participants

Two families were chosen as interviewees; composed of parents (father and mother) and family members (grandparent and uncle) who are caring for children afflicted with Duchene muscular dystrophy. The focus of the study are participants who are willing to share and talk about their experiences and who are diverse enough from one another to enhance possibilities of rich unique stories of their particular experiences (Van Manen, 1997). The scope of the study was limited only to the life experiences of parents and family members in caring a child with Duchene muscular dystrophy. Likewise, the researcher found it significant to consider notations of significant people for in-depth analysis. Also, participants are limited because Duchene muscular dystrophy is a rare type of disease.

- Pieces of Evidence

In building a complex, holistic picture of the life experiences of parents and family members caring for a child with DMD various sources are highly complementary and good case study used many sources such as interviews, participant observation, and field notes to gather pieces of evidences. But before formal investigation, participants were invited through a formal letter received by them personally.

- Interview

Interview is a face-to-face data gathering with respondents in an oral questionnaire. The researcher prepared a semi-structured interview that served as guide to be followed during interview. Prior to interview the researcher established rapport and a friendly relationship with the subjects and explained the purpose of the study to draw certain types of confidential information which the latter might be reluctant to answer. The researcher translated the questions to the respondents' dialect (Filipino) to ensure correctness and understanding. According to Yin (2009), though researchers are pursuing a consistent line of inquiry, actual stream of questions in a case study interview is likely to be fluid rather than rigid. Thus, throughout the interview process the researcher must follow line of inquiry as reflected by case study protocol and ask actual questions in an unbiased manner. Participants were also informed that the interview was recorded by making handwritten notes or audio taping, and they were assured that all gathered data will be handled with confidentially.

- Participant Observation

Observational evidence is useful in providing additional data about the subject of inquiry. Participant-observation was also employed in this study wherein the researcher assumed a variety of roles within the case study situation and participates in the events being studied. As cited by Yin (2009), participant-observation provides certain unusual opportunities for collecting case study data and the most distinctive opportunity for the researcher to gain access to events or groups that are otherwise inaccessible to scientific investigation which means there are evidences that can only be collected through participant-observation. Hence, the researcher was fortunate enough that one of the family is her husband's sibling and her neighbor to participate with the caring activities while the other family, the researcher visited the family for a short period of time to experience and observe important events to evaluate the data gathered during interview for an in-depth analysis.

- Field Notes

Field notes pertain to the researcher's conscious and coherent narrated and interpreted observations and actions during the data gathering procedure. It involves noting down the environment such as the presence of others, location, time of day, facial expression, position change, voice change and other observable changes that the participants made during the data collection. Field notes were important because they may provide, the researcher with thoughts and experiences relating to the existing problem or thoughts relating to analysis. Thus, the researcher documented what she observed during the data gathering procedure.

- Ethical Consideration

According to Rogers (2008), research ethics is the domain of inquiry that identifies ethical challenges with a view to developing guidelines that safeguard against any harm and protect the rights of human subjects in research. With this, the researcher was mindful that personal issues and dealings of parents and family members caring for a child with Duchene muscular dystrophy were private matters that entailed an ethical responsibility. Thus, the following ethical principles were observed.

Beneficence. To adhere to the principle of beneficence, the researcher was observant to ensure that the data collection process has not caused issues that may lead to emotional trauma. The comfort of the participants was also given priority. Prior to data collection, the reason for conducting interviews and observations was explained, and the researcher did not coerce the participants which meant the participants exercised their rights as autonomous individuals to voluntarily join this study.

Autonomy. The researcher obtained informed consent from the participants before the research process was carried out. According to Orb (2008), to consciously promote autonomy, the author must prepare a consent form for the participant. This means that participant must voluntarily join the study. Thus, prior to the data collection, the researcher explained the purpose and nature of the research and obtained a consent form.

Confidentiality and Anonymity. This principle was observed during the entire duration of the research process by respecting the dignity of the participants. Their identity was protected and they were given the freedom to withdraw from the study if they felt uncomfortable during the duration of the research process. Hence, before and during the data collection, the researcher explained to the participants that the data gathered were kept confidential and pseudo name was given for anonymity. Furthermore, the researcher reiterated that they are not forced to participate and if they felt uncomfortable and they were allowed to withdraw from the study.

Veracity. Throughout the process of the study, the researcher maintained the truthfulness of the data by carefully taking notes of every detail in the transcribed interviews. According to Orb (2008), veracity is referred to as the devotion to the truth. Further, the researcher provided a copy of the transcription to the participants for correction and verification.

- Data Analysis Procedure

The process of data analysis was the most difficult aspect of doing case studies. As stated by Yin (2003), several processes might be stated in the proposal that convey a sense of the overall activities of qualitative data analysis such as examining, categorizing, tabulating, testing or recombining both quantitative and qualitative data to address the objectives of the study.

- Narration of Experience

Upon securing an informed consent, demographic profile were asked from each participant. Then the researcher prepared for a face-to-face interview using semi-structured guided questions. The interviews allowed the researcher to gather information from each participant by encouraging them to talk freely and narrate stories in their own words. This technique ensured that all information needed is provided. As cited by Polit and Beck (2012), participants' freedom to respond in their own words provides as much detail as they wish and offer illustrations and explanations.

As the interview was in progress, narration of experiences was recorded with an audio recorder to facilitate the transcription conversations with the participants who agreed to a recorded interview. For the others refused the recordings were written while the interview was on going. Transcriptions from the Filipino language were translated to English language by the researcher with the help of a college English professor

- Field Notes

Field notes were also written after each interview to serve as part of the data review and checking to ensure dependability and transferability. Field notes represent the researcher's observation. Tjora (2006) mentioned, field notes are encoded with the author's conscience, understanding and interpretations and the fieldworker is not only an observer but an actor, author, teller and writer. Thus, it contains a narrative account of what is happening in the field and they serve as the data for analysis. Furthermore, Polit and Beck (2004) identified the following kinds of field notes.

Descriptive notes. Also known as Observational notes, there are objective descriptions of observed events and conversation, information about actions, dialogue and context which are recorded as completely and objectively as possible.

Reflective notes. These contain the researcher personal experiences, reflections and progress while in the field and serve a variety of purposes: methodological notes are reflections about strategies and methods used in the observations; theoretical notes which contain researcher's thought about how to make sense of what is going on and serve as starting point for subsequent analysis; personal notes are comments about the researcher's own feelings while in the field and can also contain reflections related to ethical dilemmas and possible conflicts.

- Narrative Reflections

After gathering sufficient data, the researcher read and scrutinized each transcription for several times to have an in-depth understanding of each participant's experiences. Each of the two-family cases were treated and analyzed separately through data analysis. Hence, within-case analysis and cross-case analysis were established.

The first analysis technique used was within-case analysis. The researcher cautiously identified categories and pattern of meanings within each case. Coding system was utilized to analyze the narrative caring experiences by looking for significant statements, meaning, key words or phrases related to each participant's experience. These statements were termed as initial codes – each significant statement was then provided with meaning to uncover and highlight the participants' shared meanings and these were termed as categories and was double-checked to assure that they are relevantly grounded with the data. Then, formulated meanings were organized into cluster or categories and these series of steps for within-case analysis were done one case at a time. Furthermore, summary of identified themes or patterns of meaning were provided at the end of each case story.

Cross-case analysis was then also employed to draw conclusions from the two cases. This was done by comparing the patterns from one case to another looking for similarities and differences. Detailed discussion was then written integrating the related literatures. Moreover, the researcher fairly treated the data to come up with comprehensive conclusions relevant to the purpose of this study and reviewed these against the research questions based on the themes or patterns of meaning from all the cases.

Verification and validation strategies were instituted throughout all steps of the data analysis process to preserve the integrity of the data and maintain the rigor of the study. To ensure trustworthiness, the researcher engaged in a variety of strategies such as prolonged engagement, member checking, triangulation and audit trails.

Member checking was achieved by conducting a follow-up interview with the participants of the study and by providing them an opportunity to comment on the findings. As mentioned by Polit and Beck (2012), member checking is achieved by returning to the study participants and providing feedback regarding the emerging data and interpretations, and obtaining each of their reactions. Hence, the researcher personally presented the findings to the participants to obtain their reaction and additional insights. Each of their reactions was written in a member checking form provided by the researcher (see Appendix K).

The triangulation used was in the form of the in-depth interview and through the use of written field notes. Prolonged engagement was also used so that the researcher had enough length of time for the narration of experiences and data analysis. The narration of experiences and narrative reflection process started from year 2014 to middle year of 2015. Audit trails were also used to establish dependability and conformability. Data trail included in this study were field notes (Appendix J), coded interview transcriptions of the two cases (See Appendix D, E & F) as well as the table summary of the with-in case and cross-case analysis for each of the two cases. (Appendix G)

- Debriefing Process

For debriefing process, nondirective counseling was deliberated and employed to manage the situations. According to Rogers (1945) republished by The University of Chicago Press (2015), nondirective or client-centered counseling is the process of skillfully listening to counselee, encouraging the person to explain bothersome problems and helping him or her to understand problems to determine courses of action. Hence, with the help of a guidance counselor, the researcher scheduled a date with the family respondents (Family Case #1 and 2). During group interview, the guidance counselor ask question and allow participants to narrate freely their life experiences in caring for a child afflicted with Duchene muscular dystrophy and provides them direction to help family participants become independent, self-reliant and to attain self-direction or to adjust with the situation by allowing them to explore their own problems in their own way and in a anyway arouse their defense.

III. CASE FINDINGS, INTERPRETATION, AND DISCUSSION

This part reflects a cross case analysis of the data collected. While it is not possible to generalize from just two cases, there are common trends that could be found across the cases. The cross-case analysis of data along the different patterns of meaning of the life experiences of parents and family members who are caring for a child with DMD

- Remarkable Child's Developmental Milestones

The responses of parents and family member regarding the remarkable developmental milestones of a child afflicted with Duchene muscular dystrophy. The statements showed the remarkable child development that brought families to feel doubtful with the health of their children. As evidenced by the verbalization of parents and family members in this study, they described atypical physical signs and behaviors before the diagnosis such as unusual walking, tip-toeing, frequent falling, difficulty in climbing stairs, rising from the floor with hand support (Gower Maneuver), difficulty maneuvering and riding a bicycle and unusual pronounced calf muscle. These initial inabilities caused the families to become suspicious convincing them that there was a problem that needs medical consultation.

As stated by the participant parent doctor, he started to doubt his children development when they were 1 year old. He observed that they stood, walked and cruised along walls or with the help of their caregiver until 2 ½ years old. Based on physical observations and with the assistance of two doctor specialists whom they sought consultation his diagnosis was confirmed. Likewise, these observations were acknowledged by the other participants who prompted the families to heed their instincts and give credence to the expertise and concerns of medical doctors.

Hence, the observations were confirmed by the Muscular Dystrophy Australia (2003) that Duchene muscular dystrophy cause similar patterns of weakness and disability and is inherited. Diagnosis likely happens before the age of 2 or 3 years. Most of the boys with DMD walk alone at a later age compare to the average ones. Then the parents are likely to be worried about things that are unusual like in the way they walk, their frequent falling or difficulty rising from the ground, or difficulty going up steps so by that time, a doctor must have been consulted already.

Once a child is diagnosed with Duchene Muscular Dystrophy, family lives go through significant challenges dealing with the condition. Receiving the diagnosis is a very difficult process for the families concerned. However, it is an important step in helping parents and families to adopt a broad view of life of DMD that is not focused exclusively on the negative side.

Challenges Experienced in Caring for a Child with DMD

- Emotional Challenges

It is observed that families caring for a child with DMD experiences emotional challenges. Parents and family members go through difficult feeling as evidenced by the statements by Case #1 of the father, Jose, *"It is really difficult. You could not believe that it is happening. Every day is a struggle for the family. I told myself, not my sons, they will carry my name and I want them to live and grow normally."*

This connotes the feeling of disbelief and rejection about the situation wherein the earliest and most common reaction to the diagnosis goes through various stages of the grief process. The DMD Forum (2001) explains this process clearly and concisely that the first reaction is denial. Similarly, this coincides with the mother's (lisa) testimony, *"It was difficult, I cried. Even my assistant, and so with all the people around me cried, too. Acceptance is not easy; you could not believe that it is happening."* And the grandfather's (Lolo Mariano) disbelief as he mentioned, "*Very difficult. Questions arise. My son-in-law told us that the disease was inherited from my daughter. I felt mad about it and I disagreed. My wife and I concurred that no one from our family suffered illness like that of the twins."* This statement connotes a feeling of guilt knowing that the disease is inherited from the mother as confirmed by the Parents Project Muscular Dystrophy (2002) that the disorder is caused by a genetic defect on the X-chromosomes and is believed to be inherited through genetic mutation passed from one female carrier to another. As well Hopefulness, was also seen *"We are hurting because we care for our grandson; they are with us since birth. I told myself, only God knows everything, and that I am hoping they could walk someday."*

Another response is apprehension. The family's fear for the future is evident both the father (Jose) and the mother (Lisa) imagine the worst possible scenario. *"The greatest fear is losing them; that the other will also catch the sickness because it usually happens, when the other one is sick the other one will follow or both get sick. And because they are twins, we are scared; what if one leaves us, how will we explain it, to the other one?"* Their fear is similar to the grandfather's distress, "I*t is difficult if they get sick, often times they suffer from cough and colds. They cough severely. It is so heartbreaking when I see their father do chest pumping to them to expel out phlegm."* And his apprehension of losing his grandson*, "We are not afraid of dying, but then as humans we know it is hard to accept that they will leave us and when that time comes, when one goes first how the surviving one will accept it?"*

Furthermore, they also showed uncertainties (confusion); as the mother (Lisa) revealed, *"The situation brings challenges to our family. Everyone shows different emotions, waiting for explanation about the twins' illness maybe because no one knows; what the illness is, the disease,"* and powerlessness expressed by the father (Jose), *"We all know death will come anytime. But I have already accepted the fact that my kids might go back to our Divine Creator so as of now I must keep them."*

Similarly, Family Case #2 responded with confusion, as revealed by the father (Dante), *"Though I do not understand much about their illness, I feel sorry and sad that I ask I asked myself how and why do they suffer from such of illness."* This sentiment is just like the mother's (Weng) statement, *"I do not know what to feel. They keep on asking the same questions making it irritating to answer. I told them to asks the doctor",* The mother's statement exhibited fear *"When they said Denden can no longer walk, I cried, I pity my son and I am afraid because even Renren will soon follow", as well as* powerlessness *"So we need to find ways to cure him by doing some tests. I feel hurt, pity and sadness for my children."* In the same way father (Dante) showed feeling of powerlessness and disappointment, "*I see my wife help him walk; I was just observing but deep inside I am hurting because I want to bring him to a doctor but I cannot because I do not have enough money. And my wife said that she brought my son to a faith healer because he fell down the reason why he was unable to stand; and she thought that he has fracture. She also mentioned that she brought our son to a doctor and there was an examination that needs to be done to Denden."* His responses revealed the uncle's (Arlo) disappointment *"My sister decides for her children, I feel sorry that is why if I have time I accompany and help her in taking care of my nephews and I see how she sacrifices for them."*

These findings correspond with the declaration of authors that, as the disease progresses, mothers may develop an attitude of self-blame (Rubin, 1987). Both parents may react with feelings of disbelief, denial, anger, anguish, anxiety, guilt (Buchanan et DMD Forum, 2001), fear, confusion, powerlessness, rejection (DMD Forum, 2001); and parent/child-related stress (Beresford, 1994).

Dooley's (2004) study also revealed that a parent of children with Duchene muscular dystrophy has a higher possibility of going through a major depressive episode and had significantly lower self-esteem. In addition, Holroyd and Guthrie (1986), as reiterated by Webb (2005), affirmed that parents of children with DMD are pessimistic about outcomes related to the disease, its terminal prognosis, and negative feelings towards their children and experiences resulting to chronic emotional stress.

Hence, it is important for families to know that grief is a universal response to overwhelming shock or traumatic experiences with the medical professionals such as doctors and nurses who should be pre-cautioned to display empathy to the families. Most importantly they should propose therapeutic activities to help families cope with the emotional challenges.

- Economic Challenges

As pronouced, Family Case #1 father (Jose) works hard for the family as he stated, *"The situation causes me to be more hard-working, to be workaholic so as to speak because I know my family needs to be financially prepared. In the near future my kids might need special and advance medical management. They might use respirator, and I want to give all their need."* His understanding of the disease made him to be more hardworking is his dedication to give the best for his children. It is a known fact that when a child is diagnosed with an illness like Duchene muscular dystrophy; exceptional level of care at related costs is required. The best management for DMD requires multidisciplinary approach; this means that inputs from specialists in the different fields of medicine is essential. For a child afflicted with DMD to live longer proper but costly management, such as physiotherapy to keep muscles supple and to minimize tightness of joints and regular medication (steroids) should be administered. This treatment increases muscle mass and pulmonary strength (Cwik & Brooke, 1996; Porter et al., 2001).

In addition, boys with DMD progressively grow weaker keep them mobile and maintain the boys' independence parents may think of giving them orthopedic equipment (wheelchair) and nutritious food. However, Family Case #2 faced lack of financial resources; father (Dante) narrated, *"It is hard because they are both boys and according to their doctor, they have the same illness. It is hard thinking on how I could give their needs, like food and medicine they need. It's so hard, to think because I do not want my children to suffer and although I want to bring them to a doctor I cannot because I am financially incapable."* This narration was supported by the statement of the mother (Weng), *"the salary of my husband cannot sustain all our needs. Where would I get money for Renren's daily medicine as prescribed by the doctor?"* Findings show that family case #1 experiences little economic challenges while family case #2 faces severe lack of financial resources. DMD is unpredictable; no one knows what is going to happen; therefore, it is important that families are financially stable so they can support their needs, when worse comes to worst. Chin and Clark (2007) pointed out factors that affect the quality of life in families with DMD; this involves constant awareness of the terminal nature of DMD, and availability of financial and medical resources. Furthermore, the 2006 Annual Poverty Statistics of the National Statistics of the National Statistic Coordination Board, 27.9 million Filipinos or one-third of the entire population are poor. And to address this problem the Department of Social Welfare and Development (DWSD) together implemented a Conditional Cash Transfer Program known as Pantawid Pamilyang Pilipino Program (4Ps). Family case # 2 are recipient, and the 4Ps program objective is to address structural inequities in society and promote human capital development of the poor, thus, breaking the intergenerational cycle of poverty. The attached to the grants require parents to undergo trainings on responsible parenthood, have their children undergo checkups and ensure school attendants. The program also ensures that there is sufficient resource of the health nutrition and education of children aged 0-14 years old.

Moreover, one of the determinants of health care is the family income. Families with greater material resources enjoy more secured living conditions and greater access to opportunities compared to low-income families. According to the World Health Organization-Health Impact Assessment (WHO-HIA, 2015), factors such as environment, genetics, income, educational level and relationship with friends and family have considerable impact on health. Thus, higher income and social status are linked to better health.

- Physical Challenges

Both families admit that their experience in caring for their children is a hands-on, satisfying and involves a lifetime sacrifice. As mentioned by Case#1 participants their experiences are tiring but rewarding because their children are dependent on them. They wake up often complaining of pain, asking for change of position or requesting for someone to scratch their back and any other part of their body. Gradually, they are getting totally dependent on others; that even when bitten by ants it is impossible for others to scratch the bite.

Furthermore, the second family also experienced tiredness. Participant mother stopped working to care for her children because she knows that her children need a hands-on caring, they are unable to do things on their own. Caregivers serve as the DMD child's hands and feet; and the dependency of the child is caused by the disease progression leading to the gradual skeletal and voluntary muscle weakness. George's (2006) study entitled "Chronic Grief: Experiences of Working Parents of Children with Chronic Illness" revealed that parents of children with chronic illness experience multiple stressors associated with their numerous roles. For parents who are working full time and caring for a child, the stressor related to managing work and caring responsibilities are magnified. Likewise, Edwards et al, (2007) study revealed that caregivers of disabled with high care needs have poor physical health. Hence, it is important to recognize everybody's need by helping.

- Social Challenges

Both families feel disappointment and are disheartened with the insensitivity of other people. Mother of case #1 cited that she was discouraged and upset with her children's school because she saw her sons fell down but nobody helped them. The same was with the case #2 was mother who was disappointed when she heard the health workers talk and laugh at her children's x-ray result, saying, it looks like a frog.

This finding indicates lack of support from community and health workers for their acts of insensitivity. This observation was supported by the study of Mah et al. (2008) on the parental experiences of caring for 15 cases with neuromuscular disorders, 3 of whom had DMD. They found that parents are longing for more support from health care professionals; there's insufficient support from local community agencies, and a shortage of respite facilities. Furthermore, participants' disappointment with the health workers was proven by George's (2006) study on "Chronic Grief: Experiences of Working Parents of Children with Chronic Illness" that the grief experienced by parents was exacerbated by their dealings with health professionals.

On the other hand, Helm et al. (1998) cited by Webb (2005), revealed that professional concern and support are most valued. Medical professionals should: 1) make sure parents understand all prenatal tests; 2) give the diagnosis in person to both parents at the same time; 3) do not make assumptions on all options; 5) give up-to-date printed materials on the particular disability; 6) make referrals to appropriate sources of support; and 7) present the diagnosis and be prepared to organize their feeling of loss.

Also, Parker et al. (2009) conducted a study among adults with DMD and identified an insufficient external support to the patients and family. Participants acknowledge their difficulties with provision both from medical and social services to maintain quality of life and prolong their survival. Thus, it is necessary that various health professionals must have enough knowledge to provide guidance and support to these parents, their families and the community as well.

Coping Mechanism in Caring for a Child with DMD

- Emotional Coping

Harmonious relationship with family, facing life calmly, positive outlook and redirecting attention to work are the emotional coping mechanisms of parents and family members to overcome the situation that they are in. This is evidenced by Case #1 father who mentioned, "T*he unity of the family helps a lot and seeing them every day is so rewarding. I can do everything because our kids are our source of strength",* members of family case #1 are one in citing that work help them cope with their experiences. This was acknowledged by family case #2 when the father stated "*When I am at work, for a moment I forget my problem and I am just facing life spontaneously to ease my feeling. J*ust being present as much as possible, was reiterated by uncle Arlo, *"I extend help if I do not have work. We really need to be patient and even if they cannot help financially, my parents are there only for moral support. They stay with us specifically for my sister and nephews."* Bregma (1980) mentioned by Webb (2005), conducted a study and lived with each of six families whose children had progressive neuromuscular diseases. The study discovered that parents face various problems and difficulties as they care for their children with disabilities. They stated four types of coping strategies such as: 1) family focused on the present; with a one day at a time philosophy; 2) families attempted to live as normal life as possible; 3) families reduced the risk of crises by having a proactive attitude regarding the care and services for their child's condition; and 4) families developed coping resources based on personal strength.

Similarly, Halroyd and Guthrie (1986) reiterated by Webb (2005), said that parents of children with DMD were pessimistic about outcomes in relation to the disease, especially its terminal prognosis and having negative feelings towards their children's chronic emotional stress. Hence, coping occurs in response to stressful situation and people use coping strategies depending on the nature of the stressful situation and the person using them.

- *Spiritual Coping*

Spirituality as coping mechanism is observed to be the most powerful resource in the provision of comfort, peace and resolution for patients and families facing critical illness. The families showed a spirit of trusting in the Lord, preparedness, acceptance, thankfulness and gratefulness for all the life challenges. This was indicated in the statements of the father in case #1 to anchor everything to the Lord and be thankful for the health and everyday presence of their children, and who recognized that children are God's gift. The mother also mentioned that the situation brought them closer to the Lord, and their children serve as the source of their strength, bringing harmonious relationship in the family. These testimonies of case #1 father and mother was recognized by grandfather participant as well family case #2. A research conducted by Gerson et al., (2012) entitled "Self-reported coping strategies in families of patient in early stages of psychotic disorder" revealed that families use coping strategies, such as active coping, reinterpretation, acceptance and turning to religion. Thus, it is accepted that challenges bring everyone to be more faithful to and trustful of God's Divine Power.

- Effects of the Family Experiences in Caring for a Child with DMD

Neurological illnesses like DMD, DMD bring discomfort to patient, parents and family members. For families, particularly parents, it can be distressing to see children in pain, in addition to emotional strain for it demands a lot of time, energy and resources both personal and financial. Nevertheless, experiences can also bring positive perceptions in life.

The development of being observant, caring, being a better person, and having a united and harmonious family relationship, stronger family relationship, becoming apologetic, more compassionate, cooperative and sympathetic. Experiences create knowledge and a person creates his own reality based on current perceptions interacting with past experiences and processing abilities. Parents and family members' life experiences in caring for a child with DMD construct meaning based upon the challenges they encountered. Hence, positive attitude makes life easier and brings optimism in life to avoid worries and negative thinking.

CONCLUSION

Family experiences in caring for their DMD child started when family members noticed remarkable abnormalities in the child's developmental milestones; such as-unusual walking, tip-toeing, frequent falling, difficulty in climbing stairs, rising from the floor with hand support (Gower Maneuver), difficulty maneuvering while riding a bicycle, and unusual pronounced calf muscle. These convinced them that there was problem about their child's health and that there was a need for them to seek medical assistance.

In this study, both families experienced emotional challenges in caring for their DMD children. At the start, there was a reaction of disbelief, rejection, guilt feeling, hopefulness, apprehension, distress, uncertainties, confusion, fear and disappointment. Economic challenges of the family in case #1; were with the parents becoming workaholic is evident while in case #2 there was a lack of financial resources. When it comes to the physical challenges, both families experienced tiredness. Lastly, disappointment and disheartedness were the social challenges which both families experienced.

Despite all of these challenges, parents and family members caring for these DMD children use emotional coping mechanisms of harmonious relationships within themselves. Their ultimate resort is spirituality. By putting their trust in God, this made them accept that their being in that situation is God's will; they now have a positive outlook in life.

Lastly, based on the findings of the study a program was developed to improve the life experiences of children and families with Duchene muscular dystrophy.

RECOMMENDATION

Families of Patient with DMD. This study revealed the challenges experienced and coping mechanisms used by families in caring for a child with DMD. The researcher recommends that families will be more open to studies to further gain knowledge about the disease.

Local Community. The purpose of this study is to promote community awareness about the disease hence, the researcher recommends the local community to attend lectures and read brochures about person with disabilities particularly DMD, to develop consciousness and participation in caring for patients with physical disabilities.

Health Care Provider. The researcher recommends to actively participate in seminars and trainings related to neuromuscular disorder such as Duchene muscular dystrophy in order to gain information about the illness; and to enhance knowledge and skills in providing care to both patients and families of DMD.

Nursing Education. The researcher proposes the integration of genetic competencies in the current nursing curriculum, or to establish a program that will help students acquire knowledge about neuromuscular disorders particularly, DMD

Nurse Practitioner. This study has shown the life experiences of parents and family members in caring for child with DMD; the researcher recommends that nurse practitioners should provide proper management and holistic care not only with patients but also their families.

Nursing Service Administration. The researcher recommends that the results of this study will serve as their basis in creating organizational plans, policies or programs to address issues in providing proper management and care to patients and families with DMD.

Future Researcher. This study may be used as references for further study of Duchene muscular dystrophy; however, other studies that will help gain knowledge about Duchene muscular dystrophy and other neuromuscular disorders are recommended. Hence, the developed program takes long to find result, it is recommended that future researcher should test and evaluate the program.

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