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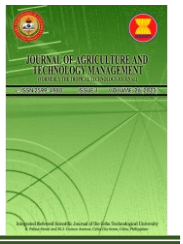

Lived experiences and academic aspirations of American citizens living with home-based care Duchenne muscular dystrophy patients

Mercita Q. Queddeng

University of Northern Philippines

ABSTRACT

The study explores the lived experiences and academic aspirations of the participants living with Duchenne muscular dystrophy (DMD), a rare neuromuscular disorder which could result in an early death due to its progression. This study used the descriptive phenomenology with purposeful sampling in the recruitment of the participants. A semi-structured interview guide was used and various platforms were considered such as actual interview in actual setting with the inclusion of videoconferencing and telephone interviews in gathering the data needed. The seven-step method of data analysis of Colizzi was utilized in data analysis in order to derive the themes of this qualitative research. Four major themes emerged that reflected the lived experiences of the American citizens in this study namely: Theme 1: The State of being physically impaired; Theme 2: Support, Social Dependency and Independency; Theme 3: Academic aspirations, Theme 4: Positive Outlook in life and dependable caregivers. The process involves the experiences of the American citizens in the care of DMD patients aside from the dependable medical ventilators and other devises to extend the life span of the Duchenne muscular dystrophy (DMD) patient under their care. Results show positive scenarios of the life experiences of the American citizens with Duchenne muscular dystrophy patients. Despite the enormous demands of their unique task, the participants showed encouraging dispositions (Theme 4: Positive outlook in life- you can do it, dependable caregiver). Further, it is noted that in spite of these challenges, setting aside the academic aspirations of the patients was never an option.

KEYWORDS: *physically impaired, federal, life span, educational aspirations, positive outlook in life*

1 INTRODUCTION

The lived experiences kindred among the individuals caring with inherited anomalies like Duchenne muscular dystrophy (DMD) is always difficult. The challenge is enormous.

Duchenne muscular dystrophy (DMD) is one of the most severe forms of inherited muscular dystrophies. It is the most common hereditary neuromuscular condition and does not exhibit a predilection for any race or ethnic group. Mutations in the dystrophin gene lead to progressive muscle fiber degeneration and weakness. This weakness may present initially with difficulty in ambulation but progressively advances to such an extent that affected patients are unable to carry out activities of daily living and must use wheelchairs. Cardiac and orthopedic complications are common, and death usually occurs in the twenties due to respiratory muscle weakness or cardiomyopathy. Duchenne muscular dystrophy (DMD) is an X-linked neuromuscular disorder characterized by progressive muscle degeneration. It leads to delayed motor milestones, typically progressing to loss of ambulation at approximately 12 years of age, followed by severe cardiac and respiratory complications. The pooled global prevalence of DMD is around 7.1 cases per 100,000 males. In approximately 10–15% of cases. Duchenne muscular dystrophy or DMD in its shorter term, is a rare genetic condition which primarily affects males, but in rare cases, cam also affect females. It is known that genetic change that causes Duchenne is the mutation in the DMD gene that happens before birth and can be inherited, or new gene can occur spontaneously. In short, Duchenne is a genetic disorder, which means mutation or error in one of the body's genes. For a better understanding of the error of the genes below is the overview: In Duchenne, the error occurs in the instructions used to make protein called dystrophin which is needed by the muscles in the body to protect them as they contract and relax. Children are unable to make the dystrophies protein, which causes their muscles to weaken overtime. Duchenne Muscular Dystrophy (Emery, E., Muntoni, F., Quinlivan, R. Duchenne muscular dystrophy, 2021)

In the study *End of Life care in Duchenne muscular dystrophy* by Hilton, T., et al. (2020) changes in the care of the end-of-life of the patients with Duchenne muscular dystrophy have become complex due to advancement of medical care, and skills or changes of medical personnel. Aspects like treatment, patient preferences, quality-of-

*corresponding author: mamabongpro@yahoo.com
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life issues, and contextual features related to legal, institutional, religious, geographic, cultural, social, and financial factors were considered. Some patients or family members cease to life prolongation if the patient finds life undesirable already.

In the study of Duchenne muscular dystrophy: deficiency of dystrophin (E. Bonilla, AF Hays and G. Salviati, 1988) they mentioned in their study entitled Duchenne muscular dystrophy: deficiency of dystrophin mentioned that the muscle cell that dystrophin is the altered gene product in DMD. They used polyclonal antibodies against dystrophin to immunochemically localize the protein cell in human muscle in normal individuals and in patients with myopathies other than DMD. Results of their study revealed that protein ass absent or markedly deficient in DMD. The sarcolemma localization of dystrophin is consistent with other evidence that there are structural and functional abnormalities of muscle surface membranes in DMD.

In the manuscript of The Lived Experience of Spirituality in Adolescents with Duchenne Muscular Dystrophy (Pehler, 2007), the lived experience of spirituality in adolescents with Duchenne muscular dystrophy was the strong desire for something unattainable that supports the need for nursing to assess spirituality in teens and determine developmentally appropriate interventions to ameliorate longing.

The study Survival in Duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation (Eagle, M., et al., 2020) used 197 records of patients with the condition Duchenne muscular dystrophy using a treatment at the Newcastle muscle gene within the duration o from 1967 to 2002. The study aimed to know if the life expectancy improved through the years with the use of nocturnal ventilation. It is noted in the results of the study that the mean survival age of patients was 14.4 years in the 1960s while 25.3 in the 1990s. The main cause of death of the patients that shortened their life span is cardiomyopathy with the mean age of 16.9 years.

In the Lancet Neurology (2018), notes on DMD had been stressed. Accordingly, improvements in the function, quality of life, and longevity of patients with DMD have been achieved through a multidisciplinary approach to management across a range of healthcare specialties. DMD care considerations focus on primary care, emergency management, psychosocial care, and transition of care across the lifespan. Many primary care and emergency medicines clinicians are inexperienced at managing the complications that these first-line providers are likely to encounter. With prolonged survival, individuals with DMD face a unique challenge related to psychosocial issues and transitions of care. Assessments of interventions are designed to improve mental health and independence, functionality and quality of life in critical domains of living, including health care, education, employment, interpersonal relationships, and intimacy.

Shelley-RaePehler, S. and Rosenberg, M. (2009) in the Journal of Pediatric Nursing of their study entitled Longing: The Lived Experience of Spirituality in Adolescents with Duchenne Muscular Dystrophy used the descriptive phenomenological method to describe the lived experiences of spirituality in adolescents with Duchenne Muscular Dystrophy and finding show that from 9 participants, the themes that surfaced is “longing” meaning the strong desire for understanding spirituality. In this study longing refers to connecting to self, and beyond self as mediated by the participants.

In the research, the lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness (Samson, A., Tomiak, E, Dimillo, J. and Lavigne, R., 2009) in their study the lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness show that the condition of the child is seen in three ways namely as a severe loss, a call to adapt or a way to rediscover the child. In this study parents demonstrate different ways of hoping such as hope for a cure, well-bine of the child and finally hope to see the child grow to become a whole person.

Qualitative research provides in-depth information on the experiencing of caring which may not be captured by questionnaires. This is particularly valuable in rare condition, where very little is known about the patient experience of living with a condition. Very few qualitative studies have explored the impact of caring for an individual with DMD in the caregiver’s own words, and none have specifically examined the impact of caring for an individual who is still ambulatory. Although seven studies identified in the systematic review of caregiver burden included interviews, only one used qualitative method and this was focused on the impact of being a sibling to an individual with DMD. A more recent qualitative study, not included in the systematic review, used serial qualitative interviews to examine the impact of caring for adult sons with DMD. This reported strengths and weaknesses associated with caring for the individual with DMD; strengths included family support and confidence in parenting ability, and weaknesses included the anticipation of ageing with the ongoing burden of caring, regrets, sharing responsibilities versus having a fixed role as a primary caregiver, and economic burden. To date, limited qualitative studies have been conducted on the life experiences of all the citizens involved in the home-based care of DMD patients. The objective of this research is to study the lived experience of hope among parents caring for a child with DMD in the specific context of psychosocial adaptation to chronic illness. In particular, the intention is to describe and to understand how hope emerges throughout the trajectory of the illness, considering the fatal outcome. In the study

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of Salzberg, D, Mann, J and McDermott, S. (2018) in their research Differences in Race and Ethnicity in Muscular Dystrophy Mortality for Males under 40 Years of Age, 2006-2015 concluded that the condition appears to be more common in white than in males of other races. In the Philippines, the condition is rare and in 2019, an estimate of only two hundred Filipinos suffer from the genetic disease and probably more cases are deemed to be undiagnosed. This study thereby explored the experiences and academic aspirations of American citizens living with home-based care of patients with Duchenne muscular dystrophy show the emergence of this condition and emphasize its existence not only the American citizens but to the Filipinos as well. The study provides positive coping and adaptation to the rare condition.

2 MATERIALS AND METHODS

The study used the descriptive phenomenology to bring out the meanings of the experiences of the participants. Moreover, purposeful sampling in the process of recruitment of the participants was utilized.

Population and Sampling

Twelve (12) participants were purposively invited; those with DMD patients all with home mechanical ventilated via tracheostomy) were recruited in Fox Lake, a village in Grant and Antioch townships in Lake County, Illinois and Burton Township, McHenry County, Illinois, United States. All the participants invited were able to speak fluently the English language, with DMD patients under their care for five years and more and were referred by medical facility team, relatives or friends. The qualitative research projected fifteen, but due to the challenge of location, the twelve American citizens qualified with the inclusive criteria and willing to participate, fortunately, data saturation was obtained.

Data Gathering Instrument and Procedure

The study made use of semi-structured interview using open-ended questions to obtain the much-needed responses of the participants. Prior to the actual interview via offshore, the author explained their rights to withdraw anytime if they wished to. Most interviews were made by telephone and face to face. Four interviews were done using telephone interviews, while only one interview was done using a video conferencing platform (skype).

Ethical Considerations

This study was reviewed and approved by the duly accredited Level 1 (Philippine Health Research Ethics Board -PHREB) of the Ethics Review Committee of the University of Northern Philippines, Tamag, Vigan City, Ilocos Sur. Ethical principles were observed in the study which include the conflict of interest, principle of informed consent, principle of privacy and confidentiality, principle of vulnerability, recruitment, benefits, compensation, and community considerations.

Statistical Tools/ Qualitative Data Analysis Tool

This study made use of the used MAXQDA qualitative data software to analyze the qualitative data. After the audio recordings were transcribed verbatim, the files were uploaded to the software. The transcripts were analyzed per participant. Coding was done through line-by-line examination of data while carefully ensuring that the main objective of the research was captured. The study made sure that the segments were reviewed and reflected to reveal the overarching patterns among the coded segments. Six themes actually became prominent, two were combined to make a total of four themes. Audit trail was kept to confirm accuracy of findings.

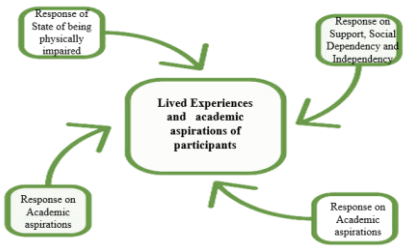
3 RESULTS AND DISCUSSION

Results

Twelve participants of ages 50-70 were the participants of this descriptive phenomenological research. Most of the participants were males, married, high school graduates, and employed. The major themes that emerged were: Theme 1: The State of being physically impaired; Theme 2: Social Dependency and Independency; Theme 3: The goal to pursue schooling, and Theme 4: Positive Outlook in life and dependable caregivers. The themes mirror the care and management scenarios enveloped within the lived experiences of the American citizens living with DMD patients. What is very commendable in this qualitative research is the academic aspirations of the participants for the DMD patients. Indeed, educational pursuit based on the results impacts everybody regardless of debilitative condition; no hindrance at all, just a challenge.

The research revolves as it could be shown in the figure below:

Thematic Concepts:



A. Theme 1: The State of being physically impaired

The main theme reflects the challenges of being physically impaired of the patient and being able to do something helpful to him. Participants recall the challenge of the debilitative condition of the DMD patients that rests in their care. Activity modification is a must to fit in to the management and care necessary.

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"I wish I could do more to his condition and I can feel limited social life due to the responsibilities attached to the care given, I need to adjust, no choice."
Participant 6 mentioned how challenging his experiences to caring to a family member with DMD.

"Yet, I do whatever I could not to let him feel physically impaired" I consider him a normal person like everybody else"

B. Theme 2: Support, social dependency and independency

This major theme relates to the well-established support from family, federal or state support which promoted better experiences associated in the care of DMD patients. Participants talked about the hardships of availing the support. Most reported pets as good support both to patients and to then, they play great roles. Participants verbalized "Mothers know best and play important roles in care; they know how to do things and can perform care where everything is right the first time and no explanations are necessary. Therefore, it is difficult for the participants to move away from home because their mothers' role as a helper is reduced. Furthermore, this transition has consequences for the career (the mother) who now needs to find a new job. "It is unpleasant and awkward. They know that they are impaired but they do not want to live that way: "It means a lot to me that I can live as normally as possible like many other people do".

C. Theme 3: Academic aspiration

The emerged major theme mirrors that they able were to experience ushering DMD patients like normal children attending academic activities. Challenging, as it could be but possible and fulfilling. For instance, participant 7 advised that in the care of DMD patients, life activities were a lot at encouraging, happy, fulfilling and close to normal with the execution of possible activities of normal daily living.

D. Theme 4: Positive outlook in life- you can do it, dependable caregiver

The main theme reflects that participant to some aspects want to be with DMD patients, experience all possible learning activities whether socially, travel and participate concerts and other recreational avenues; they have dreams and desires in life like everybody else. One participant reflected on this in the following way: "come to terms with your impairment, there is no cure, get the best out of life; seize the day". They felt that not being bitter or self-pitying was the reason why things went well in life for them. They just had to get started, get out, enjoy life and fulfil their dreams. others talked how they enjoyed bonding in spite of being totally abled with the patients. Most reported that dependable caregiver or nurse solved the puzzle of quality care and life spent to the fullest.

Discussion

This qualitative research unfolds the challenging experiences of the American citizens in the care of DMD patients. In spite of the enormous complications and demands of this unique scenario, offshore interview showed an encouraging disposition of the participants and with particular to the academic aspirations of the pAmerican citizens. Several studies were conducted already especially in the foreign lands on the lived experiences, yet this study proved to have a broader scope considering it highlighted the lived experiences of the persons in the care of the patient.

In the qualitative research on the lived experiences and academic aspirations of American citizens living with home-based care Duchenne muscular Dystrophy patients, the participants have expressed and emphasized the challenges abounding the care of a DMD patients. They reported various means to create a more meaningful experiences interrelated of all aspects is crucial in the care of DMD patients for the patient leading to a life spent to the fullest! (Theme 2: Support, social dependency and independency). The result is similar to the result of lived experiences of hope among parents of a child with DMD: perceiving the human being beyond the illness (Samson A, et al., 2009) wherein parents call to adapt or a way to rediscover the child.

Moreover, in the concept analysis on the possible learning activities in the care of a DMD patients, participants reported that a great deal of help in their experiences counts a lot with a dependable caregiver. (Theme 4: Positive outlook in life- you can do it, dependable caregiver). The result is closely related to the lived experiences of Jordanian parents having a child with Duchenne Muscular Dystrophy (Obeidat, HM, et al, 2021).

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4 CONCLUSIONS AND RECOMMENDATION

Apparently, the themes that emerged reveal that the American citizens go through varied experiences in the care of DMD patients. Nevertheless, they explore all possible means to create experiences as normal as possible and less challenging. Regardless of the difficulty of the situations, the participants tried to cope with these challenging experiences brought about in the care of DMD patients. The themes are closely related to the coping mechanism in the care of debilitative conditions like the DMD. The participants were able to adapt and cope to this financially, socially and physically demanding situation. It is very significant to note that in spite of these challenges, setting aside the academic aspirations of the patients was never an option. It is recommended for a similar study to be conducted in the Philippine setting. Though the disease condition is rare the Philippines, it is important to determine the life experiences of people in the care of the DMD patients. An assistance center must be created both foreign and offshore must be established to cater the concerns and challenges experienced of the citizens with a care of DMD patients. Results of the local study will doors to better understanding of a disease condition with limited data in the Philippines setting.

REFERENCES

Birnkrant, D. J., Bushby, K., Bann, C. M., Apkon, S. D., Blackwell, A., Brumbaugh, D., Case, L. E., Clemens, P. R., Hadjiyannakis, S., Pandya, S., Street, N., Tomezsko, J., Wagner, K. R., Ward, L. M., Weber, D. R., & DMD Care Considerations Working Group (2018). Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. The Lancet. *Neurology, 17*(3), 251–267.

Björk, M., Wiebe, T., & Hallström, I. (2005). Striving to survive: Families' lived experiences when a child is diagnosed with cancer. *Journal of pediatric oncology nursing, 22*(5), 265-275

Bonilla, E., Samitt, C. E., Miranda, A. F., Hays, A. P., Salviati, G., DiMauro, S., ... & Rowland, L. P. (1988). Duchenne muscular dystrophy: deficiency of dystrophin at the muscle cell surface. *Cell, 54*(4), 447-452.

Boyles, C. M., Bailey, P. H., & Mossey, S. (2008). Representations of disability in nursing and healthcare literature: an integrative review. *Journal of Advanced Nursing, 62*(4), 428-437.

Brown, S. E. (2000). From oppression to integration: comments on Patrick J. Devlieger's' From handicap to disability: language use and meaning in the United States'. *Disability and Rehabilitation, 22*(11), 522-525.

Chang, K. H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of advanced nursing, 53*(4), 435-443.

Cloete, L. G., & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with autism spectrum disorder in Kenya. *African journal of disability, 8*, 435.

Denzin, N. and Lincoln, Y. (2008). The SAGE handbook of qualitative research. Sage Publications. 10.1111/j.1365-2648.2001.0472a.x. crossref

Eagle, M., Baudouin, S. V., Chandler, C., Giddings, D. R., Bullock, R., & Bushby, K. (2002). Survival in Duchenne muscular dystrophy: improvements in life expectancy since 1967 and the impact of home nocturnal ventilation. *Neuromuscular disorders : NMD, 12*(10), 926–929.

Gagliardi, B. A. (1991). The family's experience of living with a child with Duchenne muscular dystrophy. *Applied nursing research : ANR, 4*(4), 159–164.

Hilton, T., Orr, R. D., Perkin, R. M., & Ashwal, S. (1993). End of life care in Duchenne muscular dystrophy. *Pediatric neurology, 9*(3), 165–177.

Kohler, M., Clarenbach, C. F., Bahler, C., Brack, T., Russi, E. W., & Bloch, K. E. (2009). Disability and survival in Duchenne muscular dystrophy. *Journal of neurology, neurosurgery, and psychiatry, 80*(3), 320–325.

Levine, H., Prais, D., Aharoni, S., Nevo, Y., Katz, J., Rahmani, E., Goldberg, L., & Scheuerman, O. (2021). COVID-19 in advanced Duchenne/Becker muscular dystrophy patients. *Neuromuscular disorders : NMD, 31*(7), 607–611.

Obeidat, H. M., Al Hadid, L. A., Al-Sagarat, A. Y., & Khrisat, M. (2021). Lived Experience of Jordanian Parents Having a Child with Duchenne Muscular Dystrophy. *Journal of pediatric nursing, 57*, 5–10.

Pehler, S. R., & Craft-Rosenberg, M. (2009). Longing: the lived experience of spirituality in adolescents with Duchenne muscular dystrophy. *Journal of pediatric nursing, 24*(6), 481–494.

Salzberg, D. C., Mann, J. R., & McDermott, S. (2018). Differences in Race and Ethnicity in Muscular Dystrophy Mortality Rates for Males under 40 Years of Age, 2006-2015. *Neuroepidemiology, 50*(3-4), 201–206.

Samson, A., Tomiak, E., Dimillo, J., Lavigne, R., Miles, S., Choquette, M., Chakraborty, P., & Jacob, P. (2009). The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness. *Chronic illness, 5*(2), 103–114.

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