Case Report
Analyzes of Life World of a Young Girl With Myasthenia Gravis: Qualitative Case Study

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ABSTRACT

Background and Aim: Myasthenia Gravis (MG) is a neuromuscular disorder and auto-immune disease that is associated with symptoms of fluctuating muscle fatigue and dysfunction of the neuromuscular junction system. This disease greatly affects various aspects of the patient's life and impacts the person's perception of the quality of life. The aim of this study was to explain and analyze life experiences with myasthenia gravis disease in a young girl.

Methods & Materials: This report is a qualitative case with interpretive phenomenological approach that examines the life experiences of a young girl with myasthenia gravis in 2019. Data were collected through semi-structured interviews and analyzed using Van Manen's phenomenological approach.

Ethical Considerations: This study was registered in the Research Ethics Committee of Khatam University (Code: 3299/100/P/98).

Results: Thematic analysis indicated that myasthenia gravis disease affects all aspects of person's life world. These four aspects include living and feelings with time, body, space, and others. Eventually, three interrelated themes emerged from the patient's perception of the world around her, including physical weakness, future ambiguity, and frustration.

Conclusion: The present study shows a clear image and understanding of the problems of living with MG in a young girl. The phenomenological world of mixed by physical weakness, ambiguity in the future, and frustration that indicating the suffering and distress that the patient experiences following the illness. The results of this study contribute to the awareness of health and rehabilitation specialists in the field of work and research in myasthenia gravis as a neurological disease.

Key words: Myasthenia gravis, Lived experience, Case report, Qualitative research

Extended Abstract

1. Introduction

Myasthenia Gravis-MG is a neuromuscular autoimmune disease that is associated with symptoms of fatigue and dysfunction of the neuromuscular system. This disease widely affects various aspects of the patient's life and affects a person's perception of the quality of life around him/her [1, 2]. Keer-Keer study concluded that people with this disease live a life of uncertainty, weakness, and a life of change [12]. Awareness and profound understanding of the lifeworld experienced by MG patients, especially the living experiences of Iranian patients in the context and cultural and socio-economic conditions of Iranian society is impor-
tant. Based on their physical condition, these patients see moment-by-moment changes in their lives. In this study, a 27-year-old girl narrates her lifeworld experience from the world around her. The aim of this study was to explain and analyze life experiences with myasthenia gravis in a young girl.

2. Materials and Methods

This is a qualitative study that was conducted with a hermeneutic phenomenological approach. This approach was introduced by Van Manen in 1990. The purpose of this method is to be aware and understand the interpretation that a person has of the phenomena surrounding his life experience [15].

In-depth, semi-structured and interactive (face-to-face) interviews were used to collect research data. The interview began with a question: "What comes to your mind when I say Myasthenia Gravis?" And then to continue and enrich the interview, exploratory questions were asked. For example: "How did you feel when you got this disease? Can you explain me with more examples?"

Attempts were made to cover all aspects of the lifeworld of the interviewee. The interview time was 68 minutes. The researcher then, after reading the text several times, isolated the meaningful phrases and units that he believed they described and interpreted the phenomenon in question. For this study, a participant with 8 years of experience with myasthenia gravis was selected. Van Manen's method of analysis for interpretive phenomenology based on the understanding of one's lifeworld is based on the revelation of four themes that represent the "existence and existential nature" of the individual and deals with the emergence of the world around him/her or his/her lifeworld. These four aspects include: Living with time, living with the body or corpus, living with the surrounding space, and finally living with others [15]. In order to observe ethical considerations, written informed consent was obtained to record the audio for the interview and the necessary arrangements were made to attend the interview session.

3. Case Report

The patient was a 27-year-old single woman with a bachelor's degree and unemployed. According to her, when she was not more than 19 years old, she developed symptoms of the disease. These symptoms included vision problems, lethargy, fatigue and ingestion problem. After the onset of symptoms, she went to different doctors in her hometown, but the disease was not diagnosed. After traveling to Tehran and performing various tests, she was diagnosed with the disease. The final diagnosis took about a year and a half. According to the patient, her illness had no genetic history, but her parents were cousins. Before the onset of the disease, the patient lived with her family in a village, who, after the disease was diagnosed, moved to the provincial capital to have access to better facilities. The economic problems of the family were many. Although the patient had a bachelor's degree, wherever she went to work, she was not hired because of her illness. This patient was not covered by any insurance and was only registered with the Welfare Organization and received a grant of a little over 1000,000 Rials per month. The cost of treatment and medicine was very high. Due to the fact that myasthenia gravis is an autoimmune disease, her motor symptoms and physical disability increased and she was no longer able to walk. The patient was single and could not marry because of her problem. According to her, before her illness got worse, she had two suitors who gave up knowing about her illness. Although the disease began at the age of 19, she continued her education before her physical condition worsened, but after her disease got worse, she was no longer able to study and could not go to postgraduate courses. Her Menarche age was 13 and she had no problems. She did not report any delay in his period. She considered herself psychologically hopeless and depressed and believed that she saw no reason to live with this situation.

4. Results

Content analysis revealed that MG had affected all aspects of the patient's lifeworld. To fully understand and be aware of what has affected one's life experience in the world, it is necessary to address these dimensions. The patient's feelings and experiences of time, body, space and others are described below.

Living with time: Past, present and future

The patient was asked to share her experience of the past, present and future of this phenomenon. "The first time I noticed the symptoms was with my eye problems. At first, I thought it was temporary, but over time, fatigue and other problems were added".

Living with the body: Physical and psychological effects of the disease

The disease is associated with severe physical problems and generally affects “living with the body” and “awareness of the body”. “I have a hard time; I cannot swallow food well. I cannot walk. I like to walk but my legs are disabled. My vision is impaired and even my sleep is difficult. I am constantly asleep. Because I am very weak”.

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Living with space: Restrictive, enhanced movement and home space

Patients with MG experience a restrictive living space, both psychologically and physically. "I can do nothing, not even my own work. Outside the house, I am very annoyed with these conditions, I also upset others. It is as if I am in another world".

Living with others: Interacting with family, friends and treatment staff

Communication and interaction with the family is very important in any part of the changes in this disease. "My family is very supportive. They even changed their place of residence because of me to have more medical and specialized facilities. My father works very hard".

I am very ashamed that I am causing trouble for my father in these constantly bad economic conditions. I mean expenses. Sometimes I do not take my medicine for a week so that my father can pay less for my medicine".

5. Conclusion

The present study showed a clear picture and understanding of life problems with this disease in a young girl. A phenomenal world mixed with physical weakness, ambiguity in the future, and despair that reflects the suffering and discomfort that the patient experiences as a result of the disease.

This result is consistent with the results of Keer-Keer research. Keer-Keer revealed that patients with MG are tired and frustrated by the unpredictable changes that are constantly occurring due to the disease condition [12]. Chen et al. showed in their research that people with MG are in a constant challenge with the disease, which in itself makes it difficult for them to adapt to changing conditions and ultimately frustrates them [14]. EC WJ et al. showed in their research that coping strategies with stress have a significant positive relationship with the quality of life of these patients. That is, if there is hope, social support for these patients will have a positive effect on improving their quality of life [21].

Physical weakness was another theme extracted from this patient's lifeworld. This weakness increased her problems with the world around her at every moment and limited her in terms of movement, space and independence. The quality of life of MG patients depends a lot on decreased physical weakness and other physical problems [22].

Ambiguity in the future in the phenomenological world of the patient was one of the themes. In this regard, the study of Kotan et al. revealed that worries about the future of the disease and ambiguity in life plans lead to a decrease in the quality of life of these patients [24]. The results of this study contribute to the knowledge of medical and rehabilitation specialists in the field of work and research in myasthenia gravis neurological disease.

Ethical Considerations

Compliance with ethical guidelines

This study was registered in the Research Ethics Committee of Khatam University (Code: No. 3299/100/P/98).

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Authors' contributions

Conceptualization, validation methodology, case analysis and writing article: Anahita Khodabakhshi-Koolaee; Research and interview: Mohammad Poor-Ebrahimi.

Conflicts of interest

The authors declared no conflict of interest.
واگاوی تجربه زیست جهان دختری جوان با بیماری میاستنی گراویس: گزارش مورد کیفی
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مقدمه
یک بیماری خودایمنی عصبی عضلانی است که با علائم خستگی و کرجکارکردی سیستم عصبی مشخص می‌شود. می‌توان نشان داد که می‌توان از جهان دختری جوان با بیماری میاستنی گراویس در کمیته اخلاق پژوهشی دانشگاه خاتم با کد مصوب پژوهشی شماره ۱۳۹۸/۱۰۰/۳۲۹۹ این مطالعه در کمیته اخلاق پژوهشی دانشگاه خاتم با کد مصوب پژوهشی شماره

بحث
بیشترین تأثیر آن بر ماهیچه‌های چشم، حرکات پلک، کار، بیداری در حالات شروع با قرارگیری، صبح، ابتلا به ناراحتی این بیماری را خستگی و کرجکارکردی سیستم عصبی می‌سازد. این بیماری به‌طور همزمان با مشکلات عضلانی و روانی می‌باشد. این بیماری با علائم آسیب‌شناسی روانی همراه است که در بیانیه‌های اولین مراحل بیماری می‌تواند به دنبال ایجاد مشکلات عضلانی و روانی در بیماری می‌باشد.

نتیجه‌گیری
نتایج این مطالعه به آگاهی متخصصان درمانی و توان بخشی در زمینه کار و پژوهش در بیماری نورولوژیکی می‌باشد. گزارش کیفی مورد پژوهش کیفی

کلیدواژه‌ها
میاستنی گراویس، تجربه زیسته، گزارش مورد، پژوهش کیفی

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مراجع
۱. Myasthenia Gravis(MG)
تجلیل شیوع بیماری میاستنی گراویس در زنان بیماران گروهی منطقه‌ای نتایجی را در مطالعات پیش‌بینی کرد. عوامل مرتبط با این بیماری از جمله گستره‌ای از نکات مهمی در زندگی بیماران به عنوان مثال از عوامل مصرف و رفتار حیاتی، عوامل مربوط به بیماری‌های دیگر، عوامل اجتماعی و ورزشی، عوامل مربوط به بیماری‌های پیرامونی، و عوامل مربوط به بیماری‌های وابسته به بیماری میاستنی گراویس می‌باشد.

به‌طور کلی، این مقاله به منظور بررسی تاثیر عوامل مختلف در افزایش شیوع بیماری میاستنی گراویس در زنان بیماران به‌عنوان یکی از بیماری‌های خاص و مهمی که می‌تواند به‌طور تاثیرگذاری در زندگی بیماران اثر بگذارد، مورد بررسی قرار گرفته است.
نگاهی به مورد

در جلسه مصاحبه انجام شد و در مدت حدود نام های شرکت کننده و آزمایش، و با توجه به کار، اثرات از هر مرحله پژوهش در تماس مراحل پژوهش را به خود در نمی گرفته.

پمیران خانم

یکی از شرکت کننده در روند مصاحبه، با نام پمیران خانم، به همراه جمعیتی از کارکنان، در جلسه مصاحبه شرکت کرد. پمیران خانم، با میزان تجربه‌اش، در جلسه مصاحبه، به عنوان یکی از شرکت کننده توانسته بود.


golzarsh_moharam

در کل، نتایج مصاحبه شروده (Member Check) نشان داد که هدف پژوهش کسب اطلاعات در مورد مشاهده‌ها و تعاملات شرکت کننده، در حال حاضر، بسیار کم است. با توجه به نتایج، شرکت کننده، در محیط‌های‌یکسان، نیازمند به بررسی و تربیت بخشی به طور محکم می باشند.

5. Credibility
6. Transferability
7. Dependability
8. Conformability
ژیست یا زمان: گذشته، حال و آینده

از پیمایش خواص به شک تجربه خود را از زمان گذشته، حال و آینده در مورد پدیده بیان کنند. پرورش‌داری که مربوط عاملین شدید با مشکلات چنین پدیده فکر می‌کرد. مواردی است، اما بطور خاص و شکیکی مشکلات ذهنی به دلیل عدم داشتن که‌آن مصرفی از معنی واقعی زندگی محسوب می‌نماید، از دیدگاه سالم یا مشکل‌های دیگری می‌باشد. پرورشی که آن مصرفی از معنی واقعی زندگی محسوب می‌نماید، از دیدگاه سالم یا مشکل‌های دیگری می‌باشد.

به طور کلی، با پرورشی تمام ازبک و چهارگاهه زیست زمان بیمار

به طور کلی، با پرورشی تمام ازبک و چهارگاهه زیست زمان بیمار

به طور کلی، با پرورشی تمام ازبک و چهارگاهه زیست زمان بیمار
می‌توان گفت که تجربه بیمار از زندگی یکی از اصلی‌ترین کلیدها در بهبود کیفیت زندگی و بهبود محنی بیمار بوده است. در این مطالعه، متخصصین در مورد تجربه زندگی دختری جوان با بیماری می‌استنی گراویس به‌خاطر کاهش وابستگی به محیط جسمانی و روان‌شناختی، فناوری و اجتماعی، ارتباط با کارکنان بیمارستان، ارتباط با دیگر بیماران و سایر فیزیکی‌ها، تغییرات جسمانی و روان‌شناختی، و مداخله‌های روان‌پزشکی و مدیریت‌های ویژه در بیمارستان در آن را بررسی کردند.

نتایج اخلاقی

منابع: [1-23]
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تکرار متغیر

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آناهیتا خدابخشی کولایی و محمد پورابراهیمی. واکاوی تجربه زیست جهان دختری جوان با بیماری جیوپاتی میاستنیگراویس: گزارش مورد کلینیکی.
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