

Self-Management experiences in Guillain Barre syndrome patients: a phenomenological study

Experiencias de autogestión en pacientes con síndrome de Guillain Barre: un estudio fenomenológico

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Abstract

Introduction: Guillain-Barre Syndrome (GBS) leads to physical and psychosocial impairments. These patients have to manage their difficult situations.

Materials and Methods: This study aimed to describe and interpret the meaning of self-management while living with GBS. In this hermeneutic phenomenological study, eleven patients with GBS were recruited. Data were collected by semi-structure interviews. The thematic analysis was used.

Results: The five themes emerging from this study are as follows: "Recognition of GBS, using coping strategies, being hopeful, relationship with God and received, and perceived social support". The participants looked for and found information concerning the nature of their illness. They used coping strategies such as denial, striving to get back to normal life, and trying to achieve greater emotional balance". They were optimistic for their health would return to normal, and they had hopes for future.

Conclusion: The participants used trust in God, praying, accepting their fate, and pleased with God to manage GBS. The patients were received and perceived instrumental, and emotional and financial support from their family members to manage their illness. By being aware of the essence of self-management in living with GBS, health-care professionals are suggested to conduct interventions regarding this theme to improve self-management in GBS patients.

Keywords: Guillain-Barre Syndrome, Self-Management, Qualitative Research, Hermeneutics.

Resumen

Introducción: el síndrome de Guillain-Barré (SGB) conduce a discapacidades físicas y psicosociales. Estos pacientes tienen que manejar sus situaciones difíciles.

Materiales y métodos: Este estudio tuvo como objetivo describir e interpretar el significado de la autogestión mientras se vive con GBS. En este estudio fenomenológico hermenéutico, se reclutaron once pacientes con GBS. Los datos fueron recolectados por entrevistas semiestructuradas. Se utilizó el análisis temático.

Resultados: Los cinco temas que emergen de este estudio son los siguientes: "Reconocimiento de GBS, uso de estrategias de afrontamiento, esperanza, relación con Dios y el apoyo social percibido y recibido". Los participantes buscaron y encontraron información sobre la naturaleza de su enfermedad. Utilizaron estrategias de afrontamiento como la negación, esforzarse por volver a la vida normal y tratar de lograr un mayor equilibrio emocional". Eran optimistas para que su salud volviera a la normalidad, y tenían esperanzas para el futuro.

Conclusión: Los participantes usaron la confianza en Dios, oraron, aceptaron su destino y se complacieron con Dios para administrar el SGB. Los pacientes fueron recibidos y percibidos como apoyo instrumental y emocional y financiero de sus familiares para controlar su enfermedad. Al ser conscientes de la esencia del autocontrol para vivir con GBS, se sugiere a los profesionales de la salud que realicen intervenciones relacionadas con este tema para mejorar el autocontrol en pacientes con GBS.

Palabras clave: Síndrome de Guillain-Barré, autogestión, investigación cualitativa, hermenéutica.

Guillain-Barre Syndrome (GBS) as the most common cause of acute paralytic neuropathy¹ is a rare and life-threatening polyradiculoneuropathy². GBS is classified in to acute inflammatory demyelinating polyneuropathy, acute motor axonal neuropathy, and acute motor and sensory axonal neuropathy³.

This acute paralytic neuropathy leads to paresthesia and movement impairment in the arms and legs⁴. Approximately one third of GBS patients have poor functional outcome at 1 and 3 years after the illness onset⁵. These patients experience lower physical function and general health compared to healthy controls⁶. Also, walking limitation can be observed in GBS patients. Reduction in walking ability leads to disability at 1-2 years of age, which can be continued for 10 years. Paresthesia is also reported in 60% of patients after 1 year⁵. Therefore, approximately one third of the patients require prolonged mechanical ventilation⁷.

These physical limitations lead to impairment in psychosocial health status of the patients with GBS⁸. They are full of stress, and the most stressful things in their life are fear of remaining paralyzed and uncertainty regarding the process of illness and fear of intubation⁹.

Due to the chronic characteristic of GBS and the impact of the illness on physical and psychosocial aspects of their life, it is important to evaluate the self-management phenomena in patients with GBS. In the literature review, no qualitative study has evaluated these phenomena in patients with GBS. This shows that this concept is unclear and unknown. Therefore, the question: "What is the meaning of self-management in living with GBS?" needs to be clarified. As the experience of each patient is unique, to clarify the meaning of self-management in living with GBS has to be investigated via qualitative approach. Among qualitative approaches a hermeneutic phenomenological approach can be useful to describe and interpret the meaning of self-management in living with GBS¹⁰.

In the literature review, only in 1 qualitative study by Forsberg et al., 2015, described the disability experience of these patients and its management process, two years after being afflicted with the illness were evaluated. It was reported that GBS patients lived with body movement restrictions. They balanced their life through support, reappraisal of their new situation and hope. They received support from healthcare workers. In order for reappraisal of new life condition, they believed that life would return to the same as before illness, they try to accept the changes and they believed life can change quickly. Moreover, they were waiting to recover and were being hopeful¹¹. Al-

though the mentioned study describes the management of GBS, the description and interpretation of self-management meaning in these patients using hermeneutic phenomenological approach would be more helpful. Using this approach, the essence of self-management in living with GBS can emerge. Therefore, this study aimed to describe and interpret the meaning of self-management in patients living with GBS.

This was a qualitative study using a hermeneutic phenomenological approach. This study was conducted in neurology clinics in Motahari, Emam Reza, and Aliasghar Hospital affiliated with Shiraz University of Medical Sciences (SUMS). Data were collected from July 2018 to June 2019. Eleven patients with GBS participated in this study. The inclusion criteria of this study were age 18-60 years, GBS diagnosed by a neurologist, spoke Persian, had ability to communicate and explain thought and feeling, and willingness to explain their experiences. Subjects who had the other chronic neurological diseases in addition to GBS were excluded from the study.

The GBS patients were selected through purposeful sampling. Semi-structured interviews were used to describe and interpret self-management experiences in patients with GBS. The participants were asked to explain "What are your self-management experiences in living with GBS?" and "What is the meaning of self-management in GBS?" The length of an interview ranged from 30 to 70 minutes. The interviews were recorded via a digital recorder and then transcribed to conduct data analysis.

The thematic analysis based was on phenomenological approach suggested by Max van Manen^{12,13}. The essences and meaning of self-management phenomenon were determine though Max van Manen approach using holistic, selective and line-by-line reading of the transcripts^{10,14}. In the holistic reading, the fundamental meaning of the text was written. In the selective reading, the transcript was searched to determine statement (s) or phrase (s) which were the meaning, and essence of self-management in GBS patients. In line-by-line approach, each sentence was read and the meaning units of this phenomenon were extracted.

Data collection and analysis were continued until data saturation.

This study was approved by the local Ethics Committee of SUMS (IR.SUMS.REC.1397.158). Informed consent was signed by all patients with GBS. They were informed about the process of the study including the aim and scope, the digital audio-taping of the interview, the benefit and risk, the confidentiality and anonymity of their information.

To increase the study validity, the phenomenological themes and insights were appropriate and original. The findings reflected the GBS patients' voices, the meaning and essence of self-management in these patients. Purposeful sampling was used to explore information. The patients were knowledgeable and experienced in self-management of GBS. The author who collected the data has spent more than 10 years in neurology wards and was aware of the participants' language, and had a good relationship and rapport with the healthcare teams as well as the participants. Data were collected during one year; therefore, prolonged engagement had occurred during this period of time. The patients with GBS reviewed the interpretive notes and themes were summaries and approved by them. Two phenomenologists approved the study process. Moreover, the authors tried to describe data to implicate data to other contexts and increase the reliability of the study¹⁰.

Results

The five themes emerging from this study are as follows:

Recognizing GBS

Using coping strategies

Being hopeful

Relationship with God

Received and perceived social support

Recognition of GBS

Recognition of GBS in the lived experiences of patients with GBS meant "looking to find out more about their illness, obtaining information concerning the nature of GBS, being knowledgeable regarding the factors that increase the syndrome' symptoms.

The patients searched in the Internet or asked the healthcare team about the signs and symptoms, etiologies, treatments, and rehabilitation interventions of GBS. In this respects, participant 3 stated:

I searched on the Internet. I found that it causes my arms and legs to have tingling sensation and muscles weakness. You will feel numbness in your legs or arms. You cannot go up 10 stairs. A CT scan and a laboratory tests will show that you have this disease.

The patients realized the nature of the disease, which is chronic. In addition, they are well aware that it is a sudden, shocking disease with terrifying progress that is accompanied by sudden weakness, loss of sensory sensation, paralysis, painful, loss of energy and restriction in physical functions, standing and walking for a long time.

Participant 11 stated:

The symptoms start suddenly. My fingers become numb. All part of my hands were numb at first. One day, when I woke up, I felt that my eyes and mouth were numb, which took a week. Then, the pain began. Slowly, my muscles didn't have sensory sense and I couldn't walk. I was completely paralyzed. My arms and legs did not move anymore.

The patients believed that workplace stress and pressure, lifelong stress and shock were probably responsible for the etiology of the disease. Participant 4 stated:

I was under lots of stress before this disease. I know I got this disease because of the stress. Before the disease, I had a lot of stress at workplace.

Using coping strategies

The subjects used coping strategies such as denial, comparing their illness with other illnesses, not disclosure of the disease, striving to get back to normal and active life, trying to achieve greater mental and emotional balance by coping with the situation and try to appreciate healthcare workers.

Some of the patients did not believe that they had GBS in the early stages, even after years of diagnosis. They described the nature of the disease as incredible. Moreover, the patients compared themselves to other patients with other diseases, and some saw themselves as normal people, and did not reveal their illness to others, and the others considered themselves as incompetent because of their inability to perform daily living activities such as mobility, bathing, going to toilet, dressing, feeding, transferring, cooking, cleaning the house, doing laundry, shopping, and etc. Participant 7 compared his illness with others and stated:

Guillain Barre Syndrome affect my mood. There was a teacher who had this illness, and when I asked about him, I was told that he was dead. We are worse than thalassemia patients. Because, we can't go to WC alone. We cannot do anything alone. You know, I've been fantasizing to walk for the past 4 years.

In spite of these limitations, the patients strive to perform their daily activities through physiotherapy and occupational therapy. The patients who were unable to move also tried to manage their work by cell phone. In addition, in order to achieve greater mental and emotional balance, the participants used positive thinking and psychological counselling. They also used the problem-solving skills to cope with their situation. Furthermore, they appreciated and were satisfied with the healthcare workers such as physician, nurse, physiotherapist and occupational therapist. Participant 11 stated:

I have a private occupational therapist at home. He gives me exercise in the pool. I do water sports at home. I want to walk faster. You know, to keep my thoughts from becoming negative, I exercise in water on a regular basis

and have positive thoughts. . . I read books. I try to help my wife as much as I can. Instead of getting out of the house to do my work, I use my cell phone. . . In order to solve my own and others' problems, I communicate with my colleagues and neighbors. I talk to them in order to keep me busy.

Being hopeful

Participants self-managed their GBS, using hope. They hoped that their health would return and that the disease' limitations would be lifted so that they could perform their daily living activities. In addition, they had hopes for the future and hoping to get back to their job. Participant 2 mentioned:

Since my arms started to move, I can eat alone and I don't need anyone to put a spoon in my mouth. That has made me hopeful. I am hopeful that my feet will move so I can walk and go to the toilet myself. . . I hope that the course of the illness will be over soon through exercising, I will recover sooner and regain my health. I have hope for the future, I am 100% hopeful. . . I give myself hope. I live with hope. Because I know if my mood improves, it will affect my immune system. I hope that others and I with Guillain Barre illness become well in the future. I give myself a lot of hope that I will get well soon.

Relationship with God

Self-management in GBS meant having relationship with God. The participants used trust in God, praying, accepting fate, illness as punishment from God, ask forgiveness from God, thanking God, and being pleased with God to manage their GBS.

The participants asked God for help at the times of pain and limitations of GBS such as paralysis, weakness, fatigue, and inability to perform daily activities. They recited the Quran and "daily prayer (Namaz)" and asked God that their symptoms would not get worsen. The patients prayed to be healed. They visited Imam Hussein (A.S) and Imam Reza (A.S) shrine and asked them to be the medium between them and God. The participants believed that the disease was from God. Some of them also thought that the disease is as punishing for their bad deeds. Therefore, they prayed to God to forgive them. They were thankful to God and were satisfied with God's will. Participant 8 stated:

I seek God's help. I ask God to help me heal my back and legs. Sometimes, when I have severe pain, I seek refuge in God. I look at God. . . I talk to God so much. I listening to Quran recitation. I pray Namaz. I pray to God that all the patients will be healed. I pray that I can rise above this divine test. I ask Imam Hussein to mediate between me and God.

Participant 2 about being fined and punished by God stated:

I talk to God and I say to God, as far as I know, I never bothered anyone that to say I maybe I am recompensing for bad things! I don't know if I'm being punished or

fined! I asked myself if I cash so much money that I'm being punished! No, never, my God, I never did a bad thing.

Received and perceived social support

The patients received and perceived social support to self-manage their disease. They needed their spouses, children, and relatives to perform their daily activities. In other words, the patients received and perceived tangible support. In addition, family, friends, and relatives visited the patients or called them. They were compassionate and affectionate toward the patients. In other words, emotional support was given to the patients.

Participant 1 received and perceived social support stated: My mom and my sister help me financially. Every day, either my brother or my wife take me to one place or another. They give me a bath. They take me to the toilet. They put food in my mouth. You know, they understand my situation and try to do all my affairs . . . My relatives come to my house. Everyone loves me. I am happy too. I understand these support. They talk to me. My relatives, my cousins (my aunt's daughter, and uncle's son) call and give me emotional support.

Discussion

Recognition of GBS was one of the theme of this study. In order to manage this illness, the participants strived to achieve some information about the nature of the illness. In a qualitative study, it was reported that patients seek more knowledge regarding their illness¹⁵. In our study, the participants perceived it as a disease with a sudden weakness, loss of sensory sensation, paralysis, pain, loss of energy and restriction in physical functions, standing and walking for prolong times. Patients with GBS reported fatigue, pain, and muscle weakness as the most common symptoms¹⁶. In a study aimed to describe experiences of disability and the management of disease in GBS patients, one of the themes emerged from them was "lived body restrictions". It was shown that these patients experience weakness and sensory sensation in their body, pain and loss of energy that limited their everyday activities for a long time¹¹. It was revealed that more than half of GBS patients had limitation in walking. They experienced sensory disturbance, loss of power in lower and upper extremities¹⁷, paralysis, disability^{4,5}, fatigue, and musculoskeletal¹⁵ pain. It was also reported that they had lower quality of life in comparison to general population⁴. Therefore, Consequently, GBS patients by recognition of their illness and symptoms, try to manage it.

In this study, using coping strategies such as denial, comparing their illness with other illnesses, not disclosure of the disease, striving to get back to normal and active life, trying to achieve greater mental and emotional balance,

and coping with the situation, and healthcare workers' appreciation was the strategies applied to manage the illness. Consistently, in a qualitative study, GBS patients attempted to increase their control and independency¹⁵. Similarly, it was reported "reappraisal of the new life situation, life had returned to the same as before, and acceptance of change" were used by these patients to manage the recovery process of illness¹¹.

The participants self-managed their illness using hope. They hoped that their health would return and that the disease' limitations would be lifted so that they could perform their daily living activities. In addition, they were hoping for the future and had hope to return to their job.

Consistent with this result, Forsberg et al. reported that GBS patients use hope and wait for recovery¹¹. It was reported that only 20% of these patients were hopeless¹⁸. In a qualitative study, GBS patients revealed that they use a positive attitude to maneuver emotional challenges of this illness. They hope that tomorrow would be a better day. Talking with their peers also led to participant becoming hopeful towards future¹⁵.

In this study, self-management in GBS meant having a relationship with God. The participants trust in God, prayed, accepted the fate, believed illness as a punishment from God, asked for forgiveness, thanked God, and asked God to manage their illness. This was a new theme in self-management of GBS. In a study on GBS, one of the participants reported that "I have faith in God. I think that faith helps"¹⁹. In fact, some patients used cognitive and spiritual strategies for pain management²⁰. In addition, in other qualitative studies on chronic diseases such as hemophilia and rheumatoid arthritis, the participants mentioned spirituality as a way to manage their disease^{21,22}. It was reported that rheumatoid arthritis patients believed to empowerment of relationship with God, and God would always be with them. Moreover, the support of God helped patients to adjust to their disease²². It was also indicated that spirituality had an important role in living condition of patients with a chronic disease called hemophilia. They perceived spirituality as "relationship with God, God as their supporter, strong religious beliefs, and spiritual satisfaction"²¹. Similarly, in this study, the participants asked God for help, prayed for oneself and others. They had hope in God, and trusted God. Moreover, patients similar to this study, accepted their fate²¹.

The patients revealed social support in their management of disease. Social support was provided by family, relatives and friends to perform daily activities. In other words, the patients received and perceived the tangible support, instrumental, psychological support from others. Similarly, patients with GBS in Sweden perceived the social support from their family and friends to be invaluable¹¹.

In this study, the essence of "self-management in living with GBS" emerged. Giving information regarding illness is crucial for patients in order to manage it. Moreover, im-

proving spirituality and hope are recommended, for patients to manage their illness. In addition, social support has an important role in living with GBS. Therefore, family members should provide social support for the patients to manage their difficult situation.

Conclusions

This study indicated that self-management of living with GBS meant recognition of GBS, using coping strategies, being hopeful, relationship with God and received and perceived social support. Thus, healthcare providers and family member of patients with GBS are suggested to gain and obtain some information regarding the illness, so that they can help them to use positive coping strategies, create a hopeful life, provide social support, and by building a better relationship with God.

Highlights: Self-management in living with Guillain-Barre Syndrome meant recognition of illness, using coping strategies, being hopeful, relationship with God and received and perceived social support.

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