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Høgskulen
på Vestlandet

Nursing Care to Patients with Guillain- Barré Syndrome

Sykepleie til Pasienter med Guillain- Barré Syndrom

Candidate Number: 312

Bachelor i Sykepleie

Høgskolen på Vestlandet/ Campus Haugesund

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Abstract

Title: Nursing care to patients with Guillain- Barré Syndrome.

Background: Guillain-Barré Syndrome (GBS) is a rare disease that attacks the peripheral nervous system. It has an autoimmune nature in which affected patients' presents a preceding acute viral or bacterial illness. GBS normally starts with a motor weakness that can lead to a total paralysis. The diseases can produce significant mortality and morbidity therefore giving care to this patient group is complex and challenges the healthcare team particularly the nurses.

Purpose: The purpose of this study is to enhance knowledge when it comes to how nurses through patient-centred care may contribute to coping of GBS patients.

Problem: How can person-centred nursing care help patients with Guillain- Barré Syndrome cope?

Method: Literature study was utilized to be able to answer the thesis problem. I used CINAHL, Medline Ovid, Svemed+, Pubmed and manual searches has also been carried out through the use of Google Scholar and the HVL library's database. In the end, I came up with 6 qualitative studies which were used.

Result: The result from the included articles related to coping of patients with GBS through the use of person-centred nursing care were presented in 6 themes: individualized plan of care, knowledge of GBS from the healthcare worker, communication & information, recognizing patients' emotions and approach to facilitating hope, support from peer groups, family, friends, healthcare team, dignity and coordination of care.

Conclusion: For nurses to be able to contribute to coping of GBS patients with the use of person-centred care nursing, it is important to learn about the disease, develop excellent communication skills, respect patients beliefs, collaborate care and individualize the patient care plan. Nurses should also help patients find good coping strategies, social support and promote hope and positive attitude. A need for further research on caring for this patient group is also suggested.

Sammendrag

Tittel: Omsorg hos pasienter med Guillain- Barré Syndrome.

Bakgrunn: Guillain-Barré syndrom (GBS) er en sjelden sykdom som angriper det perifere nervesystemet. Den har en autoimmun natur der berørte pasienter har en tidligere akutt virus- eller bakteriell sykdom. GBS starter normalt med en motorisk svakhet som kan føre til total lammelse. Sykdommene kan føre til dødelighet og sykelighet, og derfor er det komplekst å gi denne pasientgruppen omsorg og utfordrer helseteamet, sykepleierne spesielt.

Hensikt: Hensikten med denne studien er å øke kunnskapen når det gjelder hvordan sykepleiere gjennom pasientsentrert omsorg kan bidra til mestring av GBS pasienter.

Problemstilling: Hvordan kan personsentrert sykepleie hjelpe pasienter med Guillain-Barré syndrom å mestre sykdommen?

Metode: Litteraturstudie ble benyttet for å kunne besvare oppgavens problemstilling. Jeg brukte CINAHL, Medline Ovid, Svemed+, Pubmed og manuelt søk var også foretatt ved bruk av Google Scholar og HVL-bibliotekets database. Til slutt kom jeg frem til 6 kvalitative studier som ble brukt.

Resultat: Resultatene fra de inkluderte artiklene knyttet til mestring av pasienter med GBS ved bruk av personsentrert sykepleie ble presentert i 6 temaer: individualisert omsorgsplan, kunnskap om GBS fra helsepersonell, kommunikasjon & informasjon, anerkjennelse av pasientenes følelser og tilnærming for håp, støtte fra pasienter med samme tilstand, familie, venner, helseteam og verdighet og koordinering av omsorg.

Konklusjon: For at sykepleiere skal kunne bidra til mestring av GBS-pasienter med bruk av personsentrert omsorgssykepleie, er det viktig å lære om sykdommen, utvikle gode kommunikasjonsevner, respektere pasientenes tro, samarbeide tverrfaglig og individualisere pasientomsorgen. Sykepleiere skal også hjelpe pasienter med å finne gode mestringsstrategier, sosial støtte og fremme håp og positiv holdning. Videre forskning på omsorg for denne pasientgruppen er også foreslått.

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1.0 Background

1.1 Introduction

Working in the healthcare system for several years has opened my eyes to caring for patients with different needs and diagnosis. The one that caught my attention most for this bachelor study is Guillain-Barré Syndrome (GBS). GBS is an autoimmune disorder that leads to nerve damage and paralysis, mostly in the legs and lower body and less often in the arms. It is a rare disease affecting about 1 to 2 in 100,000 people per year worldwide. GBS affects both males and females in all age groups and racial backgrounds. The disease is rare in children, and chances of acquiring the disease tends to increase while we age. After the near eradication of polio, GBS is now the most common cause of acute flaccid paralysis worldwide (Parry & Steinberg, 2007). The Norwegian Directorate of Health has listed GBS as a rare disease and NHI.no reported that about 50-100 people contract the disease in Norway per year (Helsedirektoratet, 2021; NHI, 2021).

From the statistics stated above, the disease occurrence is relatively low. However, even if GBS is a disease that only affects a margin of the population it is important to conduct research and further studies on this kind of diseases in order to drive innovative approaches that enables good and quality patient care. I have met and taken care of people diagnosed with GBS. I was frightened meeting this patient group. I saw in my patients the fear of the unknown, the fear of not knowing what will happen the next day added with a feeling of hopelessness. But what if we turn those fears into something that can be useful in the practice of our profession? What if we equip ourselves with the right information and knowledge about GBS so that we as nurses can deliver good health care to this patient group and maybe to nursing care in general? A simple act of kindness and compassion can empower a person who needs care. In this study I will therefore focus on how we as nurses through patient-centred nursing care can help patients affected by Guillain-Barré Syndrome cope with this disease.

1.2. Theoretical Framework

This part will tackle the theoretical basis of the thesis. Guillain-Barré Syndrome will be explained, followed by the meaning of rare disease, coping and crisis. Getting a serious diagnosis creates a crisis in a person's life (Skarstein, 1998, p.35-36). Understanding crisis will be relevant in answering my problem statement therefore this will also be elaborated in this part. The nurse's role and person-centred care will also be explained.

1.2.1 Guillain-Barré Syndrome

Guillain-Barré Syndrome is a type of peripheral neuropathy, a condition that involves the nerves extending into the head, trunk, and limbs. It has an autoimmune nature which is often preceded by a bacterial or viral infection in the respiratory or gastrointestinal system. It causes paralysis that usually starts in the legs and ascends quickly in the body and involve the respiratory muscle. In the recent years GBS has been linked to Zika virus and can also be a rare complication of Covid-19 infection (Parry & Steinberg, 2007; Helsenorge, 2020). The syndrome was first described in 1859 by JB Landry, but because of impreciseness in his clinical description it was first in 1916, when French neurologists Georges Guillain, Jean-Alexandre Barré and André Strohl came up with more precise diagnostic criteria, that the medical community agreed that GBS be made as an actual diagnosis (Eastlack et al., 2020).

Signs and Symptoms of GBS

The first GBS symptoms are **abnormal sensations**, like tingling sensation in the feet and hands. **Muscle weakness** which is usually the outstanding clinical feature of GBS is also seen. This weakness usually begins in the legs and ascends up the body, involving the arms and hands and continues to progress involving the breathing muscles. About one-fourth of the people diagnosed with GBS develop breathing problems. **Weakness in the head and neck muscles** is also observed whereas one-half of people with GBS have **facial weakness**. Double vision may also result as the **muscles of the eyes weaken**; fifteen percent can experience **difficulty swallowing**

and handling saliva which compromises the integrity of the airway. **Tongue weakness** happens and affects the patient's speech. **Locked-in syndrome** occurs in extremely severe cases wherein there is a loss of all voluntary muscle movement and inability to communicate. The patient may appear to be comatose yet maintain full awareness of their surroundings. **Paresthesias, dysesthesias** occur and **pain** is also common. **Tenderness and painful muscle cramping** between the shoulder blades and the lower back or thighs has been reported and **formications** were also experienced by some (Parry & Steinberg, 2007, p.9-12).

Table 1. Phases of Guillain-Barré Syndrome (Atkinson et al., 2006, p.257-258)

| PHASE | DESCRIPTION | DURATION | SYMPTOM |
|----------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|-------------------------------------|--------------------------------------------------------------------------------------------------------------|
| Acute phase | Begins from symptom onset to rapid progression until no further symptoms of deterioration occur. | Can last up to 4 weeks. | Pain, muscle weakness, paralysis, possible respiratory dysfunction. |
| Plateau phase | Symptoms remain the same and do not worsen. | Can last a few days to a few weeks. | Symptoms are the same from the acute phase and no worsening. |
| Recovery phase | Patient's condition starts to improve until recovery. | Last a few weeks to 2 years. | Patients regain the use of the affected extremities, breathe spontaneously, begin to function independently. |
| Predictors of a poor recovery: 60 years above, rapidly progressive disease, axonal loss, prolonged mechanical ventilation | | | |

Diagnosis

GBS is diagnosed based on the patient's history of illness, the characteristic clinical features of acutely evolving weakness and loss of reflexes following an antecedent illness, such as an upper respiratory tract infection or diarrhea. Diagnostic tests, for example electrophysiologic studies and examination of the cerebrospinal fluid is done to confirm the diagnosis (Parry & Steinberg, 2007, p.39; Espeset et al.,

2016, p. 295)

Treatment

GBS unknown aetiology makes treatment of the disease supportive. Decreasing the duration and severity is the current aim for treatment of GBS. Most of the patients diagnosed with this disorder must be treated in the hospital for several weeks or months. The available treatment options include plasma exchange, immunotherapy, cerebrospinal filtration and intravenous steroids. Due to the fact that the majority of GBS patients' will recover, it is particularly important to prevent contractures and muscle atrophy (Atkinson et.al., 2006, p.256; Helsenorge, 2020; Toft, 2002, p.96).

Prognosis

In approximately 70 to 80 percent of GBS cases, patients experience complete return of strength while about 3 to 10 percent die within a year of GBS, which is frequently seen in elderly people and patients with more serious symptoms. A decrease in mortality of GBS was observed due to medical advancement and invention of ventilators. Today it is the later complications of GBS like infections and blood clots that cause death. Despite its good prognosis, GBS is a life-altering experience for some who suffer muscle weakness that may last for several years, and others will not be able to walk again for many months. Some experience relapse, and minor but extremely annoying symptoms may persist for years or permanently (Parry & Steinberg, 2007, p.37-69; Helsenorge, 2020).

1.2.2 Rare Diseases

A rare disease is any disease affecting a small percentage of the population. Many of these conditions are life-threatening and do not have appropriate treatments

(Valarmathi, 2021). A diagnosis is considered rare in Norway when less than 1 in 2000 people have the diagnosis. The challenge that poses for people with rare diagnosis is that those who deliver healthcare services often lack knowledge about the disease. Patients therefore do not get access to the necessary services that are essential for coping. It is also reported that they often feel alone about their situation (Helsenorge, 2019).

1.2.3 Crisis

Crisis is when a person enters into a situation where the person's previous experiences and learned reactions are insufficient to understand and master the current situation (Cullberg, 2007, p.14). Life can be turned upside down when people are struck with serious illness (Skarstein, 1998, p.35-36). Characterization of the different phases of crisis; shock phase, reaction phase, reparation phase, and new orientation phase was made clear by Cullberg, in which according to him this phases go hand in hand.

Shock phase, may last from a short moment to a few days with the person feeling a sense of unreality and maybe having troubles in remembering what has happened and what was said. People in this phase can behave in strange ways like screaming, repeating sentences over and over again or talking about a completely irrelevant topic. It is important to be aware that there is a tendency that important information given in conjunction with a shocking message results in the information being forgotten. Reaction phase is the second phase where the person begins to respond to what has happened and tries to restructure and integrate reality as functionally as possible. Mobilization of a person's defense mechanism happens in this phase. The reparation phase is a phase where acceptance and reconciliation happens. This process can be burdensome but can be helpful in coping with the situation. Reorientation phase is the last phase, which Cullberg describes as having no end. Here the person learns to live with the damage but may still experience overwhelming feelings when what has happened still resurfaces in certain situations (Cullberg, 2007).

1.2.4 Coping

Lazarus theory of stress and coping describes coping as a person's cognitive and behavioural efforts to deal with stress or a challenging situation (Brykczynski, 2014, p.101). When a person encounters stress or a crisis, the situation is first assessed as to how threatening it is which is called the primary assessment, a secondary assessment happens when the person assesses what can be done and which consequences the actions can have (Renolen, 2015, p.169).

According to Lazarus and Folkman there are two coping strategies: problem-focused and emotionally focused. Problem-focused coping is directed towards the environment, where a person for example changes access to resources by seeking support, changing routines and lifestyle or reduces external causes of stress. Nurses can help in problem-focused coping by mentally working repeatedly with a patient's statements and tries to understand, taking the initiative and inviting relatives to talk about difficult thoughts and feelings. Emotion-focused coping is when one tries to change, tolerate or reduce the intensity of what one feels so that experience of having control over oneself, feelings and situation is achieved. Folkman and Greer later on added a third coping strategy which they called meaningful coping. This is described as when one tries to find positive meaning in a stressful situation and tries to see the situation in a new light (Renolen, 2015; Kalfoss, 2016).

1.2.5 Nursing Perspective

It is challenging to provide emotional, social and psychological care to patients who have gone from living independently to being completely dependent on nursing care. The whole situation, the fear of paralysis and of dying may be overwhelming for the patients. Nurses should therefore assess the patient's level of fear as well as try to alleviate anxieties if at all possible. Being aware and knowledgeable about the pathophysiology of GBS and its effect on organs and tissues within the body is crucial in nursing care to be able to provide a high standard of care and ensure that timely,

life-saving interventions are initiated. Facilitating support groups such as peer groups, family, friends or the healthcare staff is also important (Toft, 2002, p.101-102; Bowyer & Glover, 2010, p.292)

Person-centred Nursing Care

“Person-centred nursing (PCN) is an approach to practice established through the information and fostering of therapeutic relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development” (McCormack & McCance, 2016, p.62). PCN is based on the person-centred care philosophy that values individuals' own unique values, personality, personal history and the right of each person to respect, dignity and to participate fully in their life choices (McCormack & McCance, 2016, p.161). Person-centredness is an important keyword and defined by Kitwood (1997) as “a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust” (cited in McCormack & McCance, 2016, p.36). The PCN framework developed by McCormack & McCance includes several key systems which constitute person-centred care. The framework has four key domains: prerequisites for person-centred practice; the care environment; person-centred processes; and person-centred outcomes. **Prerequisites** has to do with the nurses' attributes like professional competence, developed interpersonal skills, being committed to the job, knowing oneself and being able to demonstrate clarity of beliefs and values. **The care environment** is the context in which care is delivered, for example effective staff relationships or supportive organisational systems. **Person-centred** processes focuses on holistic care, on working with patients' beliefs and values, having a sympathetic presence, decision-making and providing for physical needs. **Expected outcome** is the result which includes care satisfaction, involvement in care, a therapeutic environment and feeling of well-being. The person is central in this framework and subject that is capable of making choices and should be involved in care (McCormack & McCance, 2016, p. 57-82).

1.3 Problem Statement

Based on what I have written on the background and theoretical framework I have come up with this research question: How can person-centred nursing care help patients with Guillain- Barré Syndrome cope?

1.4 Context and Limitation

This study will focus on the patient with GBS and how the nurse through person-centred nursing care helps them cope with the disease. Even if GBS also affects the patient's family, the thesis will not focus on the patient's family and friends. The thesis will focus on population from ages 18 years and up and will include patients diagnosed with GBS in different phases and whether they are still admitted in the hospital or discharged at home. Including articles that address patients' experiences in this study was relevant in addressing my research problem, because understanding those experiences can give guidance and deepen our knowledge on how to intervene and facilitate coping to patients' with GBS.

2.0 Method

According to Dalland a method is a procedure used to obtain knowledge and serves as a tool that helps us to collect data if we want to investigate a problem. Thidemann on the other hand describes literature study as an examination of recognized literature and research that gathers knowledge through written sources. The literature and research that is used has been critically reviewed with a systematic approach, for example checklists adapted to the method (Thidemann, 2019).

For this bachelor thesis it suited best to conduct a literature review through qualitative studies. Dalland's book stated that qualitative method aims to capture experiences and opinions people have in relation to a problem, for example through interviews. It also has the purpose of providing an understanding of experiences and

opinions in relation to a topic (Dalland, 2020). In this thesis I included six qualitative studies that will help me answering my thesis problem.

2.1 Search Strategy

To make my work systematic, I used the PICO-framework to prepare my research problem for a literature search and thereafter critical review. PICO (Population, Intervention, Context) is a useful tool that we can use to make a research problem precise and clear. PICO is utilized in qualitative methods; for example questions about feelings and experiences (Helsebiblioteket, 2021). PICO framework is shown in table 1 and how I connected it to my problem statement. I also used the framework to find related MESH-terms and theoretical terms.

P (patient, problem) – Patients with Guillain- Barré Syndrome

I (intervention) – Person-centred nursing care

Co (context) – Coping of patients with GBS

TABLE 1. Overview over terms used in the literature search

| Population | Intervention | Context |
|-------------------------------------------------------------|-----------------------------|---------------------|
| Guillain- Barre´ Syndrome | Nursing Care | Patient experience* |
| Acute Infectious Polyneuritis (MESH) | Nursing Care | experiences |
| Landry Guillain Barre Syndrome (MESH) | Nurs* | Coping |
| Acute Inflammatory Demyelinating Polyneuropathy (MESH) | Person-centred nursing care | |
| Patient | Person-centred care | |
| | Quality care | |
| Guillain-Barré syndrom | | Mestring |
| Akutt inflammatorisk demyeliniserende polyradikulonevropati | Personsentret omsorg | Pasients opplevelse |

I used CINAHL, Medline Ovid, Pubmed, and Svemed+ to do the article search.

The searches for what nurses can do to help patients with GBS cope with the disease showed a paucity of research directly related to the question. One must therefore look at studies concerning patient experience and try to infer methods for nurses on how to give a good care to this patient group. Using research articles that tell about the patients' perspective facilitates a deepened understanding and knowledge of what the patients experience and therefore may help us in improving care delivery. Since most of the articles that I found was not directly relevant to my thesis, I had to spend time reading through and sorting out the articles that were most relevant. Several research articles explaining the medical side came up but did not address my thesis problem and was considered irrelevant. I also had searches where I got no results. Because of the rarity of the disease and its occurrence, I found it challenging to find articles that will answer my research problem. I therefore needed to reformulate and used back and forth systematic searches and manual searches in HVL database and Google Scholar to be able to find relevant articles. In the end, I was able to find three peer reviewed articles, one systematic review and meta-synthesis of patients' experiences and perceptions of Guillain-Barré Syndrome and one doctoral study. I also included a peer reviewed article about the experience of parents caring for a child with rare diseases because it was relevant in answering my research problem. I presented a table in Appendix 1 on how I did my search.

2.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were used during the literature search. I made a table below to show a better overview of what I included in my research and those that are not. The terms Guillain-Barré Syndrome, Acute Infectious Polyneuritis, Landry Guillain-Barré Syndrome, Acute Inflammatory Demyelinating Polyneuropathy were also used interchangeably.

Table 2. Inclusion and Exclusion Criteria

| Inclusion | Exclusion |
|--------------------------------------------|---------------------------------|
| Nursing; Nursing care; Person-centred care | Other health care professionals |
| Guillain- Barre' Syndrome patients | Other variants of GBS |

| | |
|--------------------------------------|----------------------------------------------------|
| Patient experiences | Experiences of family, friends, significant others |
| Qualitative articles | Quantitative articles |
| Peer reviewed article | Not peer reviewed article |
| Articles from 2002 – present | Articles which are older than 2002 |
| English and Scandinavian as Language | Other non-English and non-Scandinavian Language |

As stated above I made different searches in different databases. Different combinations were also used to capture as many relevant articles as possible. Since this is a topic that is little researched on, I needed to extend the year from a 10-year old study span to a 20-year old study so as to get relevant articles. The articles that I found were patient-focused since there is little or no research articles that tackles the perspective of nurses in caring for patients with GBS. I began by reading the abstract of the article and if this turned out to be relevant for my thesis then I continued with the introduction, design and method. If it still turned out to be relevant, I read the whole article to get the whole view and highlighted the key points from it. The assessment of the articles' quality was also made thereafter. After several searches and quality checks I was left with six articles that I considered to be relevant in answering my research problem. The systematic review and meta-synthesis and another article was co-authored by the same researcher.

2.3 Source Criticism

The CASP-checklist (Critical Appraisal Skills Programme) was used to assess the quality of the included articles. See Appendix 4. This checklist tool is structured systematically and are often used by healthcare professionals to systematically assess the trustworthiness, relevance and results of published papers (CASP, 2022). The Health Library (Helsebibliotek) in Norway points out the importance of assessing the quality and context of research articles even if those articles were published in reputable journals. The article's validity, methodological quality, results and transferability should therefore be assessed and considered (Helsebiblioteket, 2018).

2.4 Ethical Consideration

According to Dalland, research ethics means safeguarding the privacy, safety and integrity of the participants (Dalland, 2021, p.168). Adhering to ethical principles means that researchers are protecting the welfare of the research participants, their rights and dignity. Examples of this set of principles are informed consent, anonymity, confidentiality, voluntary participation, potential for harm, and results of communication (WHO, 2011).

The articles that were included in this thesis have ethical approval from different ethics committees and have had written consents and anonymity from the participants. I also made sure that utilizing the results from the selected articles were made and interpreted as correctly as possible and that proper reference to theoretical and article sources were done to avoid plagiarism.

2.5 Presentation of Articles

In this section, the included research articles and their relevance to this thesis is presented in Table 3.

Table 3. Presentation of the Included Articles

| | Author, Year, Title | Method | Participants | Relevance |
|---|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|---------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | Laparidou, D., Curtis, F., Akanuwe, J., Jackson, J., Hodgson, T.L. & Siriwardena, A.N. 2021; United Kingdom Patients' experiences and perceptions of Guillain-Barré syndrome: A systematic | Systematic review and meta-synthesis of qualitative research | 5 studies | The result from this study is relevant to my thesis question because it tells about areas that are important to coping of patients' with GBS like; knowledge of the disease, importance of information dissemination, the need for individualized approach to care, |

| | | | | |
|---|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------|-----------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | review and meta-synthesis of qualitative research | | | the support from significant others, and maintaining positive attitude. |
| 2 | Akanuwe, J.N.A., Laparidou, D., Curtis, F., Jackson, J., Hodgson, T. & Siriwardena, A.N. 2020;United Kingdom Exploring the experiences of having Guillain-Barré Syndrome: A qualitative interview study | Qualitative (face-to-face and telephone interviews) | 16 volunteers with a prior diagnosis of GBS | By exploring the experiences of individuals with GBS, we can develop a better understanding of the care and support needs of this patient group. The importance of early diagnosis, experiences of inpatient care, importance of active support for recovery, the need for communication throughout the course of the illness, the need for greater awareness, knowledge, and provision of information by health-care staff were the identified factors that affects recovery. |
| 3 | Forsberg, A., Widén-Holmqvist, L. & Ahlström, G. 2015; Sweden Balancing everyday life two years after falling ill with Guillain-Barré syndrome: a qualitative study. | Qualitative research using content analysis based on individual Interviews | 35 participants from a previous longitudinal study | This study is relevant to my thesis because it highlighted the importance of person-centred care and individualized rehabilitation approach to GBS patients since recovery process is different to every individual. |
| 4 | Hooks, J.D. 2015; United States Understanding the patient's recalled experience of an acute episode of Guillain-Barre' syndrome: A qualitative descriptive study | Qualitative descriptive study with inductive content analysis | 14 participants having had moderate to severe case of GBS | This study is about the patient recalled experience during an acute episode of moderate to severe GBS. This is a particularly interesting study that is relevant in my thesis. It showed the inconsistency of nursing care and scarcity of knowledge among HcP's. Importance of person- |

| | | | | |
|---|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | | | centred care was also touched in this study. |
| 5 | Chetcuti, S., Sultana, V. & Depares, J. 2016; Malta Living with Guillain-Barré syndrome | Qualitative study by the use of Heideggerian phenomenological approach. | 4 Maltese female participants through purposive sampling 2 to 4 years following their diagnosis. | The small sample size maybe makes this study less reliable but I still considered this relevant because it provides an in-depth exploration of the 4 participants with GBS. The study also tackles the importance of positive attitude from the HcP's in helping patient cope and emphasized the need for a better follow-up care and discharge planning. |
| 6 | Currie, G. & Szabo, J. 2018; Canada "It is like a jungle gym, and everything is under construction": The parent's perspective of caring for a child with a rare disease | Interpretative phenomenological approach through semistructured interviews | 15 parents of children with rare diseases | Though this is a study of the experiences of parents of children with rare diseases and not a self-reported experience of persons with the disease, I still found it relevant in helping me answering my research problem since this talks about the integrated approach to healthcare and social support delivery and thereby improve the quality of life of patient and families with a rare disease. |

3.0 Analysis of Included Articles

I did my analysis by first looking at which of the findings in the included articles were relevant to my thesis problem. I entered these paragraphs and quotations which

were directly taken from the articles and put those into a table. I later on sorted it and found common findings in several of the articles. I identified these different domains and respectively gave them names. This table is presented in Appendix 2. I also did theme identification by the use of color coding just to be able to have a good overview of which article talks about what. This is shown in Appendix 3 (Thidemann, 2019). In the analysis of the result, 6 main themes emerged which have importance to coping of patients' with GBS: individualized plan of care, knowledge from healthcare workers about the disease, communication and information; recognizing patients emotion and approach in facilitating hope; support from peer groups, family, friends, and healthcare workers; dignity & coordination of care.

4.0 Results

In this part I will present the 6 domains that I identified from analyzing the articles.

4.1 Individualized Plan of Care

Participants felt that there was lack of personalised and person-centred care, which made participants dissatisfied with the healthcare service. This dissatisfaction did not help patients in recovering from GBS and there were some who were prompted of quitting rehab (Laparidou et al., 2021, p.10; Hooks, 2015, p.74). A participant said "I will take the bedside commode, but I will not do the bedpan. So that's really when they started telling me they were not going to move me."; "There were some during the day, and I knew who to ask for to help me but in the evening, they basically told me they were not going to help me. That I weighed too much" (Laparidou et al., 2021, p.10). This was also substantiated by Forsberg et al. and Akanuwe et al. that they were not taken seriously and needs had not been addressed by HcPs. They felt that sometimes routines in the healthcare organization were rigid and not adapted for younger GBS patients (Forsberg et al., 2015, p.606; Akanuwe et al., 2020, p.1345). Participants from Hooks' study verbalized that some HcPs are pushy during rehab with the `no pain no gain policy` while some respected their feelings of fatigue and let them

rest (Hooks, 2015,p.74). The study about parents' experiences caring for children with rare diseases also voiced that families' perspectives and knowledge should be respected and heard because they knew better because they live with their child who has the disorder (Currie & Szabo, 2018, p.98).

4.2 Knowledge about GBS from Healthcare Professionals

There is a general lack of information and knowledge of GBS among nurses and healthcare professionals (HcPs). This added to the participants' stress and uncertainty. The patient with GBS did not find it comforting when a nurse walked into the room saying that s/he knew nothing about the disease and just had to Google it. There were several of the HcPs that said they never really heard of GBS and it is often the patient's significant others that had to look for information (Laparidou et al., 2021, p.13; Hooks, 2015, p.87). Participant in Forsberg et al., said "And the home care staff who came after I was sent home, 12 or 13 of them descended on me. And they had no idea what my illness was" (Forsberg et al., 2015, p.606). HcPs also had little or no contact with children with a rare disorder over the course of their profession (Currie & Szabo, 2018, p.98).

4.3 Communication & Information

Participants felt that HcPs failed to understand or listen to their problems and experienced poor communication. One participant said "...my worst experience about this was having alarm on my bed. And you know hearing the voice that come over the intercom saying. Do not get out of bed! And to be yelled at. I mean that's the only way I can put it. You know they weren't really mean, but you know, being told, 'Don't get out of bed', you know all of the time just kind of ticked me off a little" (Laparidou et al., 2021, p.10; Chetcuti et al., 2016, p.17). Unhelpful communication experiences because of the lack of information they receive about their condition and participants were not told what to expect has also been reported. This poor communication was worse when GBS affected the participants speech (Akanuwe et al., 2020, p. 1345-

1347; Hooks, 2015, p.93). Awareness, knowledge and information provision was lacking through the patients illness journey and some participant agreed that there was a limited effort to provide useful information. Participants often cling to social media to gather useful information. They emphasized that although GBS is a rare disorder, better information about it should be provided to the public and professionals because this will help them to understand the physical and other residual problems affecting people with GBS and this may pave the way for a better access to support and support systems (Akanuwe et al., 2020, p. 1345-1347).

4.4 Recognizing Participants Emotion & Attitude in Facilitating Hope

Forsberg et al. described that some persons in the initial phase had difficulty remembering this period because they were confused and too severely ill to even care for their diagnosis. Several participants described they were frightened of the knowledge of being completely dependent on care and sudden onset of GBS disrupted their lives in an instant which made them lost and confused (Forsberg et al., 200,p.3-4; Chetcuti et al.,2016,p.17; Hooks,2015,p.76). GBS made them realise the fragility of life and ultimately changed their outlook on it. They started taking life day by day, became more thoughtful and appreciated the people around them more (Chetcuti et al., 2018, p.19). Confidence in recovery, the participants hope and determination to get better were huge motivators to coping and recovery, which was further motivated when bodily functions returned (Laparidou et al., 2021, p.14; Hooks,2015,p.76).

4.5 Support from Peer Groups, Family, Friends, Healthcare Team

The invaluable support from family and friends and from their colleagues also helps in the recovery of patients' with GBS. Practical, psychosocial and emotional support by having someone to talk to and giving them encouragements in times of loneliness were seen as valuable. Peer support can also impact patients with GBS. Hearing or receiving information from others who have survived GBS can give them hope about recovery and the future. Information coming from previously diagnosed

GBS patients' are more credible than those coming from the HcPs. Participants also appreciated the role of charities in providing support and information for people diagnosed with GBS. They even suggested that people should be informed about these charities and other social media websites as a source of information (Laparidou et al., 2021, p.14; Akanuwe et al., 2020, p.1343; Hooks, 2015, p.84). A positive support from members of the medical team which was centred on connection were also viewed effective. Participants held the esteem of those who took the time to attend their concerns and offered indications of support as needed (Currie & Szabo, 2018, p.100). However, HcPs also contributed to participants loneliness by failing to understand their needs which caused distress in participants' lives (Chetcuti et al., 2016, p.21).

4.6 Dignity & Coordination of Care

Participants in Akanuwe et al. described the experiences they had in inpatient care and how this has affected their subsequent return to full health. They described some HcPs as caring and supportive while others were not and less helpful. A participant said: "In the intensive care unit, there was a wonderful nurse. She was absolutely fantastic: she would help me wash and braid my hair to stop it getting tangled. She would spend the most time with me to try and lip read me; but some of the other nurses were not as nice at all; very unpleasant."; "Then another healthcare assistant comes in and asks me what I want for breakfast, and then chucks the toast at you. I can't feed myself. I didn't get fed till one of my family members came in and one of them fed me. The nurses were too busy, or they didn't understand" (Akanuwe et al., 2020, p. 1341). A varied expression of care from Laparidou et. al. reported that participants are satisfied with the care they received from the community and hospital. They appreciate the staff who were kind and were attending to their physical, psychological and social needs (Laparidou et al., p.14). Participants in Hooks also reported positive experiences they had from the nursing staff. A participant verbalized the little things that nurses do, how far they would go and their presence when participants needed them.

A lack of medical coordination or structured follow up care left a participant

advocating for what they need. Disjointed care forced the participants to recount their stories multiple times to different providers which added to their frustration and verbalized that it did not help their recovery. A participant said: "There is nothing. No hotline. No helpline. There is GB charities out there that will help you, but NHS, there is not. There must be other rare conditions out there that people who have them, get so frustrated that they just want to talk to somebody. There is no health professional out there". In addition, participants perceived follow-up as having no significance, and that the time was spent more on waiting than being seen by the healthcare workers (Chetcuti et al., 2016, p.18; Akanuwe et al., 2020; Currie & Szabo, 2018, p.99).

5.0 Discussion

In this part, results from the included research articles combined with the previously presented theory will be discussed to elucidate the thesis problem "How can patient-centred nursing care help patients' with GBS cope? Based on my research findings, the discussion has been divided into the following main themes:

- Individualized Plan of Care
- Knowledge of GBS from the Healthcare Worker
- Communication & Information
- Recognizing Patients' Emotion and Approach to Facilitating Hope
- Support from Peer Groups, Family, Friends, Healthcare Team
- Dignity and Coordination of Care

5.1 Individualized Plan of Care

Verbalization of an efficient and planned course of care was highly appreciated (Laparidou et al., p.10). Continuous assessment of patients and updating their care plan is required since GBS patients' progresses vary. They can function well in the morning but be completely dependent on care after a few hours (De Cort, 2011, p.32). Currie & Szabo reported that suggestions of parents in the care plan of their children

with rare diseases were turned down by HcPs. They opined that incorporation of the family's knowledge into the planning and delivery of care is important in individualizing care (Currie & Szabo, 2019). Nurses should therefore include the patients and their families in making a care plan in order to ensure that existing areas of concern are met and be remembered that care should be tailored to each individual and should not be generalized (Hooks, 2015, p.111; Tranvåg et al., 2016, p.141). This is supported by coordination of care in the person-centred nursing care theory which emphasizes the opportunity of the patient to be able to plan his care and achieve outcomes that are important for the patient. We therefore utilized the person-centred process in the person-centred nursing care framework when we work with patients' beliefs and values (McCormack & McCance, 2016, p.63-91).

GBS affects people who have had healthy lifestyles and have lived independently, therefore an extensive effort in making a plan of care is necessary throughout their hospitalization (Haldeman & Zulkosky, 2005, p.267). Skills for coping with the immediate crisis and long-term changes in everyday life need to be individually customized for each patient. Only the patient can do the coping, however nurses can motivate them and help them find a suited coping strategy (Forsberg et al., 2015; Eide & Eide, 2017). Skarstein emphasized that if we hear, understand, and deal with the patients' possible concerns such as his family, work or finances, then we can achieve good coping (Skarstein, 1998, p. 36). The Patient and User Rights Act §3-1 states that patients have the right to participate in the implementation of healthcare services. It should emphasize on what the patient desires when designing a care plan and if the patient is ineligible for consent then the patients' next of kin have the right to participate together with the patient (Pasient- og brukerrettighetsloven, 1999, § 3-1).

The acute phase of GBS during the shock stage in the crisis theory makes the patient vulnerable, helpless and confused. It is crucial for nurses to make individualization of care a priority because this facilitates patients' ability to cope. I saw patient with GBS cry because her wishes were not respected and the healthcare team ignored what the patient wanted. It is vital that nurses provide compassion, sensitivity, and empathy to GBS patients to prevent this (Haldeman & Zulkosky, 2005, p.271). During the acute stages of GBS, nurses should be aware that while patients may be

in a respirator, be quadriplegic and unable to communicate, they can still hear, see, think, and feel. Explaining to the patient and telling them frequently what is going on can make them feel safe and secure. The patient must not be left alone without some way to get help, for example a calling device that the patient can master (Simmons, 2010, p.27).

5.2 Knowledge of GBS from Healthcare Staff

Parents of children with rare diseases expressed frustration when HcPs did not do necessary searches of recent literature about the disorder. They described the exhausting responsibility that was put on them due to the lack of knowledge and understanding from the healthcare team. This damaged the parents' confidence with these professionals (Currie & Szabo, 2018, p.98). De Cort seconded the idea that nurses lacked knowledge of the special needs of GBS patients which caused discomfort and stress. This contributed to an inconsistent patient care, ranging from outstanding quality nursing care to provision of minimal basic care (De Cort, 2011, p.32). Participants in Hooks agreed with the description of nurses not knowing what to do when administering treatment and suggested that nurses should review what to do before performing procedures they are not sure of. They expressed that it would be worthwhile and comforting if their carers had sufficient knowledge and skills (Hooks, 2015, p.87-88).

The acute onset of GBS with an increasing flaccid paralysis that may affect breathing was frightening and incomprehensible for the patients. This supports the crisis theory that people hit by an unknown disease enter into a state where the person's previous experiences and learned reactions are insufficient to understand or master the current situation. The dependency and helplessness adds to their feeling of anxiety and stress (Forsberg et al., 2015). GBS patients may benefit from having the disorder explained to them and from receiving appropriate information early in the hospital stay (Parry & Steinberg, 2007, p.22).

I first met a GBS patient during my work in a secondary hospital in my home country. At the time, I had only heard about GBS from a lecture I attended. The feeling of not knowing what to do and just relying on the basic nursing care and intervention I knew made me, and my colleagues, uncomfortable. I wished I knew more so I could have done more.

The Norwegian Health Personnel act §4 demands that nurses meet their requirements and have sufficient competence within their qualification (Helsepersonelloven, 1999, §4). With this I was able to go into the domains of Person-centred nursing care theory and looked deeply at prerequisites which was described as the attributes nurses have, for example professional competence. According to the theory one can reach the centre of the framework (which are the outcomes of person-centred care) by first considering the attributes of the nurse in order to provide effective care through the care processes (McCormack and McCance, 2016, p.60). If the medical team knows and understands the disease, it can give a more optimistic outlook to the GBS patients (Parry & Steinberg, 2007, p.22).

5.3 Communication and Information

Communication in caring for GBS patients is an important aspect to focus on. Good and professional communication is person-centred, motivating and helps patients cope with the disease (Eide & Eide, 2017). Communication in the person-centred nursing framework by McCormack & McCance was described as the ability of the practitioner to communicate at a variety of levels with others (McCormack & McCance, 2016, p.217). Excellent and advanced communication skills helps the nurse to communicate important information to the patient, provide empathy, assess pain and recognize the patient's capabilities. It can therefore provide reassurance, allay fears and anxiety to the patient and their families (De Cort, 2011, p.32; Hooks, 2015, p.111; McCormack & McCance, 2016,p.66).

During my work experience and study I have learned that establishing rapport and trust is crucial if one wants to give quality patient care. However, as professionals we are expected to not just build rapport, but also to develop a trusting relationship with our patient so as to ensure that holistic needs are identified and shared decision making is made possible. We can show warmth and friendliness to our patients but our impact will only be superficial if we don't get to understand our patients or engage in important conversations (McCormack & McCance, 2016, p.66). Nurses are have the most contact with GBS patients who are admitted in the hospital and can therefore make a big difference in the patients comfort, physical and emotional well-being (De Cort, 2011, p.32). Gaining trust from a patient starts from a simple verbal or nonverbal communication that is sometimes difficult to achieve because of understaffing or work overload. I have seen that this poses challenges for HcPs in getting to better know the patient under calm circumstances so that assessing coping strategies which is best for the patient can be done (Currie & Szabo,2018, p.100; Skarstein, 1998, p. 37).

Uncertainty and knowledge deficiency can cause both anxiety and depression. Keeping patients and their families sufficiently and honestly informed is claimed to have positive effects in coping (Currie & Szabo,2018, p.100; Skarstein, 1998, p. 36-37)

The International Code for Nurses states that nurses have to ensure that "[...] the individual receives accurate, sufficient and timely information in a culturally appropriate manner on which to base consent for care and related treatment" (ICN, 2012, p. 2). In addition to giving the patient information, the nurse must make sure it is understood (NSF, n.d.). We can help patients on respirator or those unable to communicate in coping by providing them a method for communication. A set of communication cards developed by a GBS foundation is a useful tool. Alternative ways to communicate with the patient by using items such as pen and paper, picture board, and other nonverbal means can reduce the patient's and family's frustration and anxiety (Parry & Steinberg, 2007, p.22; Hooks, 2015, p.19; Haldeman & Zulkosky, 2005, p.267). Effective communication is important during both the acute and recovery

phases of GBS. Clear answers and adequate information can increase understanding and thereby increasing sense of control (Akanuwe et al.,2020,p.1345; Atkinson et al.,2006,p.260; Haldeman & Zulkosky, 2005, p.271).

5.4 Recognizing Participants Emotion and Approach in Facilitating Hope

A major facilitator to the participants recovery from GBS is their positive attitude (Laparidou et al., 2021, p.14; Akanuwe et al., 2020, p.1342). Participants reflected on the realization that life can quickly change or even end (Forsberg et al., 2015, p.607). Hope of recovery was the main source of motivation and gave them the courage to continue (Laparidou et al., 2021, p.13). The professional ethical guidelines from the Norwegian Nursing Association states that the nurses should support hope, coping and courage in the patient (Norsk Sykepleieforbund, 2022, 2.2). Nurses are reminded that there is good prognosis from GBS but patients and their families need ongoing encouragement after a frightening experience (Parry & Steinberg, 2007, p.19-144). Theories and research however implied that psychological aspects of being affected by serious illness were often neglected for many years by the healthcare system (Skarstein, 1998, p.35-36; Laparidou et al., 2021, p.17).

The high anxiety and fear in the acute phase triggers the primary and secondary assessment in Lazarus stress and coping theory. In this phase patients often have unrealistic goals for the future. Nurses must avoid interrupting this, because it is maybe necessary for the patient to process. Nurses must instead focus on the present situation, be able to constantly give hope, and honestly answer questions as they arise (Lund et al., 2016, p.260). Assessing and listening to the patients' thoughts and feelings can help nurses identify which coping strategy is best suited for the patient (Renolen, 2015, p.172). This stage can also cause patients demanding the nurse's attention. Reassurance and letting the patient know specific times when the nurse will return to the patients' room is beneficial (Atkinson et al., 2006, p.260). My experience of just staying with the patient when they are sad or frustrated made them grateful of the time I used when they were lonely. This is backed up by the sympathetic presence explained in the person-centred nursing theory, wherein emphasis is given on human

relationships and recognizing the uniqueness and value of the person.

Different coping strategies has been reported by participants. This was done in order to maintain their identity and cope with threats to the participants self-image. Participants looked for ways to manage their limitations and restrictions even if they still have residual symptoms from GBS. They needed to accept and reappraise their new circumstances and that having a positive attitude helps in their recovery (Laparidou et al., 2021, p.14-15; Forsberg et al., 2015, p.606). This corresponds to the idea of the different coping strategies by Lazarus and Folkman which was presented in the theory.

Pain is a significant part of the disease which is sometimes not given enough attention. It is usually undertreated, especially for patients who are admitted in the ICU and cannot communicate. Pain can happen during the acute phase, before the onset of weakness, during recovery and rehabilitation (Parry & Steinberg, 2007, p.13-14). Nurses' skills in systematically assessing the patients' pain is necessary to be able to give them the right nursing or medical intervention. Good observation and assessment of discomfort helps in preventing that patient from experiencing severe pain which can hinder coping and recovery. Lorentsen & Grov described that nurses can help the patient strengthen their hope and make short term realistic goals that can increase their feeling of coping with the pain (Lorentsen & Grov, 2016, p.417; Parry & Steinberg, 2007, p.19-144). Nurses can also deliver quality nursing care by helping bedridden GBS patients to frequent turning and passive range of motion because immobility can cause pain and lying in one position can be very uncomfortable.

5.5 Support from peer groups, family, friends, healthcare team

Akanuwe et al. found out that good support from family and friends was helpful in coping. Having them around to listen during times of loneliness and worry is

encouraging and extremely helpful. However some were also frustrated over the lack of understanding from family members and friends who stopped contacting them during and following their illness. These friends were unsure of how to console the participants without upsetting them (Akanuwe et al., 2021, p.1343; Forsberg et al., p. 606; Chetcuti et al., 2018, p. 18-19).

Nurses should involve and educate the family and significant others. One must use time in informing them and letting them be heard and be included in the plan of care if the patient allows it. Including the family is a central aspect in person-centred care (McCormack & McCance, 2016, p.131). Knowing that GBS is benign and transient, the nurse may view the patient's condition with more optimism than the patient. It is important to convey this optimism to the patient while also allowing him to express his despair. The nurse also plays an important role together with others in the health team in preventing depression to this patient group. By conveying to the patient that the medical staff are really optimistic about the treatment it may be easier for the patient to grab some hope (Espeset et al., 2016, p.298). Nurses should also be a patient's advocate for GBS patients because even after patients are discharged they may still have the residual effects of GBS like fatigue or pain (Parry & Steinberg, 2007, p.165).

It is highly valued to get a visit from a patient who survived GBS (De Cort, 2011, p.33). One participant in Chetcuti et al. mentioned that her outlook in life was improved after meeting other patients who overcame the same disease (Chetcuti et. Al., 2018, p. 18-19). Laparidou et al. even considered that information participants received from peer groups are more impactful and better accepted by GBS patients (Laparidou et al., 2021,p.14). It is therefore imperative that nurses know where to find these support groups for GBS and relay this information to the patient and their families (De Cort, 2011).

5.6 Dignity & Coordination of Care

Protecting patients' dignity is one aspect of consideration to delivering nursing care that is person-centred. Tranvåg stated that person-centred care and dignity-promoting care are closely connected in which autonomy, respect and empowerment is attributed to positive outcomes (Tranvåg et al., 2016, p.141). Results from the research articles that was included in this study showed flaws in the way that HcPs treated the participants. There is no dignity in care when patients are not being listened to. Nurses should be reminded not to treat a patient as if s/he is deaf, blind or stupid just because they are attached to a ventilator or are in the ICU. It is important to remember that people on a respirator can still hear, feel and think. When procedures are performed, explanation regarding the procedure or activity will help to alleviate anxiety (De Cort, 2011, p.33; Parry & Steinberg, 2007, p.22). Person-centred nursing care with dignity means providing care that supports the self-respect of the person, acknowledging the person's sense of worth and value, and doing nothing to undermine it. Caring from the heart and the concept of personalization catches respect and compassion and recognizes care practice that supports dignity, self-esteem and independence (SCIE, 2020). It is important to remember that there is a unique human being behind in every diagnosis who wants to be seen, be understood and be respected (Tranvåg, 2016, p.56). Affirming patient's dignity like a three-second pause, touching the patient and meeting their gaze can be a powerful message that we acknowledge what the patient is experiencing, that we are present and that we are there for them (Tranvåg, 2016, p.188). Continual commitment to practicing the core nursing values, empathy, care and advocacy is therefore important (De Cort, 2011, p.32). The professional ethical guidelines from the Norwegian Nursing Association states that all nursing care must be based on the basic foundation of respecting human life and inherent dignity of the individual human being. Nursing must be based on compassion, care and respect for human rights (Norsk Sykepleieforbund, 2022).

Facilitating independence to this patient group is also extremely important in achieving coping and recovery (Akanuwe et al., 2020). It is therefore important to have an effective discharge plan to help patients cope with their new situation which is a

key recommendation in Chetcuti et al. Nurses should remember to be patient even with those persons with GBS who are already discharged from the hospital because recovery can be slow and patients will have frustrating days as they undergo therapy. Collaboration from the care workers is needed in order to provide holistic care and promote positive outcomes (Parry & Steinberg, 2007).

6.0 Conclusion

How an individual copes is shaped by how that individual changes his feelings, thoughts and behavior in the face of stress or crisis so that he can again experience coherence and meaning in his life (Hestvold, 2021, p.137). Person-centred nursing care is composed of nurses' attributes working in balance with the patients' beliefs and values in order to achieve expected person-centred outcomes. After doing this literature study one can say that nurses through person-centred nursing care can help promote coping in GBS patients' by learning about the disease, by developing excellent communication skills, by respecting patients' beliefs, by providing the patient with proper information and by including them and their family in the plan of care. Nurses can also pave the way to coping for patients with GBS through active listening, continuous support and establishing trust. Being sensitive to the patients' needs, respecting and empathizing with them has a positive effect on the coping of GBS patients. It will also help to introduce patients to peer patients and make a good discharge planning and care collaboration.

There is little research made in nursing and provision of care to GBS patients, therefore I will suggest that further research should be done in this area in order to understand and gain more knowledge to later improve the quality of care delivered in this patient group.

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8.0 Appendix

Appendix 1: Search History

| Database | Search | Search words/MESH terms | Number of Hits | Read articles | Excluded Articles | Included Articles |
|-----------------------------------|--------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|---------------|-------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| CINAHL 06.10.2022 | 1 | Guillain-Barré Syndrome OR Acute inflammatory demyelinating polyneuropathy OR Acute Infectious Polyneuritis OR Landry Guillain Barre Syndrome | 2,427 | | | |
| | 2 | Nursing care OR nursing care* | 327,563 | | | |
| | 3 | Nurse OR nurs* | 958,847 | | | |
| | 4 | #1 AND #2 AND #3 + Limits (2002-2022, Peer reviewed, English) | 22 | 10 | 20 | <p>Exploring the experiences of having Guillain-Barré Syndrome: A qualitative interview study -Akanuwe et al</p> <p>Balancing everyday life two years after falling ill with Guillain-Barré syndrome: a qualitative study -Forsberg et al.</p> |
| | | | | | | |
| Medline Ovid 06.10.2022 | 1 | Guillain-Barré Syndrome OR Acute Infectious Polyneuritis(MeSH) OR Acute Inflammatory Demyelinating Polyneuropathy (MeSH) OR Landry Guillain Barre Syndrome (MeSH) | 11,801 | | | |

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|--|---|-----------------------------|-----------|--|--|--|
| | 2 | Nursing care OR care | 2,484,460 | | | |
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|--|---|-------|---------|--|--|--|
| | 3 | Nurs* | 794,371 | | | |
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|----------------------|---|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|---|-----|-------------------------------------------------------------------------------------------------------------------------------------------------------|
| | 4 | #1 & #2 limits (2002-current, English) | 441 | | | |
| | 5 | #3 AND #4 | 25 | 7 | 25 | 0 |
| 16.10.2022 | 1 | Guillain-Barré Syndrome OR Acute Infectious Polyneuritis(MeSH) OR Acute Inflammatory Demyelinating Polyneuropathy (MeSH) OR Landry Guillain Barre Syndrome (MeSH) | 11,801 | | | |
| | 2 | Coping OR cope OR adaptation | 420,958 | | | |
| | 3 | Patient experience OR experience | 784, 434 | | | |
| | 4 | #1 AND #2 | 12 | 6 | 12 | 0 |
| | 5 | #1 AND #3 | 117 | 7 | 116 | Patients' experiences and perceptions of Guillain-Barré syndrome: A systematic review and meta-synthesis of qualitative research -Laparidou et al. |
| | | | | | | |
| Pubmed 08.10.2022 | 1 | Guillain-Barré Syndrome OR Landry Guillain Barre Syndrome OR Acute inflammatory demyelinating | 12,467 | | | |

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|----------------|---|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|---|---|---|
| | | polyneuropathy OR Acute Infectious Polyneuritis | | | | |
| | 2 | Nursing Care | 838,821 | | | |
| | 3 | Patient experience | 477,474 | | | |
| | 4 | #1 AND #2 AND #3 + limits (last 10 years, meta- analysis, systematic review, RCT) | 0 | | | |
| | | | | | | |
| Svemed+ | 1 | Guillain-Barré Syndrome OR Guillain-barres syndrome OR Landry Guillain Barre Syndrome OR Acute inflammatory demyelinating polyneuropathy OR Acute Infectious Polyneuritis | 45 | | | |
| | 2 | Patient experience OR experience OR coping OR pasients opplevelse OR mestring | 4,672 | | | |
| | 3 | Nursing care OR omsorg | 9,309 | | | |
| | 4 | #1 AND # 2 AND #3 + limits (peer reviewed) | 0 | | | |
| | 5 | #1 AND #2 + limits (peer reviewed) | 2 | 1 | 2 | 0 |

*Manual searches have been made in HVL database and Google Scholar for the other three included articles.

Appendix 2: Table Categorization of Results

| THEME | SOME SUPPORTING QUOTATIONS/SENTENCES FROM THE INCLUDED ARTICLES |
|-------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Individualized Plan of Care</p> | <p>“I Participants felt that there was lack of personalised and person-centred care, lack of continuity of care, lengthy waits for referrals, and staff shortages, which made it harder for participants to receive the care they needed.”(A1)</p> <p>“participants were often very satisfied with nursing care for their physical, psychological and social problems” (A1)</p> <p>“I will take the bedside commode, but I will not do the bedpan. So that’s really when they started telling me they were not going to move me.” (A1)</p> <p>«They got me a commode because I couldn’t get upstairs to the toilet; but once I was a bit stronger, they got an extra handrail, so I could get up the stairs.»(A2)</p> <p>“Sometimes routines in the healthcare organizations were experienced as rigid, and not adapted for younger people suddenly struck by a disease such as Guillain-Barré syndrome”.(A3)</p> <p>“But they were very conscientious of working with me, knowing that I was extremely tired, extremely fatigued”. Other participants indicated that staff were not aware of the fatigue in Guillain-Barre’ syndrome and subsequently pushed them too hard in therapy”</p> <p>“that's not what works with Guillain-Barre. And they were in charge. They didn't believe me. So I just told the doctors I wanted to get out of there. I felt like I could do better at home”.(A4)</p> |

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| | <p>“Several participants identified care concerns related to the provision of care that was not personalized to the patient experiencing Guillain-Barre’ syndrome nor was the care patient centered.”(A4)</p> <p>“they felt that their needs as individuals living with GBS in the community were not understood by health care professionals. Participants expressed their gratitude for the care they received in hospital. However, in the community they felt that, as opposed to in-patients in the acute phase of illness, these same health care professionals failed to understand them, or even listen to their concerns”(A5)</p> <p>“Other parents indicated their perspectives of what their children needed were not welcomed”(A6)</p> |
| <p>Knowledge about GBS from Healthcare Worker</p> | <p>“On occasions, healthcare professionals either misdiagnosed their symptoms (e.g. thinking the participant was having a stroke) or they were feigning illness. “(A1)</p> <p>“This feeling of uncertainty was made worse by a general lack of information and knowledge of GBS, among patients and healthcare professionals. Most participants had never heard of GBS and felt that healthcare professionals were lacking knowledge of and experience with GBS, which they did not find comforting, and left them needing more information about their illness.” (A1)</p> <p>«The only thing that didn't help was there isn't a lot of knowledge out there. I think we need something out there to support people and their families. It is different when you watch someone with cancer or something because we are so well informed on it»(A2)</p> <p>They also had experienced that personnel had good knowledge of Guillain-Barré syndrome and of their specific problems.(A3)</p> <p>“They also had experienced that personnel had good knowledge of Guillain-Barré syndrome and of their specific problems.”(A3)</p> |

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| | <p>Another participant was a retired registered nurse. She stated “I had not worked in a hospital for a number of years. And I had never taken care of a patient with Guillain-Barre’...I didn’t know anything about it”(A4)</p> <p>The participants indicated that physicians and staff, for the most part, were not knowledgeable about this syndrome. In addition, participants expected that physicians and staff would have educated them more on the disorder. Some participants felt that the physician should know more than the nursing staff and should provide the education(A4)</p> <p>“And so they [the nurses] didn’t know very much about Guillain-Barre’, and I remember when they gave [the IVIG] to me, they had some questions, you know, on how to – what, I guess the procedure was...the nurses that would always come in and not really understand how...to, um, administer it(A4)</p> <p>“rarity as complexity” due to lack of information and knowledge about the disease. “No one is there to say, ‘I’ve been there or this is what you can expect”(A6)</p> <p>“Within the realm of having a child with a rare disease was the underlying perspective that parents knew more than the HcPs about the disease. “(A6)</p> |
| <p>Communication & Information</p> | <p>“Participants also felt not listened to by healthcare staff and experienced poor communication from healthcare professionals.” (A1)</p> <p>“Many participants would have liked to have received more information about GBS to improve their understanding of their condition, but also because they found information about GBS, especially on prognosis and recovery, to be reassuring.” (A1)</p> <p>“one interviewee felt that little was communicated to her until she had a tracheostomy in place and could not speak, leaving her confused about her diagnosis”(A2)</p> |

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| | <p>“Poor communication was worse when the condition affected speech.”(A2)</p> <p>«It is the awareness that needs to happen. I see about it every day because I follow it all on Facebook, but if there weren't any social media, even less people would know about it.»(A2)</p> <p>“participants also expressed feeling vulnerable and not listened to in their contacts with healthcare”(A3)</p> <p>“Participants experienced unsupportive communication with care providers.”(A4)</p> <p>“you know, you still don’t really know what the name of that truck was that hit you [and] they said: Oh don’t worry. You’ll get better. Well, you know, when you’re laying there, and you can’t even scratch your nose, and you have 93 this severe pain in your arms...it’s hard to believe when somebody says – with no more information than that – that you’re going to be better. I was sure they were blowing smoke at me. I really was”.(A4)</p> |
| <p>Recognizing Participants Emotion & Approach in Facilitating Hope</p> | <p>“participants’ hope of recovery was their main motivation, giving them the courage to continue” (A1)</p> <p>“Participants described many emotions as a result of being diagnosed with and needing care for GBS, such as frustration, guilt, elation, anger, and gratitude [19, 20]. Other common psychological responses were: feeling lost; feeling abandoned; anxiety when in the intensive care unit or connected to a ventilator; sadness; depression; and fear”</p> <p>“participants’ positive attitude was a major facilitator to their recovery from GBS and helped them realise that life wasn’t over and that things would eventually improve” (A1)</p> <p>“It is all about attitude: if your glass is always half empty, you are going to suffer terribly. The negativity will bring them down, terribly. You have to have a positive mental attitude.” (A2)</p> <p>“Having experienced paralysis and ventilator treatment, they knew that things could happen beyond their control, and</p> |

this knowledge affected things such as the way they handled goodbyes when leaving on a journey.”(A3)

“Some still had great expectations that they would improve their health status, and high hopes for their continuing rehabilitation.”(A3)

“I had no idea what it might be. I was scared. I was told I was faking it...I felt like – honestly, I was 16 at the time, and I felt like my life was over. I was a cheerleader, and I knew that was going to be over now”(A4)

“I’ve always maintained a positive outlook somehow. I don’t know. What else could I do? I mean, all I could do was do what I could do today. And hope that tomorrow was better”(A4)

“I was depressed but I worked through that. I likened my former healthy self to be a 7-foot ladder, and GBS had made me ...I was now a 5-foot ladder. I remembered what I used to do with those two feet that I’d lost. All my functionality that I lost was in that two feet of the ladder. That’s the best way I can express it in the fewest number of 79 words. But my 5-foot was now normal. Whatever’s left will be enough to have a good life”.(A4)

“First, it was just scared, confused, mad, just really angry that this is happening to me. And then in a bit there when I started, sort of, taking my first steps and doing a little bit more progress, it was determined and hopeful.”(A4)

“Another participant described his intense pain as the feeling of muscle tearing as well. He stated “one morning, you know how you stretch after you wake up? I was doing that. And I can’t imagine what it would feel like to have flesh or a muscle tear, but it almost felt like there was some sort of tear that took place, kind of, between my shoulder blades. Maybe just a hair higher than that. And from that point on, I just kept having this pain across the top of my shoulders. And it just kept getting more and more intense. And eventually, it started to radiate down my arms”. (A4)

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| | <p>“The feeling of loss attributed to GBS was exacerbated by the sudden, inexplicable onset of the illness. The onset of GBS disrupted the participants’ entire life in an instant.”(A5)</p> <p>“I could not believe how bad and how sudden it was. One minute you are healthy and the next, that’s history.... I was out at a restaurant with my husband and his colleagues..... The next morning, I tried to get out of bed and my legs felt dead.”(A5)</p> <p>“These days I accept the fact that I have a condition I need to live with. Before, I did not use to accept certain things. I used to say ‘But why me?’.... After the condition, this attitude taught me to live day by day, whatever happens.”(A5)</p> <p>“The women also lived in constant fear of recurrence of GBS” (A5)</p> |
| <p>Support from peer groups, family, friends, and healthcare professionals</p> | <p>“Another facilitator to recovery from GBS was the invaluable support from their family and friends.” (A1)</p> <p>“Participants expressed frustration over the lack of understanding from family and friends in relation to their physical limitations and the effect on the participants’ capacity and everyday life in general.”(A1)</p> <p>“Support from colleagues was also viewed very highly by participants.” (A1)</p> <p>“Peer support was also viewed as really important by participants who valued being able to talk with and receive information from others who had also been ill with and survived.” (A1)</p> <p>‘It certainly helps having good family support’(A2)</p> <p>“The participants also spoke about having received invaluable support in everyday life activities from their family and friends.” (A3)</p> <p>“limited public awareness of Guillain-Barré syndrome could be a hindrance in the work situation, as colleagues might</p> |

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| | <p>not know what was reasonable to demand and what support they could offer”.(A3)</p> <p>“Participants commented on the value of being able to talk with an individual who had also been ill with Guillain-Barre’ syndrome. This provided the participants with hope about recovery and the future”(A4)</p> <p>“I realize now that that can be very beneficial to have someone who – who might’ve gone through something similar”.(A4)</p> <p>“I try dealing with GBS myself. I have a son who is nineteen. I hide from him that I am in pain because I know he worries about me.”(A5)</p> <p>“although they found the physical barriers distressing, they were more upset when they had to face ‘human barriers’. Some friends stopped talking to Rita during and following her illness”(A5)</p> <p>“The importance of a GBS support group was also mentioned, particularly as sharing their concerns with people who went through a similar experience would have made them feel better”(A5)</p> <p>“Parent 6 discussed an ineffective system of support that relies on parents to do the therapy and the care”(A6)</p> <p>“With no one to hold your hand, unless you find someone to help you, you have to be your child's advocate. You have to find out what is available; what services you need. You spend a lot of time researching.»(A6)</p> |
| <p>Dignity & Coordination of Care</p> | <p>“healthcare professionals lacked time to discuss their condition with them properly. Specific needs, whether physical and psychological, were often not met.” (A1)</p> <p>“In the intensive care unit, there was a wonderful nurse. She was absolutely fantastic: she would help me wash and braid my hair to stop it getting tangled. She would spend the most time with me to try and lip read me; but some of the other nurses where not as nice at all; very unpleasant. “(A2)</p> |

Negative experiences often related to staff attitudes to personal care, including hygiene, toileting and feeding, rather than medical treatment.(A2)

«In regard to help and recovery from the medical profession, I would say very poor. There is nothing. No hotline. No helpline. There is GB charities out there that will help you; but NHS, there is not. There must be other rare conditions out there that people who have them, get so frustrated that they just want to talk to somebody. There is no health professional out there.» (A2)

«I did have community physio. That was when I suggested to the physio to see them once a month; and eventually he did agree to that. It was kind of like patient led; it wasn't the system doing it for me. Then I was discharged from the community physio. That was it. I have been left on the scrapheap. I felt like the system had let me down quite badly»(A2)

Participants talked about counselling in terms of support with psychological problems. Unfortunately, participants did not always receive the counselling that they needed.(A2)

having to wait a long time for referrals that evidently delayed the start of rehabilitation(A3)

the nursing staff was really quite nice, quite professional, and very, you know, attentive; but the problem was they were stretched so thin. There were so few nurses on the floor, they would hire...these nurse's aides, and they couldn't speak English; so if you wanted anything you would have to communicate with them through sign language mostly...and so that was a problem...[and] they would come in and tell me to clean my teeth, and they would set the things down in front of me, and I couldn't move my arms...it was just awful”(A4)

“It's those little things the nurses do. And I'm sure they do it for everyone. But they bring you juice first thing when you wake up because when you've been their patient for three nights in a row now, and they know you like that.

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| | <p>And...and when you need them, they're there, as far as nurses go"(A4)</p> <p>"I never got any letters for a follow-up appointment, since I was out of hospital!"(A5)</p> <p>"Today, for example, I had an out-patient appointment. I spent more time waiting rather than being seen by the medics. I would barely have the time to tell them how I am feeling."(A5)</p> <p>"Every time you meet with a clinic or hospital. You are starting at Day 1"(A6)</p> <p>"Parents noted that children's health care appointments were treated as separate entities not related to a larger plan of care. "(A6)</p> <p>"Parents also experienced limited collaboration and integration by HcPs toward an overall medical plan for their child, resulting in ineffective care and/or limited coordination of supports or resources"(A6)</p> |
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Appendix 3: Theme Analysis

| | Article 1 | Article 2 | Article 3 | Article 4 | Article 5 | Article 6 |
|--------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------|
| Topic | <p>Lack of info & knowledge</p> <p>Positivity towards recovery</p> <p>Attitude of HcP</p> <p>Support</p> <p>Dignity</p> <p>Participants Attitude</p> <p>Coordination of care</p> | <p>Knowledge of GBS</p> <p>Patients' hope & positive outlook</p> <p>Active support</p> <p>Communication/Information</p> <p>Maintaining independence</p> <p>Time/presence</p> | <p>Knowledge of GBS</p> <p>Facilitating hope & positive outlook</p> <p>Continuous support & rehab</p> <p>Involvement of family & significant others</p> <p>Continuity of care</p> <p>Flexible care</p> <p>individualized plan of care</p> <p>Information dissemination</p> <p>Accessible healthcare facility</p> | <p>Pain</p> <p>Attitude of HcP</p> <p>Attitude of patients'</p> <p>Knowledge</p> <p>Peer contact</p> <p>Time/understaffing communication</p> | <p>Attitude of HcP</p> <p>Support from family, peer group</p> <p>Participants attitude</p> <p>Feeling of helplessness</p> <p>Continuity of care</p> | <p>Lack of knowledge from HcP</p> <p>Support from the Healthcare team</p> <p>Coordination of care</p> |
| Theme | Individualized Plan of Care | Knowledge about GBS | Communication & Information | Recognizing Participants Emotion & Attitude in Facilitating Hope | Support from peer groups, family, friends, healthcare | Dignity & Coordination of Care |

| | | | | | | |
|--|------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|-------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | | | | team | |
| | <p>Attitude of HcP</p> <p>Time/presence</p> <p>Flexible & individualized plan of care</p> <p>Attitude of HcP</p> <p>Maintaining independence</p> | <p>Article 1, 2, 3,6</p> | <p>Information dissemination</p> <p>Communication/Information</p> | <p>Positivity towards recovery</p> <p>Participants Attitude</p> <p>Patients' hope & positive outlook</p> <p>Facilitating hope & positive outlook</p> <p>Fear of uncertainty</p> <p>Fear of dying</p> <p>Lost of body function</p> <p>Hope</p> <p>Feeling of helplessness</p> | <p>Support from family, peer group</p> <p>Support from the Healthcare team</p> <p>Involvement of family & significant others</p> <p>Active support</p> <p>Support from family, friends, colleagues</p> | <p>Dignity & Coordination of care</p> <p>Continuous support & rehab</p> <p>Continuity of care</p> <p>Coordination of care</p> <p>Accessible healthcare facility</p> |

Appendix 4: CASP Checklists

Exploring the experiences of having Guillain-Barré Syndrome: A qualitative interview study – Akanuwe et al.

1. Was there a clear statement of the aims of the research? YES

This was stated in abstract and introduction.

2. Is a qualitative methodology appropriate? YES

They want to explore the experiences of people with GBS in the UK.

Is it worth continuing? YES

3. Was the research design appropriate to address the aims of the research? YES.

Since the study explores the experiences of patients having GBS it was therefore appropriate that they used qualitative interview study through face to face and telephone interviews. They also used the Framework Method which was supported by NVivo 11 to transcribe the audio-recorded data to be able to analyse and transcribed collected data.

4. Was the recruitment strategy appropriate to the aims of the research? YES.

They used purposive sampling to recruit volunteers with these inclusion criteria: people with a prior diagnosis of GBS who had been discharged from hospital; can be able to give informed consent; can speak and understand English; resident in the UK. For them to be able to ensure variation in the characteristics and range of experiences, they selected participants based on age, sex, marital status, location, time since diagnosis and length of hospital stay.

5. Was the data collected in a way that addressed the research issue? YES.

The timeframe of the interview was stated. Interviews were either face-to-face or over the phone according to the participant's preference. Study information sheets and consent forms were also emailed to potential participants.

6. Has the relationship between researcher and participants been adequately considered? Not stated? YES. They described the interviewer's background and stated that he had no prior relationship with the 16 participants and that his knowledge and personal views did not influence the interviewees. Other members of the research team were also described.

7. Have ethical issues been taken into consideration?

They gained ethical approval from ethics committee of the University of Lincoln. Verbal and written informed consent form were also secured prior to the interviews.

8. Was the data analysis sufficiently rigorous? YES.

They followed the Consolidated Criteria for Reporting Qualitative Studies to ensure the research's transparency and trustworthiness. They also reached data saturation after data analysis from the 16 participants which means that there is already enough information to replicate the study.

9. Is there a clear statement of findings? YES.

They were able to clearly present the themes. They presented it in this order: importance of early diagnosis (trajectory onset phase); experience of inpatient care (crisis phase); active support for recovery (crisis and acute phases); communication, awareness, knowledge and information provision; and redefining recovery (stable phase).

10. How valuable is the research? Valuable, they stated in this research some of the factors that can affect patients coping and recovery. They also identified that further research about current and future health-care provision and support for individuals with GBS and other related conditions.

Patients' experiences and perceptions of Guillain-Barré syndrome: A systematic review and meta-synthesis of qualitative research – Laparidou et al.

1. Did the review address a clearly focused question? YES.

The review question was clearly stated in the methods: "What are the patients' experiences and perceptions of GBS and chronic inflammatory

demyelinating polyneuropathy (CIDP) and its care at diagnosis, discharge and during recovery?"

2. Did the authors look for the right type of papers? YES.

They included studies that has a qualitative research design and that reported patients' lived experience of GBS and CIDP.

Is it worth continuing? YES

3. Do you think all the important, relevant studies were included?

Maybe not. They excluded articles that are not written in English language which may have excluded important evidence.

4. Did the review's authors do enough to assess quality of the included studies? YES.

Independent reviewing and screening were done by the three reviewers. Whenever necessary and when there's any disagreement that arise over the eligibility of references, it was resolved with discussion and consultation with a fourth reviewer. They also used the CASP Qualitative Checklist to assess the quality of the research.

5. If the results of the review have been combined, was it reasonable to do so? YES.

It was well categorized into six analytical themes.

6. What are the overall results of the review? 6 analytical themes were

developed by following a GBS patient's journey. Results showed that there are several factors that can affect recovery positively and negatively. Participants in this study experienced lack of knowledge among healthcare professionals and lack of information about GBS as a negative factor affecting recovery. They also felt that needs were not being met due to fractured healthcare, lack of continuity and personalized care.

7. How precise are the results? Can't tell. The confidence interval was not given.

8. Can the results be applied to the local population? YES.

The participant covered by this study was patient diagnosed with GBS.

9. Were all important outcomes considered? YES.

10. Are the benefits worth the harms and costs? YES.

This systematic overview and meta-synthesis were definitely worth the time and effort doing. It suggests things that we can do to improve healthcare delivery and caring for patients with GBS.

Balancing everyday life two years after falling ill with Guillain-Barré syndrome: a qualitative study. - Forsberg, A. et. al.

1. Was there a clear statement of the aims of the research? YES.

It was specifically stated in the research abstract.

2. Is a qualitative methodology appropriate? YES.

The research aims to describe the experiences of disability in everyday life and managing the recovery process two years after being diagnosed with GBS.

Is it worth continuing? YES

3. Was the research design appropriate to address the aims of the research? YES

A qualitative research approach was used in this study based on individual Interviews with persons two years after the onset of GBS.

4. Was the recruitment strategy appropriate to the aims of the research? YES.

The participants were identified from a previous longitudinal study. Out of the 42 patients who were sent written information about the interview study, there were 35 of them who agreed to participate, 5 of them declined because they felt uncomfortable being recorded and 2 declined without stating the reason.

5. Was the data collected in a way that addressed the research issue? YES.

Semi-structured interview was used, and all the interviews took place in the homes of the participants. They did not discuss the data saturation.

6. Has the relationship between researcher and participants been adequately considered? NO.

They have not directly discussed the researchers' role.

7. Have ethical issues been taken into consideration? YES.

Written information was sent prior to the interview study and participation was based on verbal informed consent. They followed the principles of Declaration of Helsinki, and the approval was given by the research ethics committee.

8. Was the data analysis sufficiently rigorous? YES.

Data analysis process was presented. All authors were active in analysing the data. They derived one overall theme and four categories from the analysis. Bias was not discussed.

9. Is there a clear statement of findings? YES.

They discussed and presented their findings according to the research purpose.

10. How valuable is the research? Valuable.

Gaining an understanding that two years after falling with GBS can still give the patient bodily symptoms and a persistent loss of energy suggesting that there's still a need for rehabilitation interventions and support is still needed by this patient group the coping to manage everyday life and disability.

“It is like a jungle gym, and everything is under construction”:The parent's perspective of caring for a child with a rare disease. – Currie & Szabo

- 1. Was there a clear statement of the aims of the research? YES.** But it could have been stated clearer.
- 2. Is a qualitative methodology appropriate? YES.** Though this research seeks to interpret the experiences of parents of children with rare disease, the use of interpretive phenomenological approach (IPA) was appropriate. IPA is a method of qualitative enquiry that facilitates researchers to construct insightful interpretative accounts of experiences that enriches understanding and gives enlightenment to prominent matters in healthcare.

(Peat et. Al, BMJ Journals)

Is it worth continuing? YES

3. Was the research design appropriate to address the aims of the research? YES. They described interpretive inquiry and why it was opted for use.

4. Was the recruitment strategy appropriate to the aims of the research? YES. Participants were selected through the use of purposive sampling. Participants background and why were they selected as part of the study were also discussed.

5. Was the data collected in a way that addressed the research issue? YES. Researches justified that although the population was small, the sample size was typical for the type of method used. Interviews were conducted separately in the cases where both parents wished to participate in the study. Saturation was also discussed.

6. Has the relationship between researcher and participants been adequately considered? NO.

7. Have ethical issues been taken into consideration? YES. Anonymity of the participants was preserved and confidentiality was also confirmed.

8. Was the data analysis sufficiently rigorous? YES. Data were analyzed considering reflexivity throughout the process and interpretation was accompanied by observation, reflection, interpretation, reading, writing, and rewriting of the constructed texts.

9. Is there a clear statement of findings? YES. Results were discussed according to themes.

10. How valuable is the research? Highly valuable. Researchers have discussed that findings in this study could be transferable to other rare diseases. They also mentioned that the study contributes to HcP's understanding parent's perceptions of caring for children with rare disease related to supportive care needs.

Living with Guillain-Barre Syndrome – Chetcuti et al.

1. **Was there a clear statement of the aims of the research?** YES. The purpose was to explore the meaning of living with GBS in a Maltese community setting following discharge from hospital which was stated in the Abstract.
2. **Is a qualitative methodology appropriate?** Yes. The research seeks to illuminate the subjective experiences of research participants.
Is it worth continuing? YES
3. **Was the research design appropriate to address the aims of the research?** Yes. A qualitative design using the Heideggerian hermeneutic phenomenological approach was used which was an ideal method for this study as it addresses the complexity of individual experience.

4. Was the recruitment strategy appropriate to the aims of the research?

Yes. Potential participants were identified via the ITU patient database of a Maltese state general hospital, followed by the recruitment which was done through purposive sampling. Sample size was appropriate as it allowed for an in-depth review into the participants' experiences.

5. Was the data collected in a way that addressed the research issue?

Yes. Participants were interviewed twice in locations chosen by the participants. A gap of 6 weeks was used between the first and second interview to listen and re-listen to the audio-recordings and transcribe them. Saturation was not discussed.

6. Has the relationship between researcher and participants been adequately considered? No. Not stated.

7. Have ethical issues been taken into consideration? Yes. Approval of the study was granted by the University of Malta Research Ethics Committee. Interested participants who were willing to participate were also asked to sign a consent form.

8. Was the data analysis sufficiently rigorous? Yes. Data analysis led to the identification of three super-ordinate themes, namely Lost at Sea, Propelled into Change and The Aftermath.

9. Is there a clear statement of findings? Yes. Findings were explicitly described. The trustworthiness of the interview were already felt in the second

interview, thought they were open to the potential limitation of unconducted third brief interview.

10. How valuable is the research? Valuable. The study findings generate a number of recommendations for practice. Participants talked about the barriers they had to face while dealing with GBS, decreasing this would enable persons with GBS to cope better with the disease.