

The Value of Peer Contact in Patients Impacted by Rare Disease

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Background

- Guillain-Barre' syndrome (GBS) classified as a rare disease and is the leading cause of flaccid paralysis
 - Impacts less than 200,000 Americans concurrently
 - Impacts more than 5000 patients annually with an incidence of 1.1 to 1.8 cases per 100,000 individuals (McGrogan, Madle, Seaman, and de Vries, 2009)
- Autoimmune in nature and impacts peripheral nervous system (molecular mimicry)
- Accompanied by a variable clinical course (Walgaard et al., 2011)
 - Mild to severe cases
 - Related to variant of GBS (AIDP, AMAN, AMSAN, MFS)
- Moderate to severe cases cause significant prolonged disability in patients that can be permanent

Significance

- Rare diseases, like GBS, pose special challenges for patients, their support systems, and providers making these illnesses a critical public health concern (National Institutes of Health, 2014; Schieppati et al., 2008)
- Challenge to manage for the entire healthcare team, but particularly nurses (Haldeman & Zulkosky, 2005; Murray, 1993; Sulton, 2002; Walsh, 2006)

Significance

- Nursing plays a significant role in the provision of care to individuals with rare diseases including Guillain-Barre' syndrome
- GBS patients have reported that nursing care was inconsistent (DeCort, 2011)
- Patients have disclosed that nurses do not have an awareness of the unique care needs of GBS patients which leads to stress and discomfort for patients (DeCort, 2011)

Significance

- Few empirical or published case studies (Walsh, 2006)
- Patients have described their experience in the way of personal accounts (Bowes, 1984; Henschel, 1978; Rice, 1977; Shearn & Shearn, 1986)

Purpose

- To gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome

Research Questions

- What are individuals recalled experiences of care and caregiver interactions during an episode of moderate to severe Guillain-Barre' syndrome?
- What do individuals recall about the characteristics and environmental conditions of the clinical area(s) where they received care?
- How do individuals describe their change in knowledge of GBS over time from pre-diagnosis to current time?

Theoretical Framework

Orem's Self-care Deficit Theory of Nursing

- Patients who experience a diagnosis of moderate to severe Guillain-Barre' syndrome will experience self care deficits because of the physical and psychosocial impacts of this illness and will require nursing care to meet these needs
- Nurses should have qualifications to develop and deliver nursing care to patients who require nursing assistance (Orem, 1995)

Research Design

- Qualitative descriptive design utilizing inductive content analysis
- Rationale for design:
 - Qualitative descriptive design equips researchers with techniques that can explore a participant's view of a human problem (Creswell, 2009)
 - Allows for the rich discussion of an individual's experience keeping the researcher close to the data (Neergaard et al., 2009)
 - Paucity of literature related to this phenomenon

Recruitment Strategies

- Primary Participant Recruitment Strategies:
 - Email notification of the Guillain-Barre' Syndrome/ Chronic Inflammatory Demyelinating Polyneuropathy Foundation International's network of members (specific geographic area)
 - Posted Research Announcement on GBS Foundation Website and Facebook Page
 - Snowballing technique (chain or networking)
- Combination of these recruitment strategies allowed for maximum variation in participants
- 84 individuals responded to the research announcement

Inclusion Criteria

- Adults 18 years of age and older
- A prior self-identified diagnosis of moderate to severe Guillain-Barre syndrome
- Alert and oriented
- Able to respond to interview questions
- English as a primary or secondary language
- Able to give informed consent

Final Sample

- 14 participants who self-identified as having moderate to severe GBS
- Participants were from eight states including *Alabama, Arizona, California, Florida, Georgia, Mississippi, North Carolina, Texas*
 - Nine interviews were conducted face-to-face in-person in five different states
 - Five interviews were conducted face-to-face electronically

Data Collection

- Began after signed Research Consent Form had been received
- Demographic Questionnaire
 - 30 items
 - Created by primary researcher
- Method of completion
 - Face-to-face in-person interview – written responses
 - Face-to-face electronic interview – emailed to participant who completed the form, scanned the document and returned the form electronically to the researcher's secure email

Demographics

- 10 females (71.4%) and four males (28.6%)
- Age Range at onset of illness: 16 – 76 (average age 49.2)
- Age Range at time of interview: 19 – 79 (average age 60.8)
- Caucasian: 12/14 (85.7%)
- Married at onset of illness: 10/14 (71.4%)
- Hospitalized during course of illness: 14/14 (100%)
- Emergently admitted to hospital: 12/14 (85.7%)
- Required ICU Level Care: 10/14 (71.4%)
- Days in hospital ranged from: 5 – 405 days

Data Collection and Analysis

- Semi-structured Interview Guide
 - 11 question tool developed by primary researcher
 - Based on review of the literature and researcher's professional encounters
 - Several additional probing questions
- Interviews were digitally recorded and transcribed verbatim
 - Lasted between 35 and 110 minutes
 - Generated between 19.5 and 98.25 pages of double spaced text with transition from participant to researcher beginning on a new line of text
- Manual qualitative content analysis
 - Qualitative data analysis software was not utilized

Data Analysis Process

- Researcher utilized data analysis process outlined by Graneheim and Lundman (2004) including the following steps:
 - looked for statements that revealed a central meaning
 - defined and identified meaning units (Graneheim & Lundman, 2004)
 - established a code for that segment of data (Creswell, 2009)
 - created categories
 - Evaluated the relationship between the codes and categories to determine themes
 - Data analysis process and findings were discussed weekly with a peer debriefer (Dr. K. Stegenga)

Results

- Five major themes and 14 subthemes
 - Theme 1 Physical Manifestations of GBS
 - Theme 2 Attitudes and Emotions
 - Theme 3 Knowledge and Awareness
 - Theme 4 The Value of Peer Contact
 - Theme 5 Care Concepts

Theme 1: Physical manifestations of GBS	ST1: “ A Strange Sensation”
	ST2: A Rationalizing of Symptoms
	ST3: “The Downward Spiral”
	ST4: Pain and Fatigue
Theme 2: Attitudes and Emotions	ST5: The “Emotional Rollercoaster”
	ST6: “Attitude is Everything”
	ST7: Seeking Independence
	ST8: Concerns for Others
Theme 3: Knowledge and Awareness	ST9: “No Earthly Idea what GBS was”
	ST10: A Desire for More Knowledge
Theme 4: The Value of Peer Contact	
Theme 5: Care Concepts	ST11: Staff Knowledge and Available Information was “Remarkably Absent”
	ST12: Personalized Patient Centered Care
	ST13: Communication with Caregivers
	ST14: Impact of Achievements

Focus: Theme 4

- Theme 4: The Value of Peer Contact

Theme 4 Conclusions: Value of Peer Contact

- Participants described the importance of communication from other individuals who had experienced GBS

Information from other sources

- Information is critical in assisting individuals cope with illness
- Individuals with rare diseases often become the “information experts”
- Information Donors

Spring, 2014

Information from other sources

- Individuals found value in connecting with people impacted by the same illness
- “Experience [camaraderie] with others sharing a similar distress” (Doyle, 2015, p.66)
- Information regarding experiences from individuals with the same illness lead to coping strategies and contributed to one’s confidence and hope (Engler et al., 2016)

Recommendations for Practice and Education

- Resources are available on many rare diseases including GBS
 - Healthcare professionals and students should be educated on how to access these resources

Recommendations for Health Policy

- Create a National (or International) Rare Disease Patient Registry
- Develop standardized nomenclature and organizational structure regarding rare disease information

Recommendations for Future Research

- Further study including multiple methods to address research questions that:
 - Extend the findings of this study related to GBS (and other rare diseases) patient care needs
 - Address family members/support systems

Questions

- Questions
- Contact
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