

Title:

The Value of Peer Contact in Patients Impacted By "Rare" Diseases

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Session Title:

Global Management of Chronic Conditions

Slot:

L 07: Sunday, 30 July 2017: 8:30 AM-9:45 AM

Scheduled Time:

8:50 AM

Keywords:

Guillain-Barre' syndrome, Patient peer support/peer counseling and Rare disease

References:

Doyle, M. (2015). Peer Support and Mentorship in a US Rare Disease Community: Findings from the Cystinosis in Emerging Adulthood Study. *Patient* 8(1), 65-73.

Locock, L. & Brown, J. (2010). 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). *Social Science Medicine*, 71(8), 1498-1505.

Abstract Summary:

A "rare" disease impacts fewer than 200,000 individuals concurrently. Evidence suggests patients find value talking with peers who share similar illness experiences. This qualitative study indicated that patients with a rare neurological syndrome perceived information received from peers more favorably than from healthcare professionals. This session will discuss this theme.

Learning Activity:

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
The learner will be able to recognize the importance of peer contact in patient's experiencing a rare neurological disease.	Discuss one theme from a qualitative research dissertation study indicating the value of peer support/peer counseling in patients who were diagnosed with Guillain-Barre' syndrome, a rare neurological syndrome.
The learner will be able to list one resource for peer support for patient's experiencing a rare neurological disease.	Provide information that is available to professionals and lay individuals for patient's impacted with Guillain-Barre' syndrome.

Abstract Text:

Purpose: Rare diseases in the United States are defined as illnesses that impact fewer than 200,000 individuals concurrently. Guillain-Barre' syndrome (GBS) is an example of a rare disease that impacts the peripheral nervous system. With the eradication of polio, GBS has become the leading cause of paralysis in the U.S. GBS is an autoimmune illness that generally results in areflexia, paresthesias, and the potential for temporary yet total paralysis.

Because of the significant morbidity that patients face subsequent to the onset of this syndrome, a study was designed to better understand the patient's experience related to this illness. The stated purpose of the study was to gain a richer understanding of the patient's recalled experience of an acute episode of moderate to severe Guillain-Barre' syndrome.

Methods: The study utilized a qualitative descriptive research design with inductive content analysis. Criteria for inclusion in the study were: (a) adult patients 18 years of age and older, (b) individuals with a prior self-identified diagnosis of moderate to severe Guillain-Barre syndrome, (c) individuals who were alert and oriented, (d) individuals able to respond to interview questions, (e) individuals with English as a primary or secondary language, and (f) those who were able to give informed consent.

Results: Fourteen individuals were interviewed about their experience with moderate to severe Guillain-Barre' syndrome. These participants were from 8 states representing primarily states located within the southeastern part of the United States. Seventy one point four percent of the participants were female and 28.6% were male. All of the participants were hospitalized ranging from 5 days to 405 days. Three research questions were addressed through description of five themes and 14 subthemes. This presentation will focus on one of the themes. The theme of focus revealed the value expressed by participants related to contact with a peer who had been impacted with the same illness. There is additional evidence to suggest that patients find value in talking with peers who share a similar illness experience (Doyle, 2015). Having contact with a peer provided hope about what the future may hold including the potential for recovery. Participants described that information shared by someone who had experienced the illness was perceived as being more impactful than information shared by healthcare professionals. Information from individuals impacted with the illness was considered more impactful because it created reassurance that recovery was possible. Information from peers was also seen as being more credible than information from professional caregivers.

Conclusions: Additional research is needed with more individuals impacted with rare illnesses focusing on the value of peer support/peer counseling. It is important for patients diagnosed with Guillain-Barre' syndrome to be linked to the GBS/CIDP Foundation so that peer counselors can be linked if so desired by the individual impacted by this rare neurological illness.