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AN INQUIRY INTO THE MEANING OF GUILLAIN-BARRÉ SYNDROME

by

Janet-Lee Mace

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MASSEY UNIVERSITY**ABSTRACT****An Inquiry into the Meaning of Guillain-Barré Syndrome**

By Janet-Lee Mace

Supervisors: Associate Professor Kerry Chamberlain and Dr Robert Gregory. School of Psychology.

Guillain-Barré Syndrome (GBS) is an autoimmune syndrome characterized by a severe and rapid onset of paralysis that ascends without warning. It has an unknown aetiology and is generally unknown by most people, including medical professionals. When a person who has had GBS is asked to speak about their experience, they are likely to talk about aspects of it that are personally meaningful. Their account can be likened to a story in that it collates seemingly unconnected facts, episodes of activity and emotional attributions into a sequence that provides knowledge and understanding. A story is a powerful form for expressing suffering and experiences and so is particularly suitable for the study of trauma and illness. The actual process of creating the story, plus its presentational and organisational forms, provides sources for uncovering the identities authors choose to create and present of themselves. Six people who have had GBS were interviewed about their experience, and their stories were analysed using a narrative inquiry to discern the meanings attributed to GBS from the participants' own understandings and perspectives. The intended focus of the research was holistic and content based. The result of the narrative inquiry was a plot common to all six narratives. Namely, GBS is an inexplicable condition, during which horrendous things happen, but people do recover with time and it is likely their life view will be changed in the process. Four fundamental issues, identity, meaning, making sense and meaningfulness were drawn from the stories and configured into a narrative of the researcher's making. What the participants chose to speak about became the meanings, or themes, major and minor, of their stories. No event has meaning in itself, however traumatic events can precipitate crises of meaning. When these crises are viewed within the context of other events, and are perceived to add value to life, then they have meaningfulness. In the telling of meanings and meaningfulness, the purpose for storying and the audience to whom the story is directed are the criteria for which the storylines are chosen. Both the story and the storying provide opportunities for the authors to create and offer images of themselves, that are then open to interpretation by an audience. As a traumatic experience, GBS enabled six people to tell their stories. In doing so they were able to make sense of important issues for themselves, and re-examine the way they saw themselves and the world.

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PREFACE

Imagine ...

One day you wake up and there's a strange numb, tingling feeling in your legs. You get up out of bed and feel a bit wobbly on your feet. Bit strange, you know you hadn't been drinking last night. You stagger back to bed and next time you want to get up to go to the toilet, you can't get up.

Alternatively, you are going about your daily business, and you feel extreme pain, so much so that it stops you from doing what you intended. Each day it gets worse, and so does the numbness around your middle. "This is ridiculous, really," you say. You go to the doctor, who repeats, "No, nothing is wrong." So one day you're in the kitchen and wham, the next minute you're "just laying there heaped up on the floor." You can't get up. Can't move, too weak. Your legs feel like jelly, or worse they don't even feel.

Or imagine this ...

You are a young woman and pregnant with your first baby. At 38 weeks you come out in hives. Within 24 hours you look like you have had a stroke. You are taken to an Intensive Care Unit (ICU) and placed on a ventilator because the paralysis that started with pins and needles in your feet has progressed up your body to your face and head. Your baby is delivered straight away, but this is just the beginning

This is Guillain-Barré Syndrome (pronounced Gee-lane Bah-ray). Paralysis, out of the blue, quick and possibly total, you are left unable even to breathe without mechanical assistance.

Your brain is unaffected, but the rest of your body is totally dependent on machines or other people for its basic requirements. You cannot speak to communicate your needs. You cannot feel the gentle touch of your loved ones, but you can jolly well feel the incredible pain deep within your body.

What would that be like? What does it mean? How would you make sense of that?

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