

Intravenous Immunoglobulin Treatment, Illness Intrusiveness, and Quality of Life in Neurological Autoimmune Patients

Pamela J. Gennari, PhD

Abstract

There is scant literature regarding the psychological effects of intravenous immunoglobulin (IVIG) treatment experience on quality of life (QOL) for neurological autoimmune disease patients diagnosed with multiple sclerosis, multifocal motor neuropathy, myasthenia gravis, and chronic inflammatory demyelinating polyneuropathy. IVIG treatment experience predicted QOL in 1 Neuro-QOL subscale; illness intrusiveness mediated 9 of the Neuro-QOL subscales using bias-corrected bootstrapping for statistical significance; and personal control did not mediate the relationship between illness intrusiveness and QOL.

Problem

IVIG (a purified blood product providing healthy antibodies) is the treatment of choice for the four neurological autoimmune diseases examined (MS, MMN, MG and CIDP).

The **high cost of the therapy, complicated schedules, and long hours** of infusions may cause disruptions to the lives of the neurological autoimmune patients who receive it **affecting illness intrusiveness**.

Illness intrusiveness has been shown to be a **mediator in other chronic diseases** (Dancey, Hutton-Young, Moye, & Devins, 2002; Shawaryn et al., 2002).

Control was examined as a mediator between illness intrusiveness and QOL which might shed light on why some patients may be more affected than others by the treatment.

Purpose

The purpose of this quantitative, survey research study was to examine the relationship between the **IVIG treatment experience** (predictor variable) and **QOL** (outcome variable) in neurological autoimmune patients. **Illness intrusiveness** and **personal control** were studied as potential mediators.

Relevant Literature

The **illness intrusiveness framework** posits that disease and/or treatment factors affect illness intrusiveness which directly affects QOL. Illness intrusiveness is a mediating variable between the disease treatment and QOL (Devins, 2010).

QOL is compromised and perception of control decreased when the disease treatment interferes with goals, interests, and enjoyable activities (Devins, 2010; Poochikian-Sarkissian et al., 2008).

Treatment factors have been shown to be affiliated with increased illness intrusiveness (Bettazzoni et al., 2008; Devins et al., 1990; Poochikian-Sarkissian et al., 2008).

Research Questions

RQ1: Is the IVIG treatment experience (as measured by the Visual Analogue Scale) a significant predictor of QOL (as measured by 10 Neuro-QOL scales) in patients with autoimmune disorders who receive IVIG treatment?

RQ2: Does illness intrusiveness mediate the relationship between IVIG treatment experience and QOL (as measured by 10 Neuro-QOL scales) among individuals with autoimmune disease who received IVIG treatment?

RQ3: Does personal control mediate the relationship between illness intrusiveness and QOL (as measured by 10 Neuro-QOL scales) among individuals with autoimmune disease who receive IVIG treatment?

Procedures

The sample was convenience/nonrandom, and included 25 male and 54 female patients. Diagnoses were 30 MS, 25 CIDP, 13 MG, and 11 MMN.

Surveys included the IVIG experience visual analog scale, the IIRS scale, MHLC-Form C, and 10 Neuro-QOL subscales.

Data Analysis

Mediation analysis was used to estimate the coefficients of the model, analyze, and interpret the direct, indirect, and total effects (paths *a*, *b*, *ab*, *c*, *c'*).

Bias-corrected bootstrap confidence intervals were estimated as well as effect sizes (Hayes, 2013).

Noted in Table 1 are the results of mediation analyses of the 10 Neuro-QOL variables: satisfaction with social roles & activities, depression, fatigue, positive attitude & well-being, sleep, stigma, cognition, emotional & behavioral dyscontrol, lower extremity function, and upper extremity function.

Table 1

QOL Outcomes	P - Value	Variance Explained	Mediation/ Effect Size
SSRA	$p < .001$	46%	Yes/ Medium
Depression	$p < .001$	33%	Yes/ Medium
Fatigue	$p < .001$	39%	Yes/ Medium
PAWB	$p < .001$	27%	Yes/ Medium
Sleep	$p < .001$	36%	Yes/ Medium
Stigma	$p < .001$	25%	Yes/ Medium
Cognition	$p = .001$	16%	Yes/ Medium
EBD	$p < .001$	20%	Yes/ Medium
LEF	$P = .01$	11%	Yes/ Small
UEF	$p = .353$	3%	None

Results

RQ1: IVIG treatment experience significantly correlated with QOL PAWB.

RQ2: Illness intrusiveness mediated the relationship between IVIG treatment experience and 9 of the Neuro-QOL subscales.

RQ3: Personal control did not mediate illness intrusiveness and QOL.

Limitations

All 79 patients came from the same infusion center so generalizing to similar centers may be possible but a national population generalization may not be possible.

Patients could not be randomly selected, but volunteered. Question #13 of the IIRS was inadvertently omitted from the survey given to participants.

Conclusions

Findings show that how patients interpret or perceive the level of intrusiveness of IVIG influences their QOL.

The indirect effects showed the more positive the IVIG experience the less the patient experienced illness intrusiveness and vice versa in 9 areas of QOL. **Less illness intrusiveness indicated increased QOL.**

The results may be helpful in identifying areas where IVIG patients deem the treatment experience interferes with their lifestyle.

Social Change Implications

This study expands research for immunoglobulin (Ig) therapy and serves to advance the practice of nursing and education, management, and clinical practice for patients receiving this treatment.

Results from the study may provide insight for interventions to assist patients in adjusting to treatment.

Dissertation Chair: Silvia Bigatti; Second Committee Member: Rachel Piferi; University Research Reviewer: Susan Marcus