

275 IMPACT OF CARING FOR SOMEONE WITH A RARE RHEUMATIC CONDITION: VIEWS FROM PATIENTS AND INFORMAL CARERS

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Background: ANCA-associated vasculitis is a rare multisystem disease. Modern therapeutic protocols have turned ANCA-associated vasculitis from an acute frequently fatal disease into a chronic disease requiring long-term immunosuppression. Patients must often manage substantial burdens related to chronic illness and treatment-related side effects. Patients often need help and support to manage their disease. The aim of this study was to explore the experience of patients and of informal carers of patients about the impact of managing a rare rheumatic condition.

Methods: A qualitative approach using semi-structured interviews was used. Interviews were conducted with a purposeful sample of 18 pairs of patients with ANCA-associated vasculitis and their informal carers. The interviews were used to explore the participants experience and affects of caring. The interviews were recorded and transcribed as verbatim text and analysed using the framework technique.

Results: 18 patients (seven female) [disease: ten granulomatosis with polyangiitis (GPA); four microscopic polyangiitis (MPA); four eosinophilic granulomatosis with polyangiitis (EGPA), age range 34-78, disease duration 1- 20 years. Caregiver and patient perspectives were shared. The emerging themes were the physical and psychological impact of the disease, the need for constant vigilance and fear of the future.

Conclusion: Both patients and carers faced a range of challenges in managing a rare condition. From the seriousness of the illness, dealing with the emotional toll and knowing what to expect. This study offers insight into the experiences of patients and informal carers and health care professionals should address individuals' fears and expectations for recovery.

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