

# The Diagnosis of Hereditary Angioedema: Family Caregivers' Experiences

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The aim of this study was to understand the experiences of family caregivers in the process of diagnosing hereditary angioedema. An interpretive and qualitative research methodology based on Gadamer's philosophical hermeneutics was carried out. Data collection took place between May 2015 and August 2016 and included a focus group and in-depth interviews with 16 family caregivers. Two themes define the experiences of family caregivers: 'Family life focuses on identifying the problem' and 'Discovering and coping with a complex diagnosis.' The process of diagnosis generates fear, anxiety, uncertainty, and incomprehension. Family caregivers are the main support for patients diagnosed with hereditary angioedema. As they share in the patients' suffering, they need a diagnosis to be established to be able to cope with the disease and offer support. Family health nurses can contribute to improving the coping process in this phase of the disease. © The Author(s) 2018.

burden of illness

family caregivers

hereditary angioedema

phenomenology

rare diseases