

# Burden of Illness and Quality-of-Life Measures in Angioedema Conditions



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## KEYWORDS

- Angioedema • Quality of life • Depression • Anxiety • Burden
- Health-related quality of life • Patient-reported outcomes

## KEY POINTS

- Health-related quality of life (HRQoL) is a multidimensional concept based on subjective perception by the patient over the impact of a disease or condition or its treatment on the physical and emotional well-being.
- HRQoL assessment requires the use of validated questionnaires.
- HRQoL is decreased in chronic spontaneous urticaria (especially when associated with angioedema) and in hereditary angioedema caused by C1-inhibitor deficiency (C1-INH-HAE).
- Higher levels in depression and anxiety have been observed in patients with histaminergic angioedema as part of chronic spontaneous urticaria and in patients with C1-INH-HAE compared with general population.
- An important humanistic and economic negative impact has been elucidated in burden of illness studies in C1-INH-HAE, with impairment during angioedema attacks and in free-attacks periods, and affecting patients and caregivers.

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## INTRODUCTION

Health-related quality of life (HRQoL) is a term that has been conceptually evolving during the last decades.<sup>1–5</sup> As a simple and summarizing definition one can say that HRQoL is the individual perception of the impact of a disease, disability, or symptom across physical, psychological, social, and somatic domains of functioning and well-being. Evaluating HRQoL is commonly accepted as important for a comprehensive assessment of the patient health status, burden of disease, and treatment response. Its evaluation may help to identify physical, mental, and social health problems not detected in a conventional clinical assessment.<sup>6–8</sup> HRQoL provides essential information in the development of new drugs, health policy planning, and health resources assignment.

The most commonly used tools for measuring HRQoL are questionnaires that comprise several dimensions (physical, social, emotional, cognitive, working, symptoms, treatment secondary effects).<sup>9</sup> HRQoL questionnaires are one type of the denominated patient-reported outcomes, with increasing relevance in patient-centered medicine.<sup>10</sup> HRQoL questionnaires are classified into generic (eg, Short Form 36 Health Survey [SF-36], EuroQol [EQ-5D], Nottingham Health Profile [NHP]) or specific for a certain disease, symptom, or condition.<sup>10,11</sup> Generic questionnaires have the advantage of allowing comparison between different diseases, but usually show a lack of sensitivity when evaluating certain aspects of a particular disease and thus condition-specific questionnaires are usually preferable for this purpose.

When measuring HRQoL it is advisable to use patient-reported outcomes that meet the quality criteria recommended by experts,<sup>12,13</sup> the most important being feasibility, reliability, validity evidences, and sensitivity to change.

## HEALTH-RELATED QUALITY-OF-LIFE QUESTIONNAIRES

### *Generic Questionnaires*

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#### ***Short Form 36 Health Survey***

SF-36 is one of the most frequently used generic HRQoL questionnaires. It consists of 36 questions and eight domains (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health), besides one single item about perceived change in health.<sup>14</sup> The higher the score, the less disability (eg, a score of zero is equivalent to maximum disability and a score of 100 to no disability). One can further examine a summary of physical QoL (physical component summary) and emotional QoL (mental component summary). Subsequently, version 2.0 (SF-36v.2)<sup>15</sup> and two shorter versions (SF-12 and SF-8) have been created.<sup>16,17</sup>

#### ***EuroQoL***

The EQ-5D consists of three parts: the EQ-5D descriptive system, the EQ visual analog scale, and the EQ-5D index (index value attached to an EQ-5D state according to a particular set of weights).<sup>18</sup> The EQ-5D descriptive system comprises the following five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has three (EQ-5D-3 L) or five severity levels (EQ-5D-5 L). The index-based values (or utilities) are a major feature of the EQ-5D instrument, facilitating the calculation of quality-adjusted life years (QALYs) that are used to inform economic evaluations of health care interventions. There is also a version for children from 7 to 12 years old, called EQ-Youth version (EQ-5D-Y).<sup>19</sup> It is a short and easy tool (it takes 2–3 minutes to be completed) and has been applied in a wide range of health conditions and treatments.

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