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Quality of life in patients with hereditary angioedema correlates with angioedema control: our experience at Chandigarh, North India.

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Rationale: Hereditary angioedema (HAE) is characterized by recurrent episodes of subcutaneous and/or submucosal edema. HAE is a chronic disease and leads to major impact on quality of life (QoL). Lack of 1st line medications for treatment of HAE in India may lead to poor disease control and add to the poor QoL. However, there are no data on quality of life in patients with HAE in India. Angioedema quality of life (AEQoL) scale is a valid tool for assessment of QoL in patients with HAE.

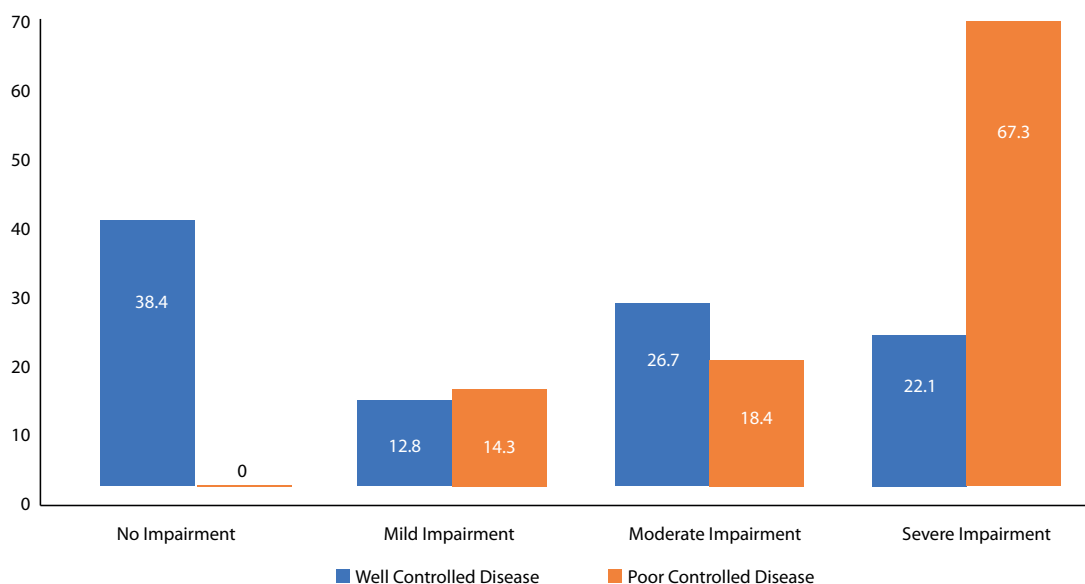
Methods: Patients with HAE > 18 years were enrolled from the Allergy Immunology Unit at Postgraduate Institute of Medical Education and Research, Chandigarh, India. Patients were interviewed telephonically by a team of experts (Clinical psychologist and fellows in Pediatric Clinical Immunology and Rheumatology). AEQoL has 17 items grouped into four dimensions: functioning, fatigue and mood, fear and shame and food. All items are rated on 5-point Likert scale. The overall score range between 0-100. Disease control was assessed by angioedema control test (AECT) within recall period of 4 weeks.

Results: One hundred thirty-five patients were enrolled in the present study (Age range 18-80 years; mean age 40.93 years). Of these, 75.5% patients reported mild to severe impairment in their QoL (23.7% reported moderate impairment while 38.5% reported severe impairment).

63.7% patients reported poor control of disease. Of these, 14.3% reported mild, 18.4% moderate and 67.3 % had severely impaired QoL. Poor control over disease had significant impact on QoL (p 0.000).

34.1% patients were concerned about unpredictability of disease and 28.9% reported that their disease was much controlled with therapy in last 1 month.

Conclusion: This is the first study to report quality of life in patients with HAE in India. Approximately 2/3rd patients have poor quality of life and it negatively correlates with disease control. Availability and access to 1st line treatment options for HAE is the need of hour.



Bar chart showing correlation between impairment in quality of life and disease control