

The Relationship between Patient Perception and Swallow Function in Patients with Ataxia-Telangiectasia – A Pilot Study

Mossey-Gaston C, Hales PA and Oscroft N

Papworth Hospital NHS Foundation Trust, Papworth Everard, Cambridge, UK

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Abstract

Purpose: To determine the relationship between patients' perception of swallowing and objective swallow function, as assessed by videofluoroscopy, in Ataxia-Telangiectasia (AT). To the authors' knowledge these relationships have not been reported previously.

Method: Patients that completed the Sydney Swallow Questionnaire (SSQ) and a videofluoroscopy as part of routine assessment at an adult AT clinic were included in the analysis. Questions selected from the SSQ reflected overall swallow severity and swallowing of thin fluids and were compared with validated dysphagia rating scales during videofluoroscopy:

- Perceived difficulty in swallowing thin fluids compared with the Penetration- Aspiration Scale for thin fluid (PAS).
- Perceived overall swallow severity compared with the Dysphagia Overall Severity Score (DOSS).

Correlations were sought between subjective SSQ responses and PAS and DOSS. PAS and DOSS were compared with SSQ results using the Mann-Whitney test.

Results: A total of 14 patients were studied. A negative correlation was found between perceived overall swallow severity and DOSS ($r=-0.505$ $p=0.066$). There was a positive correlation between perception of swallowing thin fluids and PAS ($r=0.353$ $p=0.215$). The Mann-Whitney test indicated a difference between perception of swallowing thin fluids and PAS $U=54.5$, $p=0.0456$, but no difference between perception of overall swallow severity and DOSS $U=91.5$, $p=0.765$.

Conclusion: The results suggest patients' perception is not a reliable measure of dysphagia in AT due to inability to perceive swallow function and are suggestive of a sensory impairment in this population. The sample size is small and requires further systematic evaluation.

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