

Understanding Patient and Staff Experiences of NHS Care for Ehlers-Danlos Syndrome (EDS)

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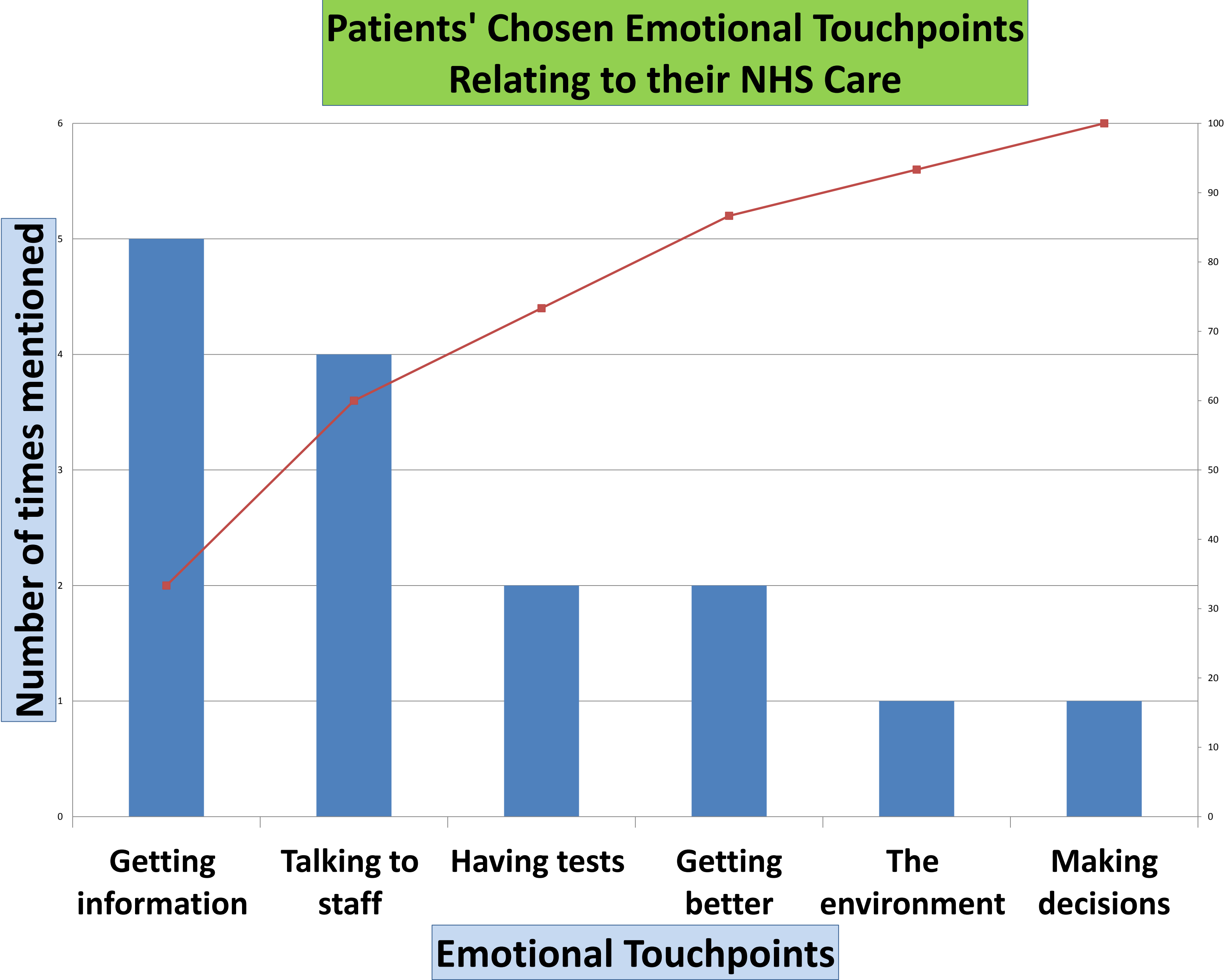
Presenting issue

A survey of patients by Ehlers-Danlos Support UK in 2017 found that 87% of respondents in Scotland did not feel that their condition was well supported by the NHS. This dissatisfaction with care is frequently echoed by patients seen within both the South East of Scotland Clinical Genetics Service (SESCGS) and the Rheumatology Service at the Western General Hospital (WGH), Edinburgh where staff have also expressed concerns about working with this complex syndrome. Multidisciplinary staff from across Scotland have been meeting with National Services Division (NSD) and patient representatives throughout 2018 to develop a patient pathway for EDS. This QI project is intended to contribute to these efforts, as well as the generation of a roadmap document for patients and professionals, by gathering data to inform a driver diagram and change ideas.

Specific aim

To understand a) the experience of 5 patients of their care from NHS Lothian for their hypermobile EDS (hEDS) using Emotional Touchpoints and b) the perspectives of staff working with hEDS within the SESC Service and the Rheumatology Service at the WGH using a brief survey, with a view to identifying opportunities for improvement by September 2018.

Initial data



QI tools employed

- Driver diagram
- Emotional Touchpoints
- Fishbone
- Process map
- Pareto chart
- Staff survey

Possible change ideas

- When the EDS Roadmap document (drawing on the recently published EDS Toolkit - endorsed by the Royal College of GPs) is complete, approach Ehlers-Danlos Support UK and The Hypermobility Syndromes Association UK to seek ideas for improvement.
- Discuss possible endorsement by charities of agreed version.
- Distribute final version to Genetics and Rheumatology Services, WGH to offer at all initial consultations for EDS.
- Elicit feedback from patients re impact of roadmap and plan further QI work accordingly.
- Explore staff responses to EDS in more depth (interviews).

Lessons learned to date

1. An understanding of QI tools;
2. Learning to think from a QI, rather than a research, perspective takes time;
3. Good relationships can form very quickly with peers sharing a passion for QI; and
4. EDS is extremely emotive for both patients and staff.

Emotions Accompanying Touchpoints

Improvements proposed by patients (N=5)

- ‘They [NHS staff] should listen¹ to you and your suggestions instead of just dismissing the patient.’**
- ‘Doctors should explain things in ways that the general public can understand.’*
- ‘There needs to be a checklist in the NHS that flags up multiple-symptom disorders.’*
- ‘A dedicated NHS website for EDS or endorsement of particular non-NHS ones would be good.’*
- ‘What they need is someone overlooking the case and all the referrals.’*

Improvements proposed by staff (N=7)

- Better information leaflets;
- Dedicated clinic with extended appointments/specialist service for EDS (including occupational therapy, physiotherapy, psychology and specialist nurse);
- Development of a clear pathway, including the diagnostic criteria and red flags that should prompt onward referral and to whom;
- Development of a multidisciplinary, information-sharing network; and
- Set up a multidisciplinary self-management programme for patients with EDS.