

Epilepsy12 Quality Improvement Case Studies 2023

Norfolk and Norwich University Hospital NHS Trust

We identified a need for a paediatric epilepsy psychology service to provide emotional and behavioural support to children, young people and their families. We used time-restricted funding to develop and test out a model of an integrated psychology team within the epilepsy service.

The initial step was to identify the level of psychological need of children and young people with epilepsy and/or non-epileptic seizures. A three-week trial of psychological screening during routine epilepsy clinics identified the level of psychological need. Screening was done with the PedsQL and SDQ questionnaire. 60% of families completed the psychology questionnaires, and caseload estimates for the service were used to estimate the level of psychological need across the service. Families screening highly were offered psychological support.

This found that:

- 50% of patients were classified as 'at risk' for health-related quality of life by parental report, and 43.8% by self-report.
- According to parental report, 38% of CYP were classified as experiencing 'very high' or 'high' emotional and behavioural difficulties overall.
- 79% of families were classified as being 'at risk' for poor health related quality of life. There is less evidence around what cut off should be used for this questionnaire, so the mean cut off from existing data was used. Even with a more conservative cut off, 29% of families would still be likely to need psychological input.
- Qualitative findings showed that families struggled with isolation, feeling different, low mood, anxiety, adjusting to their child's condition, challenges with medication, managing transition, and impact on siblings.

We planned to create and test a service model co-designed with children, young people and families to suit this population, generate qualitative and quantitative outcome data, and evaluate psychological interventions. Patients participated in the service design via focus groups and individual interviews. Families showed a strong desire for psychological input in the form of 1:1 support and group support, at different points in the epilepsy journey.

Group and individual psychological interventions for children, young people and parents were tested. We also tested out a psychology "on-call" service to the epilepsy clinics and offered clinical supervision and psychological consultation for the MDT.

Outcomes

Over 100 families have been referred for individual psychological interventions and review of these is ongoing. A Tree of Life narrative therapy group for children and young people has had positive feedback, with children and young people reporting that it has helped them feel less alone.

Next Steps

We hope to fully evaluate the service model and sustain long-term funding for psychological provision in the paediatric epilepsy services.