

P047

P047 -Developing a multi-disciplinary regional Tuberous Sclerosis clinic: the Liverpool Experience

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Introduction and aims

Tuberous Sclerosis Complex (TSC) is a rare multi-system genetic disorder characterised by the development of benign growths and diverse clinical manifestations, varying in severity, age at onset and with high clinical burden. The diverse and varied presentations and progression can be life-threatening with significant impact on cost and quality of life. Patients may also be affected by behavioural, intellectual, psychiatric and psychosocial difficulties, which often represent the greatest burden of this disease, for both families and physicians.

This complexity, combined with the rarity of the condition, often results in fragmented care provision for these patients and their families. Everolimus is now funded to treat brain (Sub-ependymal giant cell astrocytomas) and renal (growing angiomyolipomas) disease manifestations: this has stimulated service improvement efforts.

Our aims were

- To liaise with other specialities in the region to identify patients with TSC and offer them review in our regional MDT clinic
- To establish a TSC service that focuses on the quality of the patient experience and their physical and psychosocial needs
- To provide a one stop service that enabled multisystem specialist review
- Manage everolimus treatment ensuring safe administration and robust monitoring and governance
- Transitional clinics to ensure paediatric care to adult care is coordinated and patients and their families are supported
- To coproduce the service with patients and carers

Method

We have approached service development with the patient experience as the driver for improvement: this has involved application of Experience Based Co-Design (EBCD). EBCD uses storytelling to identify opportunities for improvement and focuses on the usability of the service for patients and staff. It empowers staff and patients to make changes.

Results

We have grown from having 13 patients to 33 patients in follow up. We have commenced 12 patients on treatment with everolimus, within strict governance and monitoring guidelines. All treated patients have had a favourable response to therapy.

The clinic now includes a Urologist, Nephrologists, Geneticist, Learning Disabilities nurse, Pharmacist, Clinical Psychologist and TSC specialist nurse.

This model of delivery has markedly improved patient and carer experience, and their feedback has been strongly positive.

Discussion

The Liverpool TSC service offers an MDT approach that is patient centred and addresses the complex physical and psychosocial needs of these patients. The 'one stop' clinic has improved communication and patient experience. This model can be applied to other complex rare diseases.