Evaluation of a Specialist Learning Disability Epilepsy Clinic

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Background

Epilepsy has been identified as one of the main causes of mortality in adults with a Learning Disability in the UK (Liao et al, 2022; Tyrer et al, 2022).

This is significant as rates of Epilepsy are reported to be significantly higher in people with a Learning Disability compared to the general population.

Furthermore, Epilepsy clinics for the general population are often not suitable for people with Learning Disabilities.

Therefore, it is indicated that specialist clinics should be formed to offer the necessary adjustments and support. However, such provisions for services vary greatly across the UK, due to a lack of national standards and guidance (Shankar & Mitchell, 2020).

Aim

This research study was designed to review a recently established specialist Learning Disability Epilepsy Clinic in Leicestershire using feedback from carers of patients who attended the clinic.

The specialist clinic offers reasonable adjustments to support the management of Epilepsy in people with Learning Disabilities. These include:

- Shorter waiting time to access the clinic
- Flexibility in appointment times and settings for the reviews e.g. home visits
- Offering longer duration reviews i.e. one hour
- Not discharging from clinic in case of missed appointment
- Holistic and multidisciplinary approach
- More than once or twice a year reviews to avoid crisis or frequent admission to A & E
- Offering accessible information leaflets on investigations e.g EEG and Brain MRI

This is particularly significant as the lack of reasonable adjustments have been linked to premature avoidable deaths in people with Learning Disabilities (Shankar & Mitchell, 2020).

Method

- An online survey was distributed to approximately 60 patients, parents and carers of patients that attend the clinic, which generated 30 responses.
- The survey focussed on the specialism of the clinic and the reasonable adjustments offered. The questions fell within three main categories: venue of appointments, length of appointments and the communication of clinicians.
- Template analysis was used to interpret the qualitative data to identify key themes.

Results

The responses from the survey were highly positive, citing the benefits of the specialist clinic. Analysis of the data identified 5 distinct themes that were deemed important by the participants (represented on the template analysis diagram).

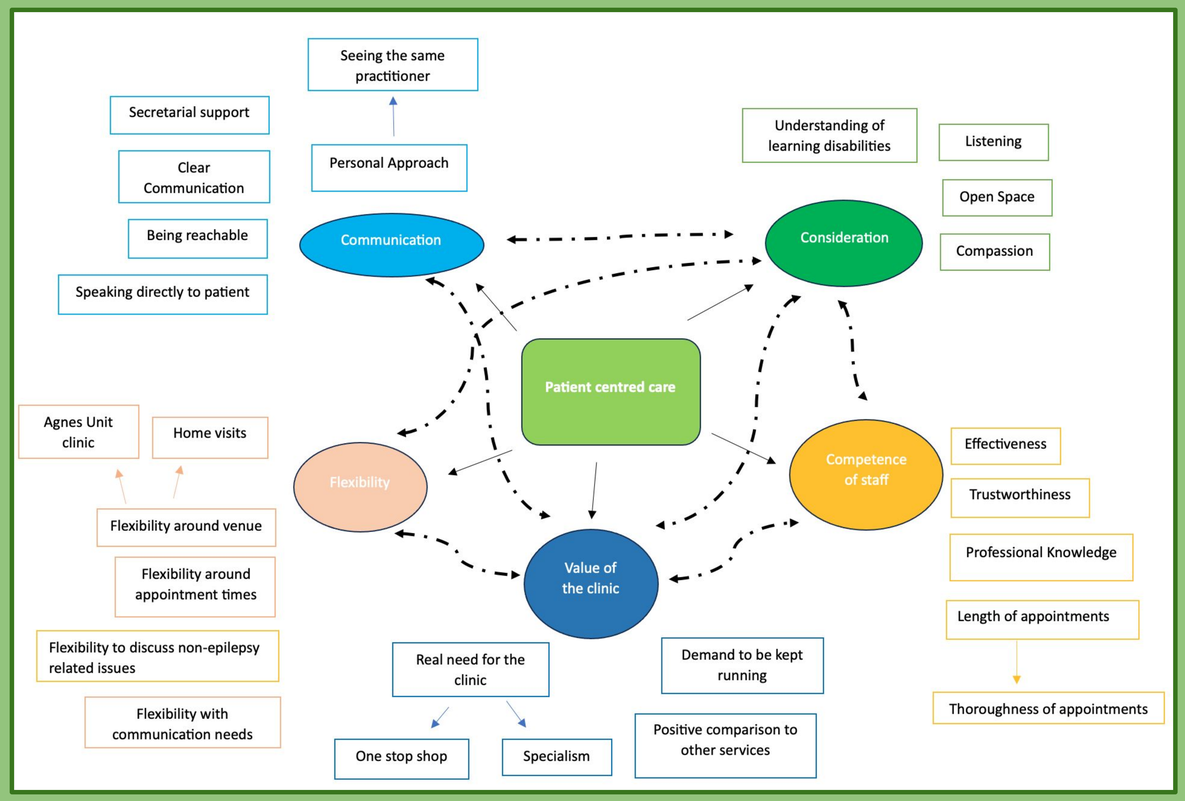
Flexibility - "*With my son, sometimes hard to get him to go out or attend. Extremely flexible, would never let you down, we are extremely grateful.*"

Communication - *"I really feel that as a patient and human being, my son matters and is cared for."*

Consideration - *"Able to feel our concerns and views are listened to and our daughter's needs attended to very well in a quiet environment."*

Competence - *"It's lovely to find somebody that when you do go to see them, you feel reassured."*

Value of the clinic - *"This clinic provides invaluable expertise from professionals who not only have knowledge of epilepsy, but also learning disabilities, autism and other complex needs. This enables the clinic to look at the individual holistically."*



Conclusion

The clinic was found to be favourable when compared to a generic service due to its specialism in catering for people with severe Learning Disabilities and Autism.

100% of participants in the study agreed it would be beneficial for the patient for the clinic to be kept running.

Future recommendations include:

- Increased staffing
- Epilepsy training for the community Learning Disability nurses
- An integrated and streamlined pathway in accessing Learning Disability multidisciplinary team for a more holistic management of Epilepsy and co-existing conditions in this population.

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Tyrer, F., Morriss, R., Kiani, R., Gangadharan, S. K., & Rutherford, M. J. (2022). Mortality disparities and deprivation among people with intellectual disabilities in England: 2000–2019. *J Epidemiol Community Health*, *76*(2), 168-174.