

The Hidden Costs of Inadequate Care: Evaluating the Economic Impact of Limited Services for Young People with Tics and the Impact of Providing Online Behavioural Therapy



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Background



Of only 17 expert specialists in the UK, 12 are based in London

Access to behavioral therapy is limited, many young people do not receive appropriate care

However, there is currently no evidence addressing the cost implications for healthcare services resulting from inadequate service provision, or the cost implications for providing a better service

In England, there are no specific national guidelines for assessing or treating young people with tics

Online, remotely delivered behavioral therapy could improve access to care



There are many barriers to care for people living with tics in the UK

Methods



This study used data from the randomised controlled trial 'ORBIT' (Online Remote Behavioral Intervention for Tics)

ORBIT compared online exposure and response prevention behavioral therapy for tics with online psychoeducation

Aged 9-17 years (av. 12 years) in England.

ORBIT participants:

Tic severity measured by the YGTSS-TTSS

224 young people

87% white
79% male

Comorbidites inc:
anxiety (27%),
ADHD (23%),
ODD (22%)

We explore costs of health service use and school absenteeism from children who participated in the ORBIT trial

We also include two case studies detailing access to care

Results

Young people get "bounced around" from service to service



The more severe the tics = more time off school



Young people saw a lot of different professionals (most contacts were not supportive)

Case Studies:

Healthcare Journey of Liam (aged 6) from 2017-2023

Visited the GP at least 6 times
7 referrals to specialist services including health psychology, neurology, CAMHS, Pediatrics and a specialist tic clinic (most were declined)
At least 7 CAMHS appointments
Received a diagnosis of tics in 2023 by a CAMHS psychiatrist and was placed on a waiting list for CBT
No treatment received at the time of gathering the data

Total cost of NHS healthcare: £3,512.55

Healthcare Journey of Yasmin (aged 12) from 2022-2023

Referred to paediatric services and neurology (both rejected)
Referred to a specialist tic service (rejected due to being out of area)
Family paid to see a private neurologist
Received multiple conflicting diagnoses
No longer attends mainstream school
No treatment received at the time of gathering the data

Total cost of NHS healthcare: £1,594.76



ORBIT participants:

For every 1-point increase on YGTSS = +£4.09 (95% CI £1.70 - £6.49) cost to NHS

ORBIT reduced tics by 4.5 point which this maintained to 2.01 after 18 months

50% used at least one specialist service and had an average of two appointments

Potential cost saving of over £1 million if all young people with tic disorders in the UK had ORBIT

Conclusion

Most young people are unable to access a specialist tic service or healthcare service that can support tics in the UK

There is a clear need to provide guidelines and services to support people with tics

Adding a tic treatment service is likely to result in overall cost savings to the NHS

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