Title.
The influence of comorbidity and complexity on outcomes of referrals to Children and Young Person Mental Health Services (UK): A mixed methods vignette study

Authors.
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Abbreviated title.
The influence of comorbidity on CYPMHS referral outcomes

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Abstract

Children and young people (CYP) with long-term physical conditions (LTCs) are four times more likely to develop mental health disorders yet many cannot access Children and Young People’s Mental Health Services (CYPMHS) or evidence-based interventions. This study aimed to understand the reasons for this; presence of LTC, additional complexity more broadly or service requirements.

79 CYP mental health practitioners were randomly assigned to read vignettes depicting a hypothetical referral letter for a child with a mental health condition alone (n=27), mental health condition and LTC (n=25), or mental health condition and neurodevelopmental complexity (Autism Spectrum Disorder-ASD) (n=27), answering questions about their likelihood of accepting the referral and proposed treatment plan.

There were no significant differences between accessing CYPMHS or being offered first line evidence-based interventions in those with a LTC or ASD compared to those without. However, additional complexity was frequently provided as a reason for rejecting referrals and not offering evidence-based intervention, with clinicians’ predicted success of intervention significantly lower for these CYP. Clinicians were significantly more likely to suggest adapting the intervention in the LTC and the ASD group to account for complexity. The research suggests a need for additional services for CYP with LTCs and those with neurodevelopmental conditions, as well as training/awareness for clinicians.

**Keywords:** Long-term physical health conditions; additional complexity; comorbidity; children and young people mental health services; evidence-based interventions.
Introduction

Long term physical conditions and associated mental health problems

A long-term physical condition (LTC) is a health problem requiring ongoing treatment that cannot be cured but can be controlled with medications/therapies (Moore et al., 2019). Approximately 15% of children and young people (CYP) have a LTC. These CYP have approximately a four times greater risk of developing a mental health disorder compared to CYP without a LTC (Hysing, Elgen, Gillberg, Lie & Lundervold, 2007). In addition to adverse outcomes associated with mental health disorders (decreased academic performance, low self-esteem), mental health problems in those with LTCs may be associated with poorer management of the young person’s physical condition (Short, Gradisar, Lack & Wright, 2013; Hood et al., 2006). It is therefore essential these CYP receive treatment for their mental health difficulties.

There is a lack of guidance for the use of evidence-based interventions of common mental health problems in CYP with LTCs, yet preliminary research suggests the interventions used for people without LTCs are effective (Bennett et al., 2019; Moore et al., 2019). There are numerous evidence-based interventions for treating mental health disorders in CYP (Chorpita et al., 2011) without LTCs. In England, the National Institute for Health and Care Excellence (NICE) recommends psychological interventions, typically cognitive behavioural therapy (CBT) or behavioural therapies as first line treatments for common mental health disorders in CYP, such as anxiety and depression and disruptive behaviour problems (National Institute for Health and Care Excellence, 2013 & 2019 & 2017). Low intensity interventions are recommended as first line treatments for some mental health difficulties, for example depression and obsessive compulsive disorder (OCD) (National Institute for Health and Care Excellence, 2005). Such interventions are typically briefer than standard interventions (around 6 sessions) and can be delivered by trained practitioners or supporters rather than
only someone with a core mental health professional qualification or equivalent, whilst
demonstrating similar efficacy to standard higher intensity interventions (Bennett et al., 2019;
Shafran, Myles-Hooton, Bennett & Ost., 2021). Similar approaches are recommended for
other anxiety disorders in CYP (Creswell, Waite & Cooper, 2019). A review of 12
randomised control trials (RCTs) also suggests that brief and low intensity evidence-based
interventions are effective in CYP with LTCs (Catanzano et al, 2020).

However, despite these interventions demonstrating preliminary effectiveness in this
group, it does not appear that CYP with chronic illness are able to access them. The
Children’s Commissioner’s Lightning Review (2016) figures show we do not know what
happens to 75% of CYP with comorbid mental health conditions and LTCs upon referral to
Children and Young People’s Mental Health Services (CYPMHS). Even when CYP with
LTCs are able to access CYPMHS, evidence suggests many do not receive evidence-based
interventions (Welch, Shafran, Heyman, Coughtrey & Bennett, 2018).

Difficulties accessing CYPMHS may simply be because CYPMHS are over capacity, and
CYP with LTCs may either a) not meet the threshold for specialised support or b) there may
be alternative services/provisions that CYPMHS can refer to. In 2019, 26% of referrals
(133,000 CYP) were rejected from specialist children’s mental health services, most
commonly because the child or young person’s condition was not considered suitable for
treatment, or because the condition/s did not meet eligibility criteria (Crenna-Jennings &
Hutchinson, 2020). However, some researchers have suggested that it may be that CYP with
LTCs are being turned away as their physical health comorbidity is viewed as too complex
for standard CYPMHS, as has similarly been found in adults (Wang, Willis, Barson &
Smallwood, 2021). Many CYP with LTCs, and particularly those with neurological
conditions, also have neurodevelopmental disorders such as Autism Spectrum Disorder
(ASD) or Attention Deficit Hyperactivity Disorder (ADHD) and it may be that it is the
presence of these additional complexities rather than the LTC itself that is linked to the view that such cases are ‘complex’. Indeed, research suggests mental health clinicians lack confidence in treating CYP with neurodevelopmental comorbidities due to insufficient training (Brookman-Frazee, Drahota, Stadnick & Palinkas, 2012; Will et al., 2018). Furthermore, whilst the evidence-based interventions (including brief and low-intensity) for neurotypical CYP have been shown to be effective in CYP with neurodevelopmental conditions with the addition of slight adaptations, many clinicians feel unsure of how to implement them in this population (Russel et al, 2020; Wood et al, 2015; Kinnaird, Norton & Tchanturia, 2017).

The present study

No studies to date have investigated why referrals for CYP with LTCs may be rejected from CYPMHS, or if accepted, why the young person may not receive an evidence-based intervention. The aim of this study was therefore to understand clinicians’ rationale for acceptance or rejection of referrals, their proposed intervention plan and their confidence in the effectiveness of any intervention offered, through use of vignettes followed by closed and open-ended questions. This is important to understand so research can be directed towards the correct mechanism; different interventions may be needed if these CYP do not meet the required severity thresholds (e.g. commissioning and providing services integrated within the physical healthcare setting), compared to clinicians considering that they do not have the required skills and confidence in the implementation and success of such therapies (perhaps suggesting a need for training).
Methods

Research Design and Participants

This study used an independent measures design with participants randomly assigned to one of three conditions/vignettes. To investigate the impact of a LTC on acceptance/rejection, we used vignettes of a child with a) a mental health condition alone and b) a mental health condition in addition to a LTC. We used a third condition of a child with a mental health condition in addition to a neurodevelopmental condition to understand whether vignette responses were associated with the presence of a chronic physical illness or whether they related to any additional complexity, particularly as many children and young people with physical illnesses may also have one or more neurodevelopmental disorders. Participants responded to a range of closed and open-ended questions regarding the referral presented in the vignette.

Epilepsy was chosen as the LTC and Autism as the neurodevelopmental condition as they are associated with high rates of mental health difficulties and among the most common LTC and neurodevelopmental condition in CYP (Weatherburn et al, 2017; Scandurra et al, 2019). Anxiety was chosen as the mental health condition across vignettes as it is frequent in CYP with epilepsy and autism (Kent & Simonoff, 2017).

Inclusion criteria were that participants had to be mental health clinicians working with CYP in the UK, from either NHS or private care to maximise recruitment. Participants were recruited via CYPMHS networks on Facebook and Twitter, through the ‘Directory of Chartered Psychologists- Child and Adolescent’ page on the British Psychological Society website and through word of mouth.
Procedure and Measures

The procedure was initially piloted with 5 participants and edited according to feedback. The survey was taken online. Participants followed the link and were taken to a welcome page on the secure platform, Qualtrics. After reading the information sheet and providing informed consent, participants completed a short demographic questionnaire. Participants were then presented with one of the three vignettes randomly assigned by Qualtrics and asked to answer the questionnaire. Upon completion participants were taken to the debrief page. Participants were told how to apply for the £100 prize draw and ask for a copy of the results. The study was approved by the university’s Research Ethics Committee (REC), project ID number: Z6364106/2021/02/65.

Vignettes.

Three vignettes were created for use in this study. All three consisted of referral letters of a 10-year-old girl named Hannah who was presenting with either a) anxiety alone, b) anxiety and epilepsy, or c) anxiety & autism. To reduce between condition variability, everything about the hypothetical patient in the vignette was kept the same (e.g. name, age, anxiety presentation) other than whether they had additional complexity (see Figure 1).
Figure 1. Vignettes presented to participants

Vignette a: Anxiety alone

Please find attached a referral letter for Hannah, a 10-year-old girl that has been presenting with severe anxiety, particularly when she is away from her parents. Hannah is the youngest of three children; she has a brother and a sister who are all close in age. Hannah worries about her parents and often feels scared when she is not with them. Hannah has not attended school for the past term due to anxiety. She also worries in general. The worry gives her tummy aches and stops her from eating. Hannah is a bright girl though her anxiety often distracts her in class and gets in the way of her friendships.

Vignette b: Anxiety and epilepsy

Please find attached a referral letter for Hannah, a 10-year-old girl that has been presenting with severe anxiety, particularly when she is away from her parents. Hannah received a diagnosis of epilepsy when she was six and now has frequent nocturnal seizures. Hannah worries about her parents and often feels scared when she is not with them. Hannah has not attended school for the past term due to anxiety. She also worries in general. The worry gives her tummy aches and stops her from eating. Hannah is a bright girl though her anxiety often distracts her in class and gets in the way of her friendships.

Vignette c: Anxiety and autism

Please find attached a referral letter for Hannah, a 10-year-old girl that has been presenting with severe anxiety, particularly when she is away from her parents. Hannah received a diagnosis of autism when she was six and has some sensory sensitivities. Hannah worries about her parents and often feels scared when she is not with them. Hannah has not attended school for the past term due to anxiety. She also worries in general. The worry gives her tummy aches and stops her from eating. Hannah is a bright girl though her anxiety often distracts her in class and gets in the way of her friendships.

Measures

**Demographics.** Participants were asked about their age, gender, profession, banding in the NHS or whether they worked in private care and their specific job role.
**Vignette Associated Questionnaire (See Appendix 1- supplementary materials).** This questionnaire consisted of a mixture of open and close-ended questions and Visual Analogue scales (VAS) enquiring about the following:

1. Likelihood of accepting the referral to their service (VAS 0-100 from 0 = not likely to 100 = extremely likely), rationale for this and what service if any they thought should see Hannah if not their service (open ended written response).

2. Type of intervention participants think should be offered, minimum skill level needed to deliver the therapy and how many sessions should be offered (open ended written questions).

3. Need to adapt their chosen intervention (yes/no) and rationale (open ended written question).

4. Anticipated success of their chosen intervention (VAS 0-100, from 0=not at all successful to 100=extremely successful) and rationale (open ended written question).

**Methods of analysis.**

*Quantitative analysis.* All Quantitative analysis was conducted on SPSS v.27.

1. **Likelihood of accepting the referral to their service.** A Kruskal-Wallis H test was used to compare the mean VAS score for each condition (anxiety, anxiety & epilepsy, anxiety & autism) for the question ‘How likely would you be to accept Hannah’s referral at your current place of work?’ This used all participants responses firstly and then a sensitivity analysis was conducted using only NHS clinicians’ responses, as private clinicians may bias the results due to the greater amount of freedom they have around accepting referrals.

2. **Type of intervention participants think should be offered.** The assumptions of a chi-square goodness of fit test were met and therefore it was used to compare the frequency of participants who suggested a first line evidence-based intervention versus those that did
not. The first line evidence-based intervention for anxiety is CBT and SSRIs (National Institute for Health Care,2014). The analysis only included answers that referenced specific interventions (i.e ‘CBT’) versus general (i.e ‘parenting work’).

3. Need to adapt their chosen intervention. A chi-squared test was used to compare the yes/no frequency for the question, ‘Would the intervention need to be adapted to account for Hannah’s presentation?’ between the three conditions.

4. Anticipated success of their chosen intervention. As the data failed to meet the assumptions for an ANOVA, a Kruskal-Wallis H test was used to compare the mean VAS score for each condition (anxiety, anxiety & epilepsy, anxiety & autism) for the question ‘Based on the information you have about Hannah and your knowledge of your chosen intervention, how successful do you think the intervention would be?’.

Qualitative analysis. Using NVivo v.12, inductive content analysis was carried out on the qualitative data, in line with analysis of previous vignette studies with a qualitative element (Jackson et al,2015; Pzeperski & Taylor,2020; Resisel,2016; Elo & Kynägs, 2008) Codes and themes were independently checked by an assistant psychologist with a BSc in Experimental Psychology to assess inter-rater reliability. The assistant psychologist analysed all of the data for those who completed the questionnaire. Inter-rater reliability was moderate (Cohen’s Kappa= 0.57). To improve the credibility and trustworthiness of the analysis, throughout the study, the first author and second MSc student tried to maintain a reflexive stance, and examined how their preconceptions and positioning (MSc students with an interest in CYP’s mental health) might impact on the research process, in particular during data collection and analysis.
Results

Table 1. Sample characteristics for participants who completed the questionnaire.

<table>
<thead>
<tr>
<th>Completed Questionnaire</th>
<th>n= 79</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Anxiety</td>
</tr>
<tr>
<td>n= 27</td>
<td>n= 25</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>2 (7.41)</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>25 (92.59)</td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>41.35</td>
</tr>
<tr>
<td>Private clinicians</td>
<td>11 (40.74)</td>
</tr>
<tr>
<td>NHS CYPMHS clinicians</td>
<td>16 (59.26)</td>
</tr>
</tbody>
</table>
Table 2. Descriptive results table

<table>
<thead>
<tr>
<th></th>
<th>Anxiety (mean)</th>
<th>Anxiety &amp; Epilepsy (mean)</th>
<th>Anxiety &amp; Autism (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likelihood of accepting referral (0-100)</td>
<td>73.96</td>
<td>64.64</td>
<td>57.15</td>
</tr>
<tr>
<td>How successful think intervention will be (0-100)</td>
<td>79.56</td>
<td>67.84</td>
<td>71.04</td>
</tr>
<tr>
<td>N participants who suggested a first line evidence-based intervention: N who did not</td>
<td>22:3</td>
<td>17:2</td>
<td>17:3</td>
</tr>
<tr>
<td>N participants think intervention will need to be adapted: N do not think it needs to be adapted</td>
<td>17:10</td>
<td>23:2</td>
<td>25:2</td>
</tr>
</tbody>
</table>

Appendix 2: Table summarising qualitative findings (supplementary materials).
1. Likelihood of accepting the referral to their service, rationale for this and what service if any they thought should see Hannah if not their service. There was no significant difference between conditions in the mean VAS score for likelihood of accepting referrals $X^2(2)=1.863$, $p=0.394$, epsilon squared=0.24 (small effect size) and therefore no post-hoc tests were run. The sensitivity analysis removing private clinicians (total=55, anxiety=16, anxiety & epilepsy=20, anxiety & autism=19) also demonstrated no significant difference between conditions, $X^2(2)=1.07$, $p=0.586$, epsilon squared=0.2.

Qualitative analysis demonstrated that most clinicians in each group would accept the referral due to impact on daily functioning:

‘There is significant functional impairment – can’t attend school, can’t concentrate when at school, not eating well and potentially impacting on seizure frequency’

(anxiety and epilepsy, psychiatrist).

Conversely, a number in each group said they would reject the referral as the presentation was not severe enough:

‘We are tier 3 CAMHS and I would refer this for early intervention initially, unless eating habits are too dangerous’ (anxiety, CAMHS practitioner).

However, whilst some clinicians in the anxiety alone condition said they would accept the referral on the basis of low complexity ($n=6$; ‘this would be a relatively straightforward case, we see lots of children like this), clinicians in both the epilepsy ($n=4$) and autism ($n=1$) groups said they would reject the referral on the basis of perceived complexity, in epilepsy stating that they ‘could not be helpful’, that she would be better suited to a place with ‘specialist skills in supporting children and families with chronic health conditions’ and that her seizures ‘complicated the picture’. Similarly, in the autism group, one clinician considered that ‘neuro issues complicate things.’ No clinicians in the anxiety alone group said they would reject the referral on this basis.
Considering other referral avenues, clinicians in all groups recommended lower tier services (anxiety alone group n = 5, epilepsy group n = 3, autism group n = 4):

‘Should be seen by Tier 2 trainee’ (anxiety, mental health nurse).

‘Should be stepped down to lower threshold services’ (anxiety and epilepsy, community mental health practitioner).

‘Would send to our Tier 2 wellbeing service, not a moderate to severe mental health problem’ (anxiety and autism, eating disorder clinician).

Some clinicians in the epilepsy group thought that Hannah should receive support from paediatric mental health specialists (n = 4), and one in the autism group thought she should go to an autism specific service:

‘She has a medical condition so should be referred to her local paediatric psychology service’ (junior doctor).

‘SEND ASD service for support in school’ (clinical nurse manager).

2. Type of intervention participants think should be offered, minimum skill level needed to deliver the therapy and how many sessions should be offered. The Chi Square goodness of fit test found no significant difference between conditions in offering a first line evidence-based intervention, $X^2 (2, n=64)= 0.1877$, $p=0.910$, Cramer’s $V=0.023$. The majority of clinicians in all conditions would offer 10-15 sessions of CBT. One participant in the anxiety and epilepsy condition thought that more sessions may be needed in order to build a relationship.

The majority of participants in the anxiety and the anxiety & epilepsy condition proposed a medium minimum skill level was needed to deliver the intervention (e.g. trainee psychologists) with those in the anxiety & autism condition split between high (qualified therapist) and low (e.g. assistant psychologist) skill level.
3. Need to adapt their chosen intervention and rationale. Results of the chi-square goodness of fit test were significant $X^2 (2, n=79) = 10.45 \ p<.01$, Cramer’s $V=0.365$. Post-hoc tests demonstrated that significantly more clinicians said the intervention would need to be adapted for the anxiety & epilepsy condition compared to the anxiety condition, $X^2 (2, n=52) = 6.16, \ p=0.013$, Cramer’s $V=0.344$, and for the anxiety & autism condition compared to the anxiety condition, $X^2 (2, n=54) = 6.86 \ p=0.009$, Cramer’s $V=0.356$.

Nine clinicians in the anxiety alone group considered that adaptation was not necessary, with only two in the epilepsy group and two in the autism group considering this to be the case:

‘her presentation would fit the standard CBT protocols we use for child anxiety’ (anxiety, CBT therapist).

‘I would suggest offering standard CBT for anxiety. If this did not work, then explore why and adapt as needed’ (anxiety and epilepsy, psychiatrist).

Whilst a majority in all groups considered adaptation necessary, in the anxiety alone group, adaptation was considered necessary primarily due to Hannah’s age (n=10) ‘She is very young, so would need to be structured for a primary school child’ (anxiety, mental health nurse).

Hannah’s age was mentioned as a reason to adapt only twice in the epilepsy group and once in the autism group. In these groups, the presence of the epilepsy and autism comorbidities were the primary reasons for adaptation.

‘Any exposure work would need to be safe and this may involve asking the medical team. There may also be specific epilepsy-related cognitions that will need addressing.’ (anxiety and epilepsy, junior doctor).
‘use Hannah’s special interests to help her engage’ or to ‘take into account any sensory sensitivities, communication needs etc’. (anxiety and autism, clinical psychologist).

4. Anticipated success of their chosen intervention and rationale. The Kruskal-Wallis H test revealed a significant difference between conditions in the mean VAS score for anticipated success of chosen intervention $X^2(2) = 6.961, p = 0.031$, epsilon squared = 0.861 (large). Post-hoc tests indicated that the mean VAS score for perceived success was significantly lower in anxiety & epilepsy condition than the anxiety condition ($p = 0.18$), and in the anxiety & autism condition versus the anxiety condition ($p = 0.30$). No significant difference was found between the anxiety & epilepsy and anxiety & autism conditions.
Discussion

This study investigated responses of CYPMH clinicians to referrals of CYP with mental health difficulties in the context of additional complexities, including LTCs and neurodevelopmental disorders. It aimed to understand the reasons for low rates of referral acceptance and provision of evidence-based interventions for CYP with LTCs. Regarding the likelihood of accepting the referral to their service, failure to meet service requirements (being too young for the service, anxiety not being severe enough and incorrect disorder type) was frequently cited as reasons for rejecting the referral. Rejection of CYP with LTCs upon referral to CYPMHS may therefore be due to broader difficulties with CYPMHS, arising from the social context within which the current services exist and limit what clinicians feel they can offer. Between 2013/2014 and 2014/2015 the rates of referrals to CYPMHS increased 5x faster than the workforce (Local Government Association, 2021). The COVID-19 pandemic has only increased this demand, with clinically significant mental health conditions in CYP rising by 50% in the first three months of the pandemic compared to 2017 (Children’s Commissioner, 2021). Services are overstretched, managing increased demands within limited budgets, and therefore thresholds for services can be very high, with strict inclusion criteria. This perhaps suggests a possible need for commissioning of services specific to CYP with mental health problems and LTCs or neurodevelopmental conditions, particularly given the high levels of mental health problems associated with having a LTC or neurodevelopmental disorder (Moore et al., 2019; Brookman-Frazee et al., 2012).

However, additional perceived complexity due to Hannah’s comorbidity was also used as reasoning for rejecting Hannah’s referral in the anxiety & epilepsy and anxiety &
autism conditions. This indicates the need to better educate and train clinicians in interventions for CYP with LTCs and neurodevelopmental conditions.

Promisingly, participants were not significantly less likely to offer a first line evidence-based intervention for CYP with additional complexity. This is contradictory to existing research, which showed that whilst the evidence-based interventions used in typical CYP are effective in CYP with LTCs and neurodevelopmental complexity, many patients do not receive them (Moore et al., 2019; Welch, Shafran, Heyman, Coughrey & Bennett, 2018; Kinnaird, Norton & Tchanturia, 2017). Our findings suggest that offering of non-first line evidence-based intervention is not specific to CYP with additional complexity, replicating previous research (Shafran et al., 2009).

The majority of participants in all three conditions thought that Hannah would need between 10-15 sessions for intervention. This suggests participants do not promote the use of brief therapies for any of these CYP, not specifically those with LTCs. Participants considered that a higher level of experience was needed to deliver the therapy in the anxiety & epilepsy and anxiety & autism conditions compared to the anxiety condition. Given many referrals are rejected due to service capacity, and brief and low intensity interventions are effective in CYP with LTCs (Catanzano et al, 2020), this suggests that greater awareness of and training in low intensity interventions may be helpful for children and young people’s mental health practitioners.

Participants in the anxiety & epilepsy and anxiety & autism group were significantly more likely to say that the intervention needed to be adapted than those in the anxiety condition. This is in line with previous research suggesting that clinicians make adaptations and/or personalise interventions to account for the presence of a chronic physical illness (Bennett et al, 2021; Morey & Loades, 2021; Wood et al, 2015; Walters, Loades & Russell, 2009).
The reasons for adapting the intervention in the anxiety & epilepsy and anxiety & autism conditions were largely due to their additional diagnosis. Overall, the adaptations suggested were not major adaptations to content, but rather personalising the intervention to account for Hannah’s individual presentation, for example ensuring the intervention was medically safe, or using special interests to increase engagement. However, there was no suggestion of flexibility in terms of session delivery, for example shorter sessions or timing sessions with medical appointments, despite research suggesting such flexibility may be helpful for CYP with LTCs (e.g. Morey & Loades, 2021).

However, despite suggesting evidence-based interventions for the CYP with additional complexities, clinicians were significantly less likely to think their intervention would be successful for these CYP. This would suggest that lack of confidence in perceived success of an intervention is not specific to LTCs, but to additional complexity more broadly.

**Strengths and limitations**

This is the first study to date to investigate CYPMH clinicians’ responses to referrals for CYP with additional physical and neurodevelopmental complexity, using quantitative and qualitative measures to collect rich data. Regarding limitations, firstly our sample of clinicians is likely to be biased, as we recruited through online mailing lists and social media and interested clinicians may be more likely to be accessing continuing professional development activities and aware of up-to-date research regarding the efficacy of standard evidence-based interventions for CYP with additional complexity than clinicians not willing to get involved, or who are not actively using social media. In addition, inclusion of participants from a variety of CYPMHS departments, such as disorder specific clinics or adolescent only clinics, meant that the referral vignette was not related to their practice. It may have been more appropriate to target CYPMHS departments that were suitable for
Hannah’s age and mental health problem, as these are where her referral would be sent in clinical practice. It is important to note that whilst the researchers tried to remain unbiased in their approach, they had prior experience with this topic, working in Great Ormond Street Hospital with Children and Young People often turned away by CYPMHS. This could have influenced the questions given to participants and the analysis of the data.

Clinical implications

Together, these results suggest that it would be helpful for there to be integrated care for children and young people who have mental health difficulties in the context of additional complexities, such as LTCs, in line with international calls (World Health Organisation, 2016; Lines, 2019). Dialogue between services would help ensure that referrals do not fall between the gaps, and improved treatment pathways could be developed through discussion between teams. Consultation from specialist teams to local CYPMHS could build confidence in local teams to provide mental health interventions to these groups of CYP. It may be that specialist training in the application of low intensity treatments would be helpful given the service gaps identified in this study.

Future research

This is a vignette study rather than investigating real referrals and it is possible that clinicians would make different decisions when presented with actual cases than when answering as part of a research study. Future research should use other methods, for example, case note reviews to further understand clinical practice in this area. Semi-structured interviews with clinicians would allow further exploration, with the possibility to clarify
statements and pursue interesting aspects of the discussion (Adeoye-Olatunde & Olenik, 2021). Using additional recruitment strategies, for example recruiting from within CYPMHS, would be helpful to increase the diversity of the sample of clinicians.

**Conclusions**

Many clinicians across all three groups would reject referrals because they did not meet service requirements (for example being too young for the service, anxiety not being severe enough and incorrect disorder type). However, additional complexity was used as a reason against acceptance of referrals and offering of evidence-based interventions in these groups. Furthermore, clinicians’ predicted success of their chosen intervention was significantly lower for CYP with LTCs and with neurodevelopmental conditions compared to those without, which was partly due to the additional complexity of having a LTC or a neurodevelopmental condition and uncertainty around how to treat them. The research suggests a role for improved integrated care, as well as specific training and awareness of effective interventions for mental health disorders in these CYP, particularly that additional complexity does not mean that an evidence-based treatment cannot be applied with appropriate modifications (Bennett et al., 2015; Bennett & Shafran, 2022).

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**Declaration of conflicting interests.**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.
References


Appendix 1: Vignette associated questionnaire

Would the intervention need to be adapted in any way to account for Hannah's specific presentation?

Yes

No

If yes, please explain in what ways.

[Blank]

If no, please explain why.

[Blank]

Please just ATTEMPT to answer the below questions as best as possible (you can always right 'unsure')

What do you think is Hannah's main difficulty?

[Blank]

How likely would you be to accept Hannah's referral at your current place of work?

0 10 20 30 40 50 60 70 80 90 100

Very unlikely (0) to very likely (100)

[Blank]

Please explain your answer

[Blank]

What intervention do you think should be offered? Please explain your answer.

[Blank]
Based on the information you have about Hannah and your knowledge of your chosen intervention, how successful do you think the intervention would be?

0  10  20  30  40  50  60  70  80  90  100

Not at all successful (0) to very successful (100)

Please explain.

How many sessions of treatment should be offered and why?

What minimum skill level of therapist would be needed to work with Hannah (e.g. assistant psychologist, trainee clinical psychologist, consultant clinical psychologist) and why?

If you were treating Hannah, would you need to seek out advice from another professional? If so, who and what advice would you need?

What additional information would you need to make an informed decision on the previous questions? (e.g. how treatment works in this group of patients)

Have you ever worked with a case like Hannah's before?

Yes

No

If so what similarities did they have (e.g. same diagnoses?)
If you would not be likely to accept the referral, who/where do you think would see Hannah?
### Appendix 2: Table summarises qualitative findings

<table>
<thead>
<tr>
<th>Likelihood of accepting referral</th>
<th>Anxiety</th>
<th>Anxiety &amp; Epilepsy</th>
<th>Anxiety &amp; Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accept (n=23, NHS=13, Private=10)</strong></td>
<td>1. Severe impact on daily functioning (n=7, NHS=6, private=1)</td>
<td>1. Severe impact on daily functioning (n=9, NHS=7, private=2).</td>
<td>1. Severe impact on daily functioning (n=9, NHS=8, private=1).</td>
</tr>
<tr>
<td></td>
<td>2. Experience working with anxiety cases (n=7, NHS=6, private=1)</td>
<td></td>
<td>2. Experience working with these disorders (n=5, NHS=5, private=0).</td>
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<tr>
<td></td>
<td>3. Lack of complexity (n=6, NHS=6, private=0)</td>
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<td></td>
<td>4. Met service requirements (n=1, NHS=1, private=0)</td>
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<td></td>
<td>5. Working in private practice means have the time and there are no thresholds (n=3, NHS=0, private=2)</td>
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</tbody>
</table>
| **Reject (n=4, NHS=3, private=1)** | 1. Failed to meet service requirements (n=9, NHS=8, private=1):  
   - Incorrect mental health disorder (n=3, NHS=2, private=1).  
   - Not severe enough (n=4, NHS=4, private=0).  
   - Too young (n=2, NHS=2, private=0). | 1. Failed to meet service requirements (n=6, NHS=6, private=0):  
   - Incorrect mental health disorder type (n=1, NHS=1, private=0).  
   - Not severe enough (n=5, NHS=5, private=0). | 1. Failed to meet service requirements (n=11, NHS=10, private=1):  
   - Not severe enough (n=8, NHS=8, private=0).  
   - Too young (n=3, NHS=2, private=1). |
|                                 | 2. Lacking time for new patient (n=1, NHS=0, private=1). | 2. Epilepsy complexity (n=4, NHS=2, private=2). | 2. Lacking time for a new patient (n=2, NHS=1, private=1). |
| **Accept (n=15, NHS=10, private=5)** | 1. Severe impact on daily functioning (n=9, NHS=7, private=2). | | |
| **Reject (n=10, NHS=8, Private=2)** | | 2. Epilepsy complexity (n=4, NHS=2, private=2). | 3. Autism complexity (n=1, NHS=1, private=0). |
| **Reject (n=9, NHS=6, private=3)** | | 3. Lacking time for a new patient (n=1, NHS=1, private=0). | |
### Where else if not accepting?

1. Private clinician with more time (n=2, NHS=1, private=1).
2. Lower tier/level support e.g tier 2 CAMHS (n=5, NHS=5, private=0).
3. Voluntary sector (n=1, NHS=1, private=0).
4. General CAMHS (n=2, NHS=1, private=1).

### Where else if not accepting?

1. Sent for support in a hospital (n=4, NHS=3, private=1).
2. Private clinician with more time (n=3, NHS=1, private=2).
3. Lower tier/level support e.g tier 2 CAMHS (n=3, NHS=3, private=0).
4. Sent to voluntary sectors (n=1, NHS=0, private=1).

### Where else if not accepting?

1. Lower tier/level support e.g tier 2 CAMHS (n=4, NHS=4, private=0).
2. School (n=1, NHS=1, private=0).

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<table>
<thead>
<tr>
<th>Likelihood of offering evidence-based intervention</th>
<th>Type of intervention</th>
<th>Type of intervention</th>
<th>Type of intervention</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>CBT (n=21, NHS=15, private=6).</td>
<td>CBT (n=16, NHS=13, private=3).</td>
<td>CBT (n=15, NHS=15, private=0).</td>
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<tr>
<td></td>
<td>Family therapy (n=2, NHS=1, private=1).</td>
<td>SSRIs (n=1, NHS=1, private=0).</td>
<td>Psycho-education (n=2, NHS=2, private=0).</td>
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<tr>
<td></td>
<td>Parent led intervention (n=1, NHS=1, private=0).</td>
<td>ACT approach (n=1, NHS=0, private=1).</td>
<td>Local clubs (n=1, NHS=1, private=0).</td>
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<td></td>
<td>Socratic dialogue (n=1, NHS=0, private=1).</td>
<td>EMDR (n=1, NHS=0, private=1).</td>
<td>Play therapy (n=2, NHS=1, private=1).</td>
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<tr>
<td></td>
<td>Integrative child psychotherapy (n=1, NHS=0, private=1).</td>
<td>Individual therapy (n=1, NHS=1, private=0).</td>
<td>Counselling with parents (n=2, NHS=0, private=2).</td>
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<tr>
<td></td>
<td>No suggestion (n=2, NHS=0, private=2).</td>
<td>Parenting work (n=1, NHS=1, private=0).</td>
<td>School intervention (n=1, NHS=0, private=1).</td>
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<tr>
<td></td>
<td></td>
<td>Systemic work (n=1, NHS=1, private=0).</td>
<td>No suggestion (n=4, NHS=2, private=2).</td>
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<tr>
<td>Time required</td>
<td>15+ sessions (n=3; NHS=3, private=3).</td>
<td>15+ sessions (n=7; NHS=4, private=3).</td>
<td>15+ sessions (n=2; NHS=2, private=0).</td>
</tr>
<tr>
<td></td>
<td>10-15 sessions (n=8; NHS=5, private=3)</td>
<td>10-15 sessions (n=10; NHS=8, private=2)</td>
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</tbody>
</table>
- 10-15 sessions (n=13; NHS=7, private=6)
- <10 sessions (n=12; NHS=8, private=4),

**Experience level needed**
- Fully qualified high intensity therapist (n=6; NHS=2, private=4),
- Trainee therapist (n=13; NHS=11, private=2)
- Assistant Psychologist (AP) (n=4; NHS=4, private=0).

<table>
<thead>
<tr>
<th>Need to adapt</th>
<th>Not adapt (n=9, NHS=8, private=1)</th>
<th>Not adapt (n=2, NHS=2, private=0).</th>
<th>Not adapt (n=2, NHS=2, private=0).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. For young age (n=10, NHS=6, private=4).</td>
<td>1. Epilepsy complexity (n=14, NHS=8, private=6).</td>
<td>2. More sessions needed due to autism (n=2, NHS=0, private=2).</td>
</tr>
<tr>
<td></td>
<td>2. All interventions should be adapted (n=3, NHS=0, private=3).</td>
<td>2. For young age (n=2, NHS=1, private=1).</td>
<td>3. For young age (n=1, NHS=0, private=1).</td>
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<td></td>
<td>3. Severity of social issues (n=1, NHS=1, private=0).</td>
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</table>

**Expected success of intervention**

**Perceived success (n=27, NHS=16, Private=11):**

**Perceived success (n=18, NHS=13, private=5)**
1. Good evidence-base of chosen intervention for treating anxiety in CYP with epilepsy (n=5, NHS=5, private=0).

**Perceived success (n=25, NHS=20, private=5)**
<p>| | | |</p>
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<tbody>
<tr>
<td>2.</td>
<td>Not too complex a case (n=6, NHS=6, Private=0).</td>
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<tr>
<td>3.</td>
<td>Successful past case like this (n=3, NHS=0, Private=3).</td>
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**Perceived lack of success (n=0)**

**Unknown success (50:50, n=0, but others gave reasons for not knowing)**

1. General uncertainty in factors predicting success, e.g. motivation (n=7, NHS=5, Private=2).
2. Too young for intervention to be successful (n=4, NHS=2, Private=2).
3. Complex relationship issues (n=1, NHS=0, Private=1).

**2. Successful past cases like this (n=2, NHS=1, Private=1).**

**3. Anxiety is not too severe (n=1, NHS=1, Private=0).**

**1. Successful past cases like this (n=5, NHS=5, Private=0).**

**3. Anxiety not too severe (n=2, NHS=2, Private=0).**

4. Young age (n=2, NHS=1, Private=1).

**Perceived lack of success (n=1, NHS=1, Private=0).**

**Unknown success (50:50, n=6, NHS=4, Private=2, but others gave reasons for not knowing)**

1. General uncertainty in factors predicting success e.g. motivation (n=13, NHS=7, Private=6).
2. Uncertainty in how to treat epilepsy related mental health problem as a reason for lack of predicted success of intervention (n=2, NHS=1, Private=1).

**1. General uncertainty in factors predicting success, e.g. motivation (n=6, NHS=5, Private=1).**

**2. Autism complexity (n=5, NHS=4, Private=1).**

3. Uncertainty in how autism related anxiety would respond (n=1, NHS=1, Private=0).

Inter-rate reliability was checked using Cohen’s Kappa= 0.57