Understanding the most important treatment FAQs for young people with ADHD and their families as part of the development of a decision aid for ADHD

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Introduction and aims

- Research into parent treatment preferences for ADHD has indicated that interventions are needed to ensure parent preferences are informed, evoked and discussed during the process of planning treatment with a clinician (Brinkman and Epstein, 2011).
- Clinician use of shared decision making (SDM) appears to be low in the context of developmental and behavioural difficulties like ADHD when compared to other conditions. (Lipstein, Lindly, Anixt, Britto, 2015)
- A recent child mental health service audit in the UK showed that although 83% of clinicians believe they usually or always discussed the range of treatment options available with young people, only 30% of young people felt that they were given enough information to make a choice about the treatment they received (Edbrooke-Childs et al., 2015)
- There are indications that SDM can be misunderstood by clinicians as 'a means to encourage families to accept clinicians' preferred treatment' rather than a partnership between equals. The incorporation of decision aids into clinical practice may facilitate SDM in the context of choosing treatment for ADHD (Fiks, Hughes, Gafen, Guaevara, Barg, 2011)
- The short-term aim of this project was to develop a list of the most important frequently asked treatment preference-sensitive questions from parents of children with ADHD. These questions have since been used to develop two decision aids which are being refined in a London child mental health service using quality improvement methodology.
- The decision aids, called i-THRIVE Grids, will be freely available to download from http://www.implementingthrive.org in August 2017.

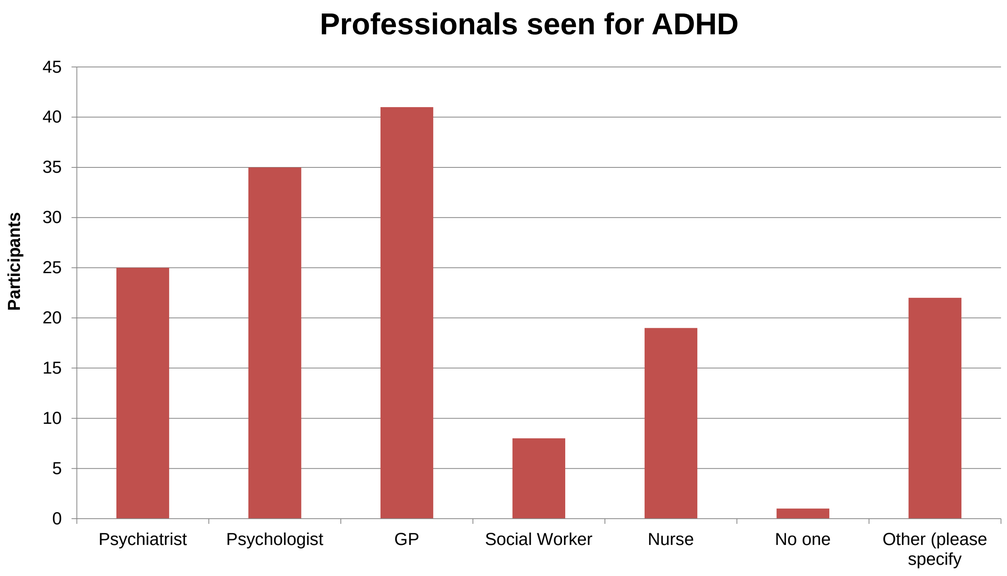
Methods

- A scoping review was conducted to identify treatment preference-sensitive, frequently asked questions of parents and young people about ADHD.
- The list of questions derived from this review was combined with the frequently asked questions identified Barr et al. (2016) in a US national survey of individuals with depression.
- The resulting list of 48 distinct questions ranged from "How will this help me get better?" to "Are there any risks or side effects from this type of help or support?"
- Seven questions were eliminated from this list as they were not treatment preference-sensitive , resulting in 41 questions which were put into a electronic survey for individuals to complete.
- Participants were recruited from a variety of sources (e.g. Facebook, peer support groups) and had the opportunity to enter a prize draw.
- Participants were asked to rate how important each of the 41 questions were when choosing care or treatment for their child with ADHD, and then ranked their top five most important questions
- This ranking system was used to determine the final list of ten most important questions.
- Participants were asked to select the risks/side effects for their child that were most important to them. (Paediatric Formulary Committee, September 2016-2017)

Results

Participants (*n*= 75) included parents of children with ADHD in the United Kingdom who started the survey, with 89.33% (*n*=67) completing the demographics/first page. Participants' ages ranged from 21 to 56 with an average of 37.34 years. 95.52% (*n*=64) of participants were female while 4.48% (*n*=3) were male. 94.03% (*n*=63) listed their ethnicity as White or White British, 4.48% (*n*=3) Mixed, and 1.49% (*n*=1) Black or Black British. 98.51% (*n*=66) reported that they were comfortable reading and writing in English. 17.91% (*n*=12) of participants were located in Northwest England, 16.42% (*n*=11) in London, and 14.93% (*n*=10) were located in the East of England.

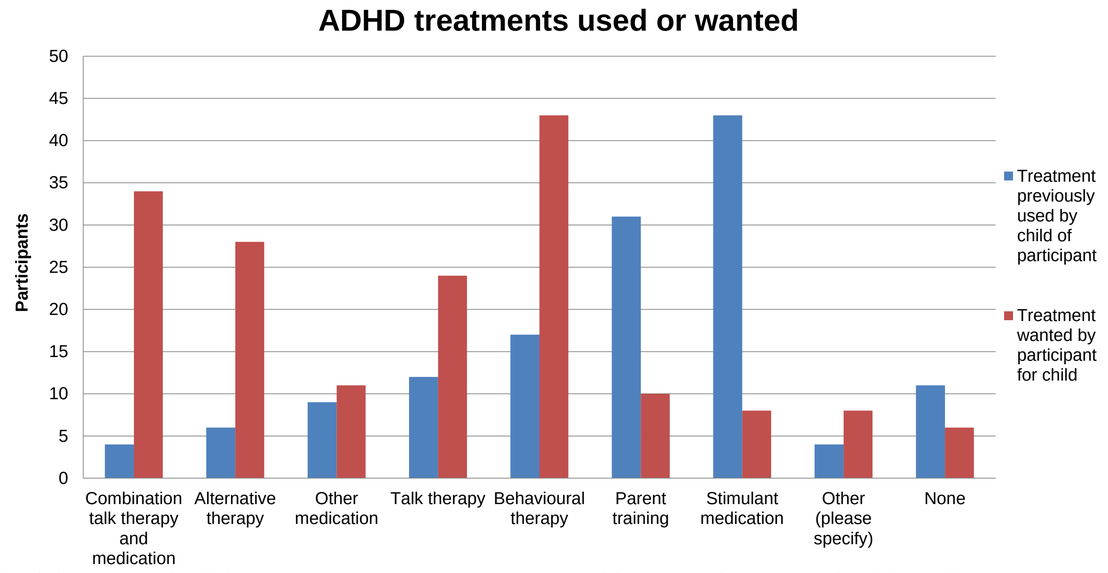
92.54% (*n*=62) of participants stated that their child was currently being treated or awaiting treatment for ADHD, while 7.46% (*n*=5) were not. 67.16% (*n*=45) stated that their child had previously received treatment for ADHD, and 32.84% (*n*=22) stated that their child had not previously received treatment for ADHD. The variety of professionals seen by participants for their child's ADHD is shown below.



Other professionals seen by participants included an occupational therapist (OT), a paediatrician, an ADHD specialist, an ADHD nurse, a neurodevelopmental consultant, a health visitor, a family support worker, an ADHD coach, an educational therapist, school staff, child and adolescent mental health services (CAMHS), and a professor in ADHD and autism spectrum disorder (ASD).

Previously used treatments for ADHD included stimulant medication (64.18%, *n*=43), parent training (46.27%, *n*=31), behavioural therapy (25.37%, *n*=17), talk therapy (17.91%, *n*=12), none (16.42%, *n*=11), other medication (13.43%, *n*=9), alternative therapy (8.96%, *n*=6), combination talk therapy and medication (5.97%, *n*=4), and other (5.97%, *n*=4). Other treatments listed included occupational therapy, weight therapy, and a combination of CAMHS, a support group, and an adolescent child group.

Parents wanted to try a variety of treatments for their child's ADHD. Behavioural therapy (64.18%, *n*=43), combination talk therapy and medication (50.75%, *n*=34), and alternative therapy (41.79%, *n*=28) were the three most preferred treatments. 8.96% (*n*=6) stated that they did not want to try any treatment for their child's ADHD. Other treatments that parents wanted to try included attention-based tasks, being told what support is out there, acupuncture, a different education system, and melatonin.



Participants ranked the 41 treatment preference-sensitive questions for ADHD in order of importance. The ten most important questions to parents when choosing care or treatment for their child's ADHD are listed below.

Ten most important treatment preference-sensitive questions

Frequently Asked Questions	Participants who selected this question as one of their top five most important questions
1. How will this help my child get better?	21
2. Is it safe?	20
3. Will this help improve my child's symptoms	16
4. What will this involve for my child?	14
5. Will it change my child's personality?	13
6. Are there risks or side effects to this type of help or support?	13
7. Will my child see the same people for the duration of this help or support?	13
8. What are the long-term outcomes for medication?	12
9. Will my child do better in school?	9
10. What will happen?	9

Finally, participants selected the risks/side effects for their child were most important to them. Anxiety (80.00%, *n*=36), trouble sleeping/insomnia (71.11%, *n*=32), and agitation (62.22%, *n*=28) ranked highest for participants.

Discussion and implications

- While more than half of parents who started this survey stated that their child had tried stimulant medication as a treatment for ADHD (64.18%, *n*=43), a large proportion of parents wanted to try other treatments like behavioural therapy (64.18%, *n*=43) or combination talk therapy and medication (50.75%, *n*=34). These data indicate that there are other treatments that parents would like for ADHD that they have not yet received, and that perhaps a decision aid that listed all of the treatment options for ADHD at the beginning of the treatment decision process would be helpful in choosing a treatment that is best for the family.
- The ten treatment preference-sensitive questions identified in this research highlight the issues that parents consider most important when choosing care for their child with a diagnosis of ADHD.
- The incorporation of these questions into a decision aid for treatment of ADHD may increase the likelihood that this decision aid facilitates SDM.
- Further research is needed into young people's preferences in the planning of treatment for ADHD.

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