Overcoming barriers to effective early parenting interventions for attention-deficit hyperactivity disorder (ADHD): parent and practitioner views

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Abstract

Background  The importance of early intervention approaches for the treatment of attention-deficit hyperactivity disorder (ADHD) has been increasingly acknowledged. Parenting programmes (PPs) are recommended for use with preschool children with ADHD. However, low ‘take-up’ and high ‘drop-out’ rates compromise the effectiveness of such programmes within the community.

Methods  This qualitative study examined the views of 25 parents and 18 practitioners regarding currently available PPs for preschool children with ADHD-type problems in the UK. Semi-structured interviews were undertaken to identify both barriers and facilitators associated with programme access, programme effectiveness, and continued engagement.

Results and conclusions  Many of the themes mirrored previous accounts relating to generic PPs for disruptive behaviour problems. There were also a number of ADHD-specific themes. Enhancing parental motivation to change parenting practice and providing an intervention that addresses the parents’ own needs (e.g. in relation to self-confidence, depression or parental ADHD), in addition to those of the child, were considered of particular importance. Comparisons between the views of parents and practitioners highlighted a need to increase awareness of parental psychological barriers among practitioners and for better programme advertising generally. Clinical implications and specific recommendations drawn from these findings are discussed and presented.

Introduction

Although most frequently diagnosed during the school years, attention-deficit hyperactivity disorder (ADHD) is now acknowledged to affect individuals across the lifespan (Barkley et al. 2004) with such problems being recognized as one of the most common reasons for preschool referrals to mental health services (Wilens et al. 2002). A combination of pharmacological and psychological treatment approaches are recommended for school-aged children with ADHD (Taylor et al. 2004). However, medication can have side-effects (Handen et al. 1991; Graham & Coghill 2008) and parents can have reservations about its use for controlling behaviour, particularly in young children (Berger et al. 2008). The need for an alternative early intervention approach using non-pharmacological treatments, such as parenting programmes (PPs), has been increasingly recognized (Daley 2006; Sonuga-Barke & Halperin 2010; Sonuga-Barke et al. 2011; Charach et al. 2013).
Current clinical guidelines recommend the use of group-based PPs for preschool children with ADHD (NICE 2008). Evidence from systematic reviews show that PPs can improve a range of outcomes (Bunting 2004; Barlow & Parsons 2009; Charach et al. 2013). However, effects on core ADHD symptoms are less well established (Sonuga-Barke et al. 2013) and factors such as low ‘take-up’ and high ‘drop-out’ rates can have a significant impact on effectiveness. Studies found 35–68% of families with a child with disruptive behavioural problems declined to take part in PPs (Barkley et al. 2000; Cunningham et al. 2000), and where families do start treatment, dropout rates are high [up to 40% for PPs (Forehand et al. 1983; Patterson et al. 2005) and 40–60% for child mental health services (Kazdin 1996)].

Understanding the barriers to treatment ‘take-up’ and ‘drop-out’ is crucial for the development of more effective interventions. Most studies consider such barriers in relation to disruptive behaviour problems generally. Poor engagement and ‘dropouts’ have been found to be influenced by demographic variables including; low income, single parent status, education/occupation, family size, minority status and maternal age (Webster-Stratton & Hammond 1990; Kazdin 1995; Cunningham et al. 2000; Reyno & McGrath 2006). Other factors include child variables (e.g. severity of behaviour), and parent variables such as maternal psychopathology (Kazdin 1995; Reyno & McGrath 2006). A recent meta-synthesis of qualitative research highlighted a range of psychological (e.g. stigma), situational (e.g. childcare issues) and programme/service barriers (e.g. unhelpful) faced by parents (Koerting et al. 2013). These findings are broadly consistent with Kazdin’s ‘barriers to treatment’ model which has been used to predict increased rates of cancelled and/or missed appointments (Kazdin et al. 1997; Kazdin & Wassell 1999). However, a sizable proportion of variance in early treatment termination remained unexplained and it has been suggested that Kazdin’s model may not adequately encompass the parents’ views (Owens et al. 2007). In addition, dropout rates vary across different diagnostic groups, with ADHD associated with one of the highest dropout rates (Johnson et al. 2008). This suggests that it would be beneficial to examine barriers in relation to specific disorders both in relation to parent and professional views.

The current paper attempts to understand the reasons for low uptake and completion of early PPs for ADHD. Opinions of families with the most complex needs (e.g. presence of maternal psychopathology, child co-morbidity) and those who may be considered ‘hard-to-reach’ and ‘difficult to treat’ (e.g. living in areas of social deprivation) were sought. The barriers experienced by these groups are relatively unexplored in the literature.

Our study is also the first to investigate views of both ‘hard-to-reach’ parents of children with preschool ADHD-type problems, and PP practitioners. The research questions were:

- What are the barriers faced by these parents in relation to accessing and engaging with currently available PPs for preschool children with ADHD?
- What could be done to help maximize ‘take-up’ and minimize ‘drop-out’ rates from such programmes?
- How could treatment be improved in order to maximize the effectiveness for families?

**Method**

A qualitative approach involving semi-structured interviews was used to capture participants’ views as well as to generate information on clinical decision making and aid policy development (Jack 2006).

**Participants**

Purposeful sampling (Ritchie & Lewis 2003) specifically targeted families who may be considered ‘hard-to-reach’, and those with complex needs. Along with practitioners with ADHD-related experience, several sources were used for recruitment, which were based within one National Health Service (NHS) Trust in the South of England:

- **Sure Start Children’s Centres**, which aim to improve services for families with preschool children in areas of high deprivation (Melaugh et al. 2008);
- **Adult Mental Health Services and Child and Adolescent Mental Health Services (CAMHS)**;
- **Speech and Language Therapy (SALT) Clinics and Portage Home Visiting Service**: Both services work with preschool children with complex needs.

Eighteen practitioners, all experienced with providing services for and/or running PPs for preschool children with ADHD-type problems, were recruited (Sure Start; n = 5, Adult Mental Health Services and CAMHS; n = 6, SALT and Portage; n = 7). Thirteen parents were referred to the study by practitioners who worked with the family and identified their child as presenting with preschool ADHD-type problems (Sure Start; n = 11, Mental Health; n = 2). An additional 12 were recruited via three local ADHD support groups. These were parents of slightly older children (up to 12 years) many of whom had a formal diagnosis of ADHD (Table 1 for demographics).

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Three parents had mental health issues (depression or ADHD), two had large families (5+ children), one had learning difficulties, one had been a teenage mother and several had other children with difficulties (ADHD, Oppositional Defiance Disorder, Downs Syndrome). Other issues included domestic violence (n = 1) and substance abuse (n = 1). Two parents had also previously dropped out of a PP. These reports, together with other demographic details, support this as a ‘hard-to-reach’ sample (Doherty et al. 2003; Cortis et al. 2009).

**Procedure**

Semi-structured interview questions were based on themes derived from our qualitative literature synthesis (Koerting et al. 2013). Interview questions were piloted through two focus groups consisting of: (1) parents from an ADHD support group; and (2) Sure Start practitioners and Educational Psychologists. Questions focused on three areas: (1) barriers and facilitators to accessing PPs for preschool ADHD; (2) factors that impact on the effectiveness and success of these PPs; and (3) barriers and facilitators to continued engagement with PPs.

The study received approval from both University and NHS Research Ethics Committees. Heads of services from which participants were recruited were provided with information relating to the study. This was passed to staff members and families with a preschool child whom they considered to have ADHD-type problems. All participants gave signed informed consent for participation and audio-recording of the interviews. Recruitment continued until data saturation was reached.

**Analysis**

Transcripts were organized within ATLAS ti and analysed thematically using a Framework Analysis approach (Ritchie & Spencer 1994). Analysis was primarily conducted by ES, JK and MK, who were closely supervised by SL, an experienced qualitative researcher. Framework Analysis involves a systematic process of sifting, charting and sorting data to facilitate the emergence of key concepts and themes. This involves five stages: (i) familiarization; (ii) identification of a thematic framework; (iii) indexing; (iv) charting; and (v) mapping and interpretation. During the familiarization stage all transcripts were read and discussed by ES, JK and MK. Early coding was completed in vivo (line-by-line, using respondents’ own language and meaning). This formed the basis of our thematic framework, which was applied to all data during the indexing stage. Data were then sorted according to the initial emerging themes (charting) enabling examination of the range of responses within each initial theme. Parent and practitioner interview transcripts were also grouped and analysed separately so that disparities could be explored within each theme. During the final stage themes and concepts were refined and associations examined.

**Results**

Thirteen themes are presented under the following three domains: ‘Parent Factors’ (psychological barriers, situational barriers and motivation and capacity to change parenting practice); Programme Factors (initial approach to families, support for parents’ own needs, individually tailored and flexible programme, implementation of strategies at home, importance of realistic expectations and highlighting progress, additional contact and group delivery format) and Service Factors (awareness and advertisement, inter-agency collaboration and therapist characteristics). Within each theme differences and similarities between parent and practitioner views are discussed.
Parent factors

Psychological barriers

Parents often raised issues associated with low self-confidence, mostly in relation to attending group-based PPs. Feelings of shame/embarrassment (associated with attending a PP and relating to their child’s behaviour) and a fear of being judged as a ‘bad parent’ were also common. Parents also worried about involvement with other services, especially Social Services.

... Worrying – Will that judgement then lead to something? Will I be considered an ‘okay parent’ and if I’m not an ‘okay parent’ will they start intervening more than I want them to in my family life? (Parent P36)

Some practitioners showed awareness of such issues but others did not mention this theme.

Situational barriers

Both parents and practitioners highlighted a range of situational barriers, including being a single and/or young parent, having several children or having an unsupportive family/partner. Concerns regarding the time commitment required to attend a PP and that this might not be the top priority when families are faced with multiple challenges were also raised.

... where X is really active all the time it’s hard work to do anything – just going to the shop takes an hour to get ready. So, it might be a time thing, like, can I really fit that 2 hours into my day when I’ve got all of this to do. (Parent P53)

Inconvenient session times and locations, child care issues and the lengthy duration of programmes were considered important barriers. Practical reasons for missing sessions included illness and medical appointments, work commitments, and difficulties relating to their child’s behaviour (e.g. getting excluded, phone calls from school). Other factors, mainly mentioned by practitioners, included; lack of education, cultural issues, domestic violence and financial difficulties.

Motivation and capacity to change parenting behaviour

Both parents and practitioners reported great difficulties associated with changing established parenting approaches. It was suggested that parents who believe that their child’s problems have nothing to do with their parenting or do not feel ready, motivated, or able to make changes to their own behaviour reduced the desire to access and/or engage with PPs.

I think sometimes people expect you to do the work for them – so they expect a miracle cure by the end without putting in anything themselves. (Parent P59)

Regarding increasing motivation the most common suggestions mentioned by both groups were; use of rewards and encouragement, focusing on the positives and having realistic expectations about improvements. Sharing successful strategies between parents was also seen to help improve self-confidence, motivation and a feeling of being valued within the group.

Programme factors

Initial approach to the family

A number of practitioners suggested an initial home visit to build trust with the parent, and to explain the benefits of the programme. Both parents and practitioners highlighted the importance of parents feeling able to make their own decision about starting a programme as opposed to being made to attend. The use of a buddy scheme (where parents are paired up with each other or introduced prior to the course starting) or bringing a family member, friend or ‘family support worker’ was also suggested to help support parents.

Support for parents’ own needs

In order for parents to be able to follow a PP successfully both groups felt that parents needed to have their own needs met first. Specific support in relation to mental health problems, domestic violence and low confidence was considered vital.

If you’ve got a parent with mental health problems, with horrendous childhood experiences, with domestic violence, with any of these really horrible experiences, unless you do some work about getting them to understand their own behaviour, and also letting go of that hurt, you really haven’t got a chance in getting them to change what they’re doing with their child. (Practitioner P50)

The identification and treatment for specific conditions such as depression and parent ADHD was also regarded as important.

Parents need their own diagnosis and medication. That is probably top of the list because if you have ADHD yourself then doing a parenting group and trying to be consistent is an absolute nightmare. So actually in almost
every group I’ve run I’ve ended up with one or two parents probably going off to their GP and asking for their own diagnosis. (Practitioner P48)

*Individually tailored and flexible programme*

Both groups spoke of parents disengaging if they found the programme not relevant for their own child with a large number of parents expressing a desire for individual support.

... If you do it on an individual basis, then they will get something out of it instead of just like a general topic. (Parent P62)

Practitioners spoke about the need for flexibility, particularly with regards to dealing with ‘crisis moments’. The importance of adapting the programme to support children with complex problems (e.g. additional language, communication and/or learning difficulties) was raised. The use of both generic and specifically targeted programmes, as well as linking with other support services (e.g. Speech and Language Therapy) was also mentioned.

*Implementation of strategies at home*

Difficulties implementing strategies was a common theme within both groups. Practitioners stressed the importance of modelling strategies and giving relevant, real life examples. Support from partners/fathers and other key family members were also suggested as important.

... I think these parents, group of parents – they haven’t seen a role model of dealing with difficult behaviour or ordinary behaviour, and they can’t put the energy to do that because of their own problems. So that modelling is so important, and to show them that’s how it’s done. When you talk theoretically to those families it doesn’t fit and that’s why a lot of time they will withdraw from the group because they can’t take it. (Practitioner P44)

*Realistic expectations and perception of progress*

Both groups reported that parents were more likely to ‘drop-out’ if the type of improvements they expected did not materialize quickly enough. The importance of having realistic expectations and the ability to spot small and subtle changes was highlighted. Having such improvements specifically pointed out by the therapist and understanding that strategies may not work all of the time was also reported as beneficial by parents.

... actually looking at what you’ve achieved so far and although you think that you’re rubbish at it you’re actually not cos you’ve achieved quite a lot! (Parent P3)

*Additional contact*

The importance of regular practitioner-parent contact between sessions was highlighted by both groups. Telephone calls and/or text messages as reminders of upcoming sessions or when a parent missed a session were seen to be particularly important. Some respondents mentioned that text messages were preferable as they could be less threatening. The availability of catch up sessions and additional individual one-to-one support was also seen as valuable, especially for families with complex needs. A wish for some form of follow-up session(s), or post-programme support was also raised by some parents.

*Group delivery format*

The group delivery format of PPs received more coverage from parents than practitioners. Views were polarized with intra-group relationships.

Positive aspects included; finding out that other people have similar problems, feeling less alone, building relationships with likeminded people, sharing problems and solutions, gaining a support network and feeling valued.

Sometimes you feel as if it must be in your head – it’s like, is my son the only one like this? But when you hear other parents actually saying ‘oh, my son does this, and my child does that’ – oh, he does that too, and then you pick up pointers from other parents – what they do and stuff, so I think it is helpful. (Parent P56)

In contrast some parents mentioned difficulties going to a group programme by themselves, highlighting issues with confidence and socializing. This was a particular problem raised by the majority of parents who had not actually attended a PP themselves. Feelings around ‘not fitting in’ with the group were also mentioned as reasons for dropping out. This appeared to be driven by disparities in factors such as age, culture, education, marital status, severity of child’s problems and perception of progress.

They’ll typically say – I sat there when they were talking about they won’t eat their dinner nicely and my child is running around the room trying to strangle the dog and screaming and shouting, running in the road and blah, blah, blah, and it just felt so awful because I had to talk
about what mine was doing and it was so different to what everyone else's child was doing. (Practitioner P48)

Service factors

Awareness and advertising

Only one practitioner mentioned lack of awareness of PPs as a reason for not attending a PP whereas this was a common point raised by parents. This was a common theme among the subgroup of parents (n = 7) who had never attended a PP. Four of these were recruited from voluntary ADHD support groups and the majority were not aware of any potential PPs available to them. Most of this group mentioned that lack of awareness/advertising of programmes was a major barrier to effective engagement with programmes. However, they were also able to mention other potential barriers – many of which reflected the broader views of the group.

Suggestions from parents for raising awareness of PPs mainly focused on where information/leaflets should be placed with the most common suggestion being within general practitioner (GP) surgeries. Both groups highlighted the importance of ‘word of mouth’, e.g. through groups of parents where those working with young children (e.g. GP, health visitors, school staff) to be able to both spot potential clinical issues (e.g. ADHD) and have up-to-date information of PPs to pass on.

...if you’ve got a parent saying to a group of parents ‘yes I came and I only missed one for a doctor’s appointment because it is really working for X’ it goes far further than me saying ‘please come – it’s great’. (Practitioner P42)

Inter-agency collaboration

Parents expressed a desire for all practitioners who come into contact with young children (e.g. GP, health visitors, school staff) to be able to both spot potential clinical issues (e.g. ADHD) and have up-to-date information of PPs to pass on.

Practitioners mentioned the need for agencies to collaborate to optimize the referral process (e.g. using existing agencies with a good relationship with the family) and to provide better holistic care, especially for those with complex needs.

I think it is multi-agency working. It is not only the child and the family in those...[hard-to-reach]. You have to identify the whole family dynamic in those, and mostly there are a lot of social issues in those families. Mental issues in the mum, personality disorder in the mum, learning difficulty in mum, and not being able. It’s mainly factors around the mum or the dad themselves – the parents or the carers themselves – and that’s a big piece of work. (Practitioner P4)

Therapist’s characteristics and therapeutic relationship

The role of the therapeutic relationship was seen as crucial. Parents wanted the therapist to have plenty of direct experience working with children with challenging behaviour and for him/her to be a parent. Both groups highlighted the importance of good knowledge of specific disorders such as ADHD.

It’s no use going to see someone that hasn’t really had the hands on experience and then give a group and don’t really know what they’re talking about... (Parent P53)

Both groups spoke of the importance of a strong relationship between the parent and the therapist. This was facilitated by commonalities between them and by the therapist adopting a non-judgemental, informal and caring approach. Parents specifically wanted to feel on ‘the same level’ as the therapist. Practitioners also mentioned their own need for support and supervision.

Discussion

Low ‘take-up’ and high ‘drop-out’ rates are significant barriers to PP effectiveness. The aim of the current study was to focus specifically on attitudes to early PPs for ADHD with ‘hard to reach’ and ‘difficult to treat’ families, who are often overlooked.

The current study also placed a greater focus on seeking potential solutions and improvements rather than concentrating solely on barriers in order to help clinicians and service providers to better support these complex families.

Our themes were broadly consistent with the existing literature relating to PPs in general (see Table 2). These included both psychological and situational barriers, and a desire for individually tailored, flexible PPs that incorporate additional contact in-between sessions, if required. The importance of raising awareness and advertising of PPs, good inter-agency collaboration and a positive therapeutic relationship were also consistent with existing literature (Koerting et al. 2013). The current sample also highlighted difficulties in implementing new strategies. Previous studies demonstrated that parents disengage if they find the programme unhelpful (Attride-Stirling et al. 2004; Patterson et al. 2005; Friars & Mellor 2009); our sample spoke of this more specifically in relation to perceptions about the child’s progress, highlighting the importance of realistic expectations and a desire for progress to be made explicit by the therapist. We also identified a number of additional elements when considering early PPs for ADHD specifically. These new themes were ‘motivation and capacity to change parenting practices’, ‘initial approach to the family’ and ‘additional support for parents’ own
needs'. These themes are likely to be either associated with the specific focus on ADHD and/or our complex, 'hard-to-reach' sample.

Parental motivation was specifically highlighted by the current sample. This could be an area of particular importance for families with ADHD as motivational deficits have been found in adults with ADHD (Volkow et al. 2009; Cubillo et al. 2012). Previous research has demonstrated the benefits of a brief intervention designed to increase parents’ motivation in relation to attendance and reported adherence with a PP for children with conduct problems (Nock & Kazdin 2005). The second novel theme 'Initial approach to the family' covered suggestions relating to early contact with families. Explaining the benefits of the programme, addressing parental concerns and setting up realistic expectations were all considered to be highly beneficial. The final novel theme focused on the desire for interventions to be targeted towards the parent’s needs in addition to those of the child. This is especially important considering the strong familial component to ADHD (Williams et al. 2010) and findings from previous research which suggest that PPs are less beneficial for children whose parents demonstrate symptoms of ADHD themselves (Sonuga-Barke et al. 2002; Harvey et al. 2003).

In general, lack of parental self-confidence and sense of self-efficacy could be seen as factors underlying many barriers (e.g. 'psychological barriers', 'motivation and capacity to change parenting practice', 'additional support for parents' own needs' and 'group delivery format'). Previous research has highlighted the importance of parenting self-efficacy as a predictor for positive treatment experience among mothers participating in a behavioural PP for their school-aged child with ADHD (Johnston et al. 2010). This would suggest that the use of underpinning theory and evidence-based practices to guide the delivery of PPs may be an important step forward.

Overall, there was often agreement between parents and practitioners. However, some practitioners demonstrated poor recognition of psychological barriers and parents’ lack of awareness of programmes. Also, parents often spoke of the social/group aspect of the programme which were less pronounced in practitioners’ accounts, suggesting that practitioners had less awareness of pertinent issues for parents.

**Recommendations and implication for clinical practice**

We make the following recommendations to improve engagement in early treatment interventions for children with ADHD.

**Awareness and advertisement**

It is important to raise awareness among professionals of potential psychological barriers faced by parents and maintain good communication between agencies about currently available PPs. Greater advertisement of programmes aimed at hard to reach groups would be beneficial.
Thorough initial assessment

Any additional psychological and situational barriers facing the family should be fully explored. Parents need a clear explanation of what the PP involves, how it could be of benefit and a realistic expectation regarding expected behaviour change/progress. The appropriateness of a group-based versus an individual programme should also be considered.

Support for parents’ own needs

Assessment/treatment of maternal mental health problems (e.g. depression and adult ADHD) should be provided either prior or alongside the PP. Supporting parent self-confidence, parenting self-efficacy and motivation should also be an important part of the PP itself.

Flexible, individually tailored programme with targeted support relating to ADHD core symptoms

Emphasis should be placed on helping parents to implement strategies at home, through techniques such as modelling and scaffolding. Therapists need to have a good knowledge and experience specifically relating to ADHD and additional contact in-between sessions is desirable. Highlighting improvements/progress explicitly (e.g. through video clips) is also beneficial.

Limitations and future direction

It should be borne in mind that our findings are limited to a parent sample of white females, all of whom spoke English as a first language. It is possible that different or additional themes may have emerged when interviewing fathers, or parents from an ethnic minority background; both of these groups are also considered hard to reach. A number of the parents were also selected via practitioners and thus may not necessarily be typical. In addition, some parents had children who were school-aged rather than pre-schoolers. While interviewers enquired specifically about the time when their children were pre-schoolers, there is always a potential for bias in retrospective accounts. Finally, not all parents had attended a PP by the time of the interview, so they did not have direct experiences of attending a PP. However, if was felt that ascertaining the views of these families, particularly with regards to why they have not accessed such a programme, was of importance.

Future research is needed to develop instruments that help provide a thorough assessment of both the needs of the parent and the child. Psychological factors such as confidence levels, parenting self-efficacy and motivation should also be considered. Evaluating the cost-effectiveness of PPs, perhaps more intensive treatment approaches, will also be of importance.

Key messages

- PPs should address the needs of the parent in addition to those of the child.
- PPs need to be better advertised and raising awareness of possible parental psychological barriers among practitioners would be beneficial.
- Parental motivation was considered influential with regard to both accessing and engaging with PPs and treatment effectiveness. This may be an area of particular importance for families of children with ADHD.

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Conflict of interests

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