

Parent perceptions of participation in a parent-mediated communication-focused intervention with their young child with autism spectrum disorder

Autism
2020, Vol. 24(8) 2129–2141
© The Author(s) 2020



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1362361320936394
journals.sagepub.com/home/aut



Kathy Leadbitter¹ , Wendy Macdonald², Carol Taylor¹,
Karen Leneh Buckle¹; and the PACT Consortium*

Abstract

Paediatric Autism Communication Therapy is a parent-mediated, video-aided, communication-focused intervention for young children with autism spectrum disorder. It has been shown in a UK randomised controlled trial to lead to improvements in parent–child communication and family quality of life, together with a sustained reduction in child autism symptom severity. This qualitative study examined parental perceptions of their participation in Paediatric Autism Communication Therapy within the context of the randomised controlled trial. Semi-structured interviews were carried out with 18 parents within 12 months of completion of the therapy. The thematic analysis provides insights into parents' hopes, expectations, and learning processes when working with Paediatric Autism Communication Therapy therapists and carrying out daily practice in the home. Parents reported positive changes in their interaction and relationship with their child and improvements to their child's communication and interaction. Some also highlighted poignant realisations and emotional challenges associated with taking part in this post-diagnostic therapy. Practical difficulties were also emphasised. Implications for the clinical practice of parent-mediated interventions with young children with autism spectrum disorder are discussed.

Lay abstract

Paediatric Autism Communication Therapy is an intervention for young children with autism spectrum disorder that focuses on parent–child communication. In Paediatric Autism Communication Therapy, the therapist and parent watch videos of the parent and child playing together. The therapist coaches the parent to carefully observe the child's communication and to interact with their child in a more sensitive and responsive way. Parents are encouraged to use the strategies with their child at home. Paediatric Autism Communication Therapy has been shown to lead to long-term improvements in parent–child communication and family quality of life. This study aimed to explore parents' perceptions of their participation in Paediatric Autism Communication Therapy. Interviews were carried out by an independent researcher with 18 parents. Parents discussed the learning processes they went through when working with Paediatric Autism Communication Therapy therapists and carrying out home practice. Some parents described initial doubts about the approach and hesitations about being videoed and analysing video material. In time, most parents came to really value the therapy and their relationship with the therapist. They reported positive changes in their interaction and relationship with their child and improvements to their child's communication and interaction. Some also highlighted poignant realisations and emotional challenges associated with taking part in this post-diagnosis therapy. Practical difficulties were also emphasised, including the time commitment, accessibility of therapy venues and difficulties in occupying the child during therapist–parent discussion. Implications for the clinical practice of parent-mediated interventions are discussed.

¹University of Manchester, UK

²Greater Manchester Mental Health NHS Foundation Trust, UK

*The PACT Consortium: Catherine Aldred, Barbara Barrett, Sam Barron, Karen Beggs, Laura Blazey, Katy Bourne, Sarah Byford, Tony Charman, Julia Collino, Ruth Colmer, Anna Cutress, Jonathan Green, Clare Harrop, Tori Houghton, Pat Howlin, Kristelle Hudry, Dharmi Kapadia, Sue Leach, Ann Le Couteur, Helen McConachie, Andrew Pickles, Sarah Randles, Vicky Slonims, Kathryn Temple, Lydia White.

Corresponding author:

Kathy Leadbitter, Division of Neuroscience & Experimental Psychology, University of Manchester, Room 3.312, Jean McFarlane Building, Oxford Rd., Manchester M13 9PL, UK.
Email: Kathy.Leadbitter@manchester.ac.uk

Keywords

Autism spectrum disorders, interventions, psychosocial/behavioural, parent-mediated, qualitative research, communication and language, pre-school children

Introduction

Many interventions for young children with autism spectrum disorder (ASD) are parent¹-mediated (either in one-to-one sessions with a therapist or as a member of a parent group) whereby a trained practitioner shares therapeutic strategies with the parent, who is then encouraged to use these strategies with their child outside the session. There is little or no direct work between the practitioner and child. There is a growing body of evidence to support the use of parent-mediated interventions, especially for pre-school children with ASD (National Institute for Health and Care Excellence, 2013; Nevill et al., 2018; Oono et al., 2013). These interventions include social communication-focussed therapies (e.g. Pickles et al., 2016; Rahman et al., 2016) and naturalistic developmental behaviour interventions (e.g. Kasari et al., 2015; Schreibman et al., 2015).

Understanding parental perceptions

The success of any parent-mediated intervention is heavily dependent on initiation, engagement and commitment from parents who often already experience considerable pressures on their time, energy and wellbeing (Dykens et al., 2014; Hutton & Caron, 2005). Irrespective of its efficacy and potential clinical and cost effectiveness, parents' perceptions of an intervention and its plausibility, feasibility and sustainability will bear a direct influence on intervention initiation and engagement (Mackintosh et al., 2012; Stahmer et al., 2017). These perceptions will also influence their commitment to carrying out between-session practice (V. A. Green, 2007; Stahmer & Pellecchia, 2015). Qualitative methodologies that elicit parental perceptions thus have a valuable role within clinical trials of such interventions (Cheng & Metcalfe, 2018; Moore et al., 2015) and will inform the real-world implementation of the intervention as it moves beyond the context of the trial. They also offer opportunities to investigate the personal experiences of participants providing (a) a better understanding of processes that may be relevant and contribute to or inhibit the documented quantitative intervention effects (Hodgson et al., 2018; O'Cathain et al., 2013) and (b) insight into potential emotional and relational outcomes not accessible through the trial quantitative hypotheses and measurement (Bölte, 2014).

Previous qualitative research has examined parental perceptions of a range of autism interventions, including naturalistic developmental behavioural interventions (Carr & Lord, 2016; Pickard et al., 2016; Stahmer et al., 2017), applied behavioural analysis (Grindle et al., 2009), adapted responsive teaching (Freuler et al., 2014), a group-based 'Managing Repetitive Behaviour' intervention (Hodgson et al., 2018), music therapy (Allgood, 2005) and equine

therapy (Tan & Simmonds, 2018). These studies have provided insight into the feasibility, acceptability and perceived effectiveness of individual interventions. In addition, there are common themes that arise across these studies, namely, the impact of the intervention on the parent themselves, including increased parental empowerment, confidence, understanding and skills (Allgood, 2005; Carr & Lord, 2016; Hodgson et al., 2018; Pickard et al., 2016; Stahmer et al., 2017); extended benefits for the whole family (Carr & Lord, 2016; Grindle et al., 2009; Tan & Simmonds, 2018); the value of a supportive parent-professional relationship (Allgood, 2005; Carr & Lord, 2016; Freuler et al., 2014) and the barriers to and burdens of intervention participation, often in terms of time, financial costs and inconvenience (Carr & Lord, 2016; Freuler et al., 2014; Grindle et al., 2009; Hodgson et al., 2018; Pickard et al., 2016).

Paediatric Autism Communication Therapy

Paediatric Autism Communication Therapy (PACT) was designed to improve social communication competencies in children with ASD through enhancing the parent-child social communication interaction (Aldred et al., 2004; J. Green et al., 2010; Pickles et al., 2016). PACT was developed from theoretical principles and empirical research and adopts the rationale that children with ASD require adapted interaction specifically matched to their individual level and style of social communication (Yoder & Warren, 2001). Through video-aided observations and facilitative questioning, therapists coach parents to increase their 'synchrony', that is, to carefully observe their child's communication and interaction and to adapt their own communication style to interact with their child with enhanced sensitivity and responsiveness. Parents are encouraged to implement the new strategies during daily home practice. For a more detailed description, see J. Green et al. (2010).

The PACT trial

The efficacy of PACT was evaluated within the UK Pre-school Autism Communication Trial (PACT trial) and a six-year follow-up study (J. Green et al., 2010; Pickles et al., 2016). One hundred and fifty-two families were randomised to either PACT plus treatment-as-usual or to treatment-as-usual alone. PACT therapy consisted of 18 clinic-based sessions with a trained speech and language therapist over the course of a year and 20–30 min of daily home practice. Trial results showed that PACT enabled parents to communicate with their child with enhanced synchrony and children initiated more communication with their parent (J. Green et al., 2010). Parental synchrony mediated 79% of the improvement in child communication with the parent and the

improved child communication with the parent mediated 97% of the improvements in autism symptomatology (Pickles et al., 2015). A primary outcome treatment effect of reduced autism symptom severity was found at treatment endpoint and remained 6 years later (Pickles et al., 2016). PACT also showed a positive effect on a parent-nominated measure of family experience and quality of life (Leadbitter et al., 2018).

Aims of this study

This pre-specified qualitative phenomenological study documents parental perceptions of participation in PACT within the PACT trial, including reflections on their subjective experiences of participating in PACT sessions, working with PACT therapists and implementing the intervention on a day-to-day basis; perceived benefits and limitations of the intervention for themselves, their child and their family; and consideration of the costs, challenges and/or negative consequences associated with participation.

Methods

Sampling

Families were randomly selected for this qualitative study from the pool of families who had completed the PACT trial and had been randomised to the PACT arm (including those who had withdrawn from/not engaged with the therapy). Sample selection and analysis were conducted concurrently, in an iterative fashion, with families being approached up until the point of data saturation. Families were contacted by letter and invited to take part in an interview about the 'experience of the treatment that [they] received', to be conducted by an independent researcher to ensure confidentiality. By the end of the sample selection process, 26 families had been approached, 16 had volunteered to participate and 10 did not respond. Interviews were conducted with 12 families, at which point data saturation was reached. Of these 12 families, one family had actively withdrawn from the therapy after three sessions (but had stayed within the trial itself allowing further contact to be made). The other families had received between 8 and 18 of the planned 18 sessions (see data in Table 1). All interviews were conducted within 12 months of therapy completion (M (standard deviation, SD) = 8.33 (3.23); range = 2–12 months) and prior to dissemination of actual trial outcomes.

Participants

Participants were 18 parents from 12 families: 6 individual parents (all female) and 6 male–female couples who were interviewed together. Family, parent and child characteristics are presented in Table 1, alongside data on therapy dosage, therapeutic alliance (parents' quality of engagement with the therapy and therapist) and child response to therapy

(improver, intermediate or non-improver). Individual parent/family demographics are not presented to preserve participant confidentiality.

To have participated in the PACT trial, children were aged 2–5 years, diagnosed with autism and meeting cut-offs for 'core' autism on the Autism Diagnostic Observation Schedule–Generic (Lord et al., 2000). Parents needed adequate spoken English. Full trial eligibility criteria are detailed in J. Green et al. (2010).

Procedure

A semi-structured interview schedule (Appendix 1) was developed by an independent qualitative researcher, in collaboration with senior members of the PACT trial team. This independent researcher had no formal training in PACT but had an understanding of the aims, rationale and methods of the intervention. She had had no previous contact with participating families. Interviews (55–150 min) were conducted by the independent researcher in the parents' homes. These were audio-recorded, transcribed verbatim and transcripts were anonymised. Field notes were made during the interviews to support the audio files.

Analytic strategy

Data analysis was conducted with thematic analysis using a constant comparison method (Braun & Clarke, 2006; Creswell, 2007; Glaser & Strauss, 1967). Data gathering, transcription and data analysis were conducted in parallel. A preliminary coding framework was devised from initial transcripts. As further data were collected and analysis progressed, alterations and additions were made to the framework. Data (single or groups of sentences) were allocated to the coding framework and examined for relationships within and between the codes. The interviews were read and re-read, and close attention was paid to the transcripts for any data which differed from the coding framework. The themes and relationships that resulted from this process were then explored in the ongoing interviews. Interviews continued until saturation was reached. The saturation process operationalised within this study was 'thematic saturation' (Guest et al., 2006), that is, data collection and analysis continued until the point that new data produced little or no change to the coding framework, with no new themes being identified; the final three consecutive interviews produced no new themes. The thematic structure was then finalised, and illustrative quotations were selected. The analysis was led by the independent researcher with emergent and final themes discussed with trial investigators and revised following feedback.

Results

This article focuses on parent perceptions of PACT; themes that fell outside of the scope of this article are not included

Table 1. Sample characteristics.

Family characteristics	N= 12
Trial sites	
London	3
Manchester	4
Newcastle	5
Family income ^a	
<£20k	4
£20–40k	2
£40–60k	3
Over £60k	3
Parent characteristics	
Age (in years)	
M (SD)	35.6 (6.14)
Range	23–45
Ethnicity	
White British	14
Other	4
Country of birth	
UK	13
Outside UK	5
Marital status	
Married/co-habiting	16
Single	2
Current/most recent occupation	
Professional/administrative	10
Manual/no occupation	8
Highest level of qualification	
Bachelor's degree or higher	9
Below degree level/no qualifications	9
Child characteristics	
Age at trial baseline (in months)	
M(SD)	44.42 (7.04)
Range	33–58
Age at qualitative interview (in months)	
M (SD)	67.17 (8.31)
Range	52–82
Mullens Scales of Early Learning ^b Age Equivalence (baseline, in months)	
M (SD)	27.08 (11.30)
Range	12.5–49.5
ADOS-G algorithm score ^c (baseline)	
Module 1 n	
M (SD)	16.89 (3.79)
Range	12–22
Module 2 n	
M (SD)	17.33 (1.53)
Range	16–19
Child gender	
Male	11
Female	1

(Continued)

Table 1. (Continued)

Therapy variables	N= 12
Number of completed sessions ^d	
M (SD)	14.08 (5.02)
Range	3–18
Parental therapeutic alliance ^e	
N	11 (missing= 1)
M (SD)	29.89 (8.63)
Range	20.33–43.50
Child response to therapy ^f (n)	
Improver	5
Intermediate	4
Non-improver	3

SD: standard deviation.

^aMean UK household income in 2008–2009 was £31k (Statista, 2019).^bMullens Scales of Early Learning (Mullen, 1995) mean age equivalence from the Visual Reception and Fine Motor subscales at trial baseline are provided as an indication of the range of child non-verbal developmental abilities within the sub-sample.^cAutism Diagnostic Observation Schedule-Generic (Lord et al., 2000) algorithm total scores provided as proxy for child autism symptom severity (possible range = 0–24; higher score = higher symptom severity; autism threshold = 12).^dMaximum therapy dosage = 18 sessions.^eTherapeutic alliance measured by the 'PACT Alliance Questionnaire' (Taylor, 2015; Taylor et al., 2017), a parent-rated questionnaire assessing the parents' quality of engagement with the therapy and therapist (low score = high alliance; range within full trial sample: 20–44).^fChild response to therapy, categorised using the Reliable Change Index (RCI) of changes between trial baseline and endpoint on the Autism Diagnostic Observation Schedule-Generic (Lord et al., 2000) algorithm total scores; methodology detailed in Hudry et al., 2018; RCI categorization within full therapy sample: 35% improvers, 39% intermediate, 26% non-improvers (Hudry et al., 2018).

(parents' response to their child's ASD diagnosis, the impact of the child's autism on siblings and reflections on participating in the trial rather than the therapy per se). Themes and subthemes are shown in Figure 1. Quotes are provided verbatim. To protect anonymity, names have been removed, and all references to study children are reported using male pronouns.

The backdrop to the therapy: emotional starting point, hopes and expectations

Children were often referred to the PACT trial soon after their ASD diagnosis, and it was clear from the narratives that, when entering the therapy programme, parents were in very varied emotional 'places' and at diverse points in terms of adaptation to the diagnosis. Parental hopes and expectations about what the intervention would achieve also varied considerably. Some parents expressed gratitude for any input at all. Others hoped that taking part in the therapy would help them to understand more clearly their child's needs and learn strategies to promote their child's development.

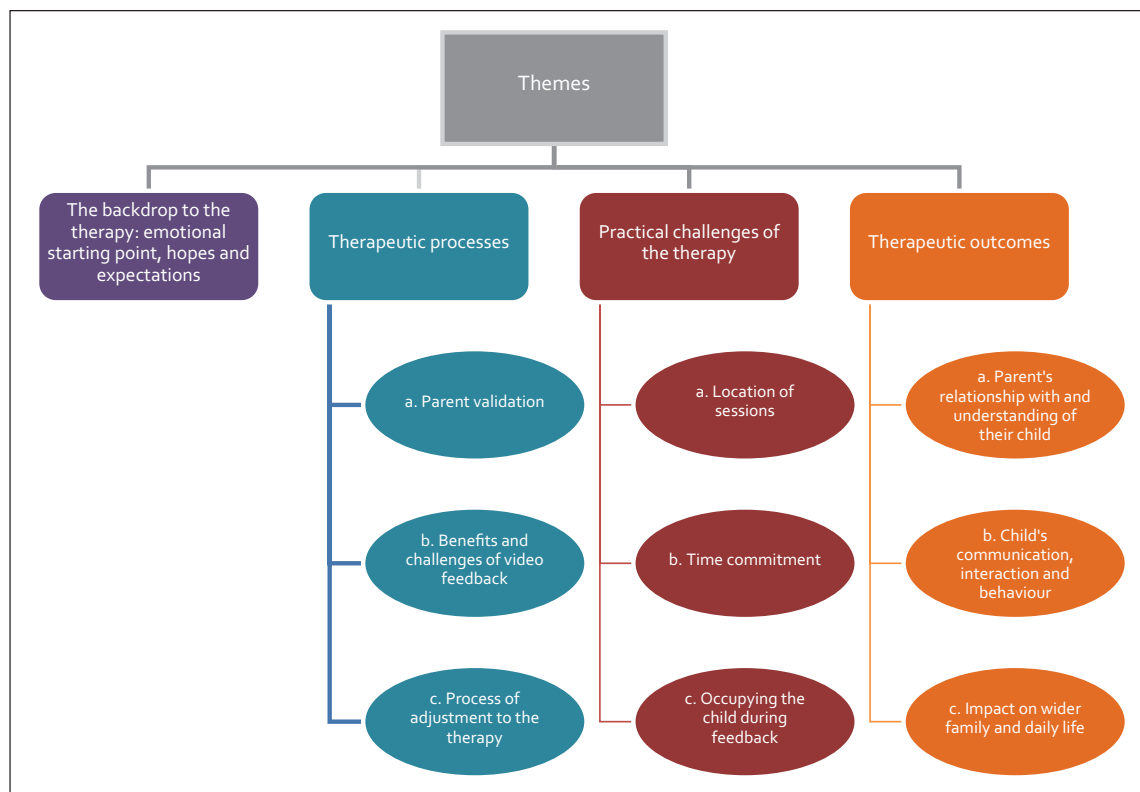


Figure 1. Schematic diagram of themes and subthemes.

I was hoping they could teach me more to teach [child's name] and help him.

In contrast, other parents had high expectations for the intervention. One commonly-held hope was that their child would quickly start to speak.

I was thinking it was, like, oh, they're going to give me some miracle potion or something and show me how to do things and they're going to teach him how to talk straight away.

There was also evidence that parents were unsure of the role of speech and language therapists. Some parents assumed, because of their title, that their main focus would be on spoken language, rather than communication and social interaction more generally. These initial expectations impacted on parents' perceptions of the therapy and, to some extent, their evaluations of the therapy's success; this is described in more depth in the following sections.

Therapeutic processes

Participants reflected on the benefits and challenges of engagement with the therapeutic process. Three common themes emerged: (a) parent validation, (b) benefits and challenges of video feedback and (c) process of adjustment to the therapy.

Parent validation. Parents developed close working relationships with therapists. All interviewees expressed holding their therapist in high esteem. Therapists were described as patient, empathic and positive. Their ability to understand the challenges faced by parents and to do so without judgement was valued. A number of parents spoke directly about or alluded to the regular judgement and criticism they felt in social situations with their child. Receiving recognition and praise from the therapist was a source of validation for them and an important part of the intervention. For some this was their only experience of being seen and acknowledged as a good-enough parent.

The speech therapist, she was lovely, she was absolutely fantastic. She was really understanding when we had problems . . . she was understanding and sympathetic, but it was difficult . . . and she saw how difficult it was.

For some parents, receiving praise from the therapist was a positive thing, but it took them some time to get used to this as they were unused to receiving praise and feeling like they were getting things right in their interactions with their child.

She was, like, wanting to big up you all the time . . . 'you've done really well' and I just wasn't used that.

Benefits and challenges of video feedback. An integral part of PACT is the therapist and parent reviewing videos of parent–child play together and reflecting on aspects of the interaction. Parents discussed both benefits and challenges of this process. Parents felt that the video feedback allowed them to see things in their interactions with their child which were surprising and revelatory and also enabled them to see the progress they were making over the course of the therapy in a tangible way.

You can't think of everything and you don't see all the little things that go right or wrong or anything, so it is so very, very good to watch yourself back on it.

Being filmed was really good . . . and being able to watch it back afterwards I felt was the best bit really.

Watching the videos allowed parents to begin to see and read the less clear communicative signals their child was sending, making them more attuned and responsive to their child's needs. The therapists often highlighted interactional phenomena of which parents were unaware and which helped them recognise positive aspects of their interaction with their child.

It was good to see them [those] things that she [therapist] would point out that you wouldn't have noticed.

For some parents, analysis of the video could be challenging, particularly in the early stages of the intervention. One mother said she felt 'under the spotlight'. However, as time went on, they became accustomed to the process and in all cases came to value this part of the intervention.

It was like you was being analysed, everything you'd just done, was like she was like ripping it all to bits and putting it in little [chunks], and I didn't like that, but it was good in the end . . . it was only like when you'd been into it a few weeks that you understand why . . .

Most parents recognised and valued the therapist's ability to lead them to a discovery rather than directing them. One parent, however, reported feeling frustration at the facilitative questioning style used by therapists.

I found it a bit frustrating because it was the same questions, and very simple questions, were asked all the time. It sounds awful but it's like, 'What is [child's name] doing here?', and it was pretty clear he was pressing a button on something, I sound awful, don't I, but that used to frustrate me a little bit.

Process of adjustment to the therapy. All parents ultimately found the opportunity to reflect on the way they played and interacted with their child rewarding, but it sometimes took time to get to this point. Some reported that, at first,

they were uncomfortable with the therapy aims because they felt that they should be directing and teaching their child to engage in 'educational' activities. However, the process of therapy changed their ideas about how to play with their child.

Parent: The first video when she said, "Just play. Show me how you play with him". I thought I was right. I thought mum should tell child what to do and he should obey . . . that's what I saw mums doing because they teaching children, they saying what to do . . . but she [therapist] said it's not right, should be different . . . So I was not agreeing first time [. . .]

Interviewer: And how . . . did you change your mind about that?

Parent: Yeah, because, if, like she said, if I do what he want he will play longer.

Some parents wanted rapid change in their child and found it very difficult at first to be patient and take things more slowly, even when they recognised that this was a helpful thing to do. One mother struggled to see any benefits and felt impatient and frustrated. However, over time, her view changed, and she began to understand the point of what she was doing.

But it just wasn't fast enough for me. Because I wanted everything yesterday and that was . . . what kept me going, because I knew what she [therapist] was doing was right but it just wasn't happening quick enough. It wasn't until you understood that it wasn't going to be quick term fix, to go there and have your couple of hour sessions and do that . . . and it was only like looking back on the different things that she did do, like you thought, right, it was okay.

Practical challenges of PACT

The practicalities of attending PACT sessions and carrying out the daily home practice created challenges for some parents.

Location of sessions. PACT sessions were mostly delivered within a clinic setting, which may have been a distance from families' homes and an unfamiliar setting for the child. For many parents, the travel was burdensome and sometimes tiring for the child, making engaging in the activities of PACT much more difficult. For one, it became too difficult to continue, and she had to withdraw from the therapy; another could only continue when sessions were moved to the home.

He didn't like the small [therapy] room . . . he was okay for the first two or three sessions and then he started, like, screaming and not wanting to go in . . . Because he just

wouldn't go into the room or even the building at one point, so it had to be changed and it had to be at home . . . It worked better at home.

For others, the therapy venue brought about a happy experience for the child, particularly if the location was familiar.

He liked the [name of venue], he liked that, but I think it was because it was in that place, where he was used to going.

Time commitment. The time commitment required by the therapy (average 4 h/week) could be challenging for some parents, particularly for those in employment. They could see the advantages the intervention conferred on them and their child, but there were times when it was difficult to find the time to attend sessions and do home practice. Some children, particularly those who were anxious or active, struggled with the length of the sessions, and this caused stress for their parents.

I just felt the sessions were a bit long. Because they could be an hour and a half, they could be two hours; it just depended on how much we had to talk about that day really . . . it's just [child's name] is very on the go, so it's quite difficult for me . . . It just got to an hour and it just started getting a bit awkward.

Occupying the child during feedback. During therapy sessions, a video was made of parent-child interaction, and the video was then used for therapist-parent reflection and discussion. Sometimes, the child was engaged in a preferred activity during therapist-parent feedback or occupied by another family member. However, for others, this was not possible, and consequently, some parents struggled to devote their attention to the feedback. They would have welcomed someone who could play with and distract their child.

The only thing I found really hard, [child's name] found it stressful the fact that he couldn't get my attention afterwards, 'cos I had to try and watch the video and talk to [therapist's name] and I found it so hard and I think he did 'cos he mithered [pestered] to death, 'Mummy, mummy, mummy, mummy', and, er, I was torn between the two, trying to concentrate and him.

Therapeutic outcomes

The fourth overarching theme focussed on parents' perceptions of the impact of the therapy on themselves, their child and their family.

Parents' understanding of, and relationship with, their child. A thread running through the narratives was a process of learning for parents that resulted in a new and deeper understanding of their child's interests, capabilities and

communication and their adoption of a more sensitive and responsive interactional style.

You're learning so much to be on his level and letting him, you know, do what he wants to do and follow it . . . it was a really big learning curve really, it was very good.

Parents described a greater ability to empathise with their child and see things from their perspective.

I put my eyes behind [child's name]'s eyes and I just imagine for a minute that I am in [child's name]'s little head and try and look at it from his angle . . . and you probably react totally different to the way you would initially react, because you have looked at it from his point of view.

Many of the interviewees talked about the difference between the first and last video of the PACT intervention and expressed pride at the progress they had made with their child.

Eventually, probably by the last session, then I was like, 'Look what I've just done!'

For many, PACT had led to changes that were maintained at the time of the interview. Some parents talked about the PACT home practice and recognised that the techniques had become so embedded and generalised that they used them across everyday interactions and routines with their child.

It's still rubbed off now . . . it's kind of extended from the play to everyday things, really.

One parent reported that, when playing with her child, she still 'heard' the therapist's voice.

I actually sometimes, just for a minute, I often hear [therapist's name] say, 'Just hold back'.

However, the sentiment of maintained change was not shared by all. One mother expressed that, once the trial was over, she practised the therapy less actively and her sense of being instrumental in her child's achievements diminished.

I think it's just because you let things [go], whereas you were going there you had to keep doing like your little bits of things that you were doing, you sort of slide out of that a little bit now, and school has sort of took over and is steering him in that way, so you sort of think well the school is doing it now, not the school's doing it, but the school is responsible for how good he's doing.

Parents described how the work with the therapist had helped them to realise that they possessed great knowledge and ability to help their child and that by the end of the therapy, they had a new and deeper understanding of their child.

It was a revelation to me . . . I thought I was the only person who knew my child . . . and I didn't . . . now I know him best . . . but I didn't at the start of PACT.

All parents reported being won over by the strengthening of their relationship with their child.

You know, and it took a while. It was about between halfway to three quarters of the way through, he just became a different little person. He'd sit there for longer playing, he'd want me involved, and he was good at kind of, he wasn't getting frustrated because I was making him wait too long, because I managed to get my timings right. And when he reached out, I'd just be on to it, you know . . . and then he was cuddling as well.

This mother describes the impact on her in the most concise and moving way of all:

I have always loved my son . . . but I fell in love with him after this [PACT].

Child's development. Some parents reported improvements in their child's verbal and non-verbal communication and interaction and perceived these to have stemmed from the techniques they learnt in PACT.

The joint attention improved significantly. I've got more eye contact . . . he got better at his non-verbal communication.

As described in the 'hopes and expectations' section, many parents longed for spoken language as an outcome of the intervention. Some parents reported that PACT helped their child to talk, and this was an achievement which was understandably prized.

It was, um, hard work but it was rewarding work 'cos he did get to talk, 'cos he didn't speak until he was, um, over three [years of age].

Other parents were proud of their child's progress although they could not be sure that it was entirely because of PACT.

Um, well, his communication, I mean he started to talk so that was a big thing, but that could have been his age, you know, it's very hard 'cos he was so young.

However, others reported that their child had not started to use spoken language, and this was difficult to come to terms with.

Because we were hoping his speech would have improved with the intervention, but it didn't. Because I was constantly labelling . . . but it just hasn't really happened, you know.

Along with improvements to communication and interaction, some parents also described improvements in their child's behaviour and often attributed this to more effective child communication skills.

Bad days are fewer. But I think that's, I think he's not got so many frustrations now, that was one of the main things I think and of course he can communicate now.

For some, even if a child's behaviour continued to be quite challenging, there were more subtle changes which could be extremely rewarding for the parents. For this mother, the increase in her son's enjoyment of her company and physical affection had been 'wonderful'.

So, [improvements to] the behaviour side, not so much really. It's more like I've noticed that he likes doing things with us more since doing the PACT . . . getting us involved with cuddles and that sort of thing.

For some parents, the therapy had entailed a painful coming to terms with the extent of their child's disability. One parent described that although her child had made progress with PACT, she and her husband were still 'grieving for the loss of the child we thought we were going to have' and her hope that her child would talk had not been realised. This mother valued the intervention, but it had brought home for her the consequences of her child's disability and the possibility that he might never learn to speak. A second mother described that despite her best attempts in engaging with the therapy, the pace of her child's development was slower than she had hoped, and this brought home for her the severity of her child's autism.

We were a little bit like, oh God, and it kind of made us realise how, what a problem his autism is, how severe it is really, you know.

Impact on wider family and daily life. The effects of PACT on the wider family were evident in a number of accounts. For many, the progress made during the intervention allowed members of the wider family to see the child more positively, rather than just seeing 'the autism'.

And my husband, my family all suddenly saw [child's name] as opposed to the autism.

The effects of PACT on parental confidence and self-efficacy also sometimes extended out to the whole family.

We are so pleased with the progress he's made, it has been fantastic. I think the PACT trial was a huge, it was hugely important to him. And it was hugely important for the whole family, it is kind of a family confidence it gave the whole family really.

Discussion

This qualitative study, using thematic analysis, provides insights into parents' perceptions of intervention outcomes, their learning journey and process of change, the value of

the relationship with the therapist and poignant emotional challenges and practical difficulties associated with participation in a parent-mediated early intervention.

Parents' perceptions of therapy outcomes

Parents' perceptions of therapy outcomes were largely convergent with the quantitatively measured outcomes reported in the PACT trial studies (J. Green et al., 2010; Leadbitter et al., 2018; Pickles et al., 2016), such as enhanced parental synchrony, increased child initiations and improved family wellbeing. There were also findings that have not previously been clearly evidenced in our quantitative studies. Perhaps, the most striking is the reported strengthening of the parents' relationship with their child: increased closeness, enhanced enjoyment in spending time together and increased attunement with, and even love for their child. In addition to these positive outcomes, parents described possible unexpected and unintended adverse consequences: disappointment that the therapy did not quickly lead to spoken language for their child, ongoing struggles with accepting their child's condition and initial doubts about the therapeutic strategies and style. These consequences were particularly salient in those parents who described initial hopes that PACT would be a 'magic wand'. These positive and negative affective and relational outcomes can prove challenging to measure in a standardised, blinded and quantitative way, but it is only through identifying these important measurement targets that we will fully understand all outcomes, prioritise the development of appropriate measurement tools and strengthen our future outcome measurement.

Mechanism of change

The mechanism of change within PACT is increased parental synchrony (careful observation of the child's communication and enhanced sensitivity and responsiveness in parental communication with the child; Pickles et al., 2015). This study offers insights into the journey of therapeutic change taken by parents towards a more synchronous interactional style: from initial doubts, to perseverance with the therapy, to appreciation of the benefits of video feedback, to careful observation of and reflection on the interaction and, finally, to the adoption of a synchronous style. Parents described this new synchronous style of interaction in terms such as 'being on the child's level', following the child's lead, seeing things from the child's perspective, giving the child space and getting their 'timings right'. Many parents who took this journey developed a solid belief in the value of the strategies and an appreciation for improvements that their child made. Edwards et al. (2018) described a journey taken by parents from the disorientating experience of diagnosis through initial high expectations and a wish to minimise the impact of ASD,

through to an acceptance of the lifelong nature of the condition and a development of expertise in their own child. This description fits with the narrative of some of our interviewees who described how PACT helped them along a similar journey. A small number of parents in our sample, however, were still at the earlier stages of this process, focusing on the diagnosis, the extent of their child's disability and the lack of development of spoken language.

Relationship with therapists

Parents greatly appreciated the validation they received from their PACT therapist and the prominence afforded to their own expertise and capabilities as parents. For many parents, this came at a time when they felt judged and disempowered in their parenting role. The beneficial effects of support and empathy engendered by a collaborative parent-professional relationship have been reported in qualitative evaluations of other ASD interventions (e.g. Allgood, 2005; Carr & Lord, 2016; Freuler et al., 2014) and are reinforced by this study. A consistent, strong therapeutic alliance, in and of itself, has been shown to improve outcomes (De Greef et al., 2017). Furthermore, some interviewees reported that the facilitative style adopted by PACT therapists meant that they were empowered to value and harness their own expertise as their child's therapist. This process of empowerment may play a part in the longer term benefits evidenced in PACT (Pickles et al., 2016).

Limitations

This study sought the perceptions of parents who were enrolled in a 'new therapy' delivered with high fidelity within the specialised context of an efficacy RCT. Parents had already consented to the trial and invested time and effort in participation. While the details of the therapy delivered in the trial should be essentially the same as in the community, it may be that there are additional experiences related to the trial context that would not generalise to general clinical settings. A related potential limitation concerns the representativeness of parents' opinions from the wider trial cohort: parents needed an additional opt-in to these interviews, and this presents a risk of selection bias towards parents with more positive experiences. An additional concern is the extent to which parents felt able to offer a candid opinion within their interviews, with both positive and negative accounts. Some evidence suggests that parents can be reluctant to express negative views if those views can be linked back to them or if they recognise that therapists have been trying to help them (e.g. Freuler et al., 2014). We attempted to mitigate these concerns by (a) inviting a random selection of participants, including those who had withdrawn from therapy, (b) sending invitations and conducting interviews after the family's involvement in the trial was complete, (c) having the information gathered by

an independent researcher who made every effort to reassure parents that their responses would not be identifiable and (d) emphasising that the researcher was seeking their views so that future improvements could be made. It is reassuring that: within the sub-sample, there is a wide range of family, parent and child characteristics; there are varying levels of engagement, parental therapeutic alliance and child response to the therapy (Table 1), broadly reflecting that of the full sample; there was one parent who discontinued with the therapy and another who experienced significant difficulties; and negative consequences and challenges were indeed reported within the interviews.

An interesting question is whether there were any expected topics that did not come up within the thematic analysis. There was relatively little reflection on the parents' experiences, during the intervention period, of the daily home practice which formed an integral part of the therapy, the challenges this may have presented, or whether compromises were made in therapy enactment. This may have been because there were no specific interview prompts on this topic (see Appendix 1). Information on this important aspect of therapy adherence was not captured quantitatively or qualitatively within the trial. This reflects a wider under-reporting of parent enactment within parent-mediated intervention studies due, in part, to the methodological challenges of obtaining objective measures of the delivery of an intervention that is designed to be flexible, opportunistic and naturalistic (McConachie et al., 2015). This is an important avenue for future research. Other themes that were not widely discussed were the understanding and adoption of therapy strategies by other family members and whether issues arose when only one family member developed expertise in PACT. A further unexplored theme concerns the goodness of fit of this intervention with other approaches on offer in community or educational settings. These are all important considerations for the real-world implementation of a therapy, and there are ongoing endeavours to evaluate therapies across multiple caregivers and settings (e.g. J. Green et al., 2018; Shire et al., 2016).

Clinical implications

These findings have important clinical implications. They highlight the different emotional places in which parents find themselves in the post-diagnostic period, the developing nature of parental understanding of their child's needs and the range of different hopes and expectations parents bring to a post-diagnosis therapy. Through our analysis of parents' reflections, it is clear that these differences affected the way in which parents engaged with and evaluated the therapy. To render therapy as accessible and effective as possible for all families, therapists play a crucial yet complex role in identifying each individual parent's current emotional starting position and level of understanding and adjusting the pace and format of intervention delivery in response (Aldred et al., 2011). Therefore, our findings reinforce the clinical

importance of individualisation and flexibility within post-diagnosis intervention.

Furthermore, our findings underline the additional therapeutic work that therapists may need to carry out alongside the 'nuts and bolts' of the therapy approach, supporting parents emotionally: to understand and accept their child's development, abilities and disabilities; to appreciate the benefits of parent-child interaction; and to have realistic expectations for the pace of developmental change. This role has been highlighted by qualitative studies of other early interventions (e.g. Carr & Lord, 2016; Freuler et al., 2014; Hodgson et al., 2018). Some parents may require targeted therapeutic support with their understanding and psychological adjustment before they are fully able to embrace a parent-mediated programme aimed at building their interaction with their child. These findings also highlight the importance of early expectation management and sensitive frankness about the role of speech and language therapists and the absence of any 'miracle cure'. Therapists need an awareness that, for many parents, there is likely to be a process of adjustment to the style of the therapy and initial hesitations about interactions being videoed and analysed. Therapists can support parents through these early stages and encourage them to persist in the expectation that, with time, many parents will adopt the strategies and begin to see their worth.

Parents of young children with ASD are juggling competing demands on their time, priorities and energy (Dykens et al., 2014; Giallo et al., 2011; Quintero & McIntyre, 2010). Effective interventions need to be practical, feasible and easily accessible (Carr & Lord, 2016; Carr et al., 2016). Several studies have highlighted the challenges for parents in dedicating time to attend therapy sessions and carry out homework (Carr & Lord, 2016; Freuler et al., 2014; Hodgson et al., 2018). Our findings re-emphasise the importance of careful attention to these practicalities. Many of the challenges described by parents related to these aspects of taking part: the time commitment of sessions and home practice, the length of sessions and the inconvenience, unfamiliarity and autism-unfriendliness of therapy venues. If unresolved, such challenges can contribute to increased parental stress, and in this study, they were the only factors described by parents that led to considerations of non-participation. Our findings suggest that, to ensure accessibility and engagement, careful consideration needs to be given to the ease of access, familiarity and autism-friendliness of the therapy venue and to more opportunities to support or occupy the child during video-feedback and discussion.

In response to the practical challenges reported in this article, as well as the need to evaluate therapies across multiple caregivers and settings, the PACT team is currently trialling a new iteration of PACT which is delivered concurrently within the home and educational settings and using video telecommunication software (PACT-G Trial; J. Green et al., 2018; www.pact-g.org). It is hoped that through delivery in the

home or pre-school/school setting, the child will feel more 'at home', the burden of travel will be removed/reduced, and there will be more opportunities for the child to be occupied and/or cared for while the parent gives their attention to video feedback and discussion. The use of teleconferencing technology also has potential to remove practical barriers as video material of adult-child interaction can be made at home or school prior to the session and then shared and discussed between therapist and parent/teacher over teleconferencing at a later time without the child present. Other practical solutions could include providing 'entertainment' to occupy the child during feedback and discussion, such as video material, a games console or a therapy assistant to watch over and play with the child (such solutions were found within the trial to work for some children, but not all).

This study has provided important insights into parents' perceptions of PACT and the potential benefits and challenges to parents of participation in the therapy. These insights and their implications for clinical practice will be informative to practitioners delivering PACT and similar parent-mediated therapies.

Acknowledgements

We would like to express our gratitude to the parents who generously offered their time and insight when participating in the interviews. Thank you to Amelia Pearson and Dr Dharmi Kapadia for administrative support and to Prof Helen McConachie and Dominic McConnell for valuable comments on the manuscript. The PACT trial was sponsored by the University of Manchester and principally funded by the UK Medical Research Council (G0401546), the UK Department for Children, Schools and Families and the UK Department of Health. The PACT trial and this qualitative study were approved by the UK Central Manchester National Health Service Research Ethics Committee (REC reference: 05/Q1407/311).

Author contributions

W.M. developed the interview schedule, carried out data collection and led on the analysis. K.L. led the interpretation and writing with significant input from C.T. and K.L.B.

Declaration of conflicting interest

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

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Kathy Leadbitter  <https://orcid.org/0000-0002-0744-2800>

Note

1. Throughout this article, the term 'parent' is used to refer to any primary caregiver of a child.

References

- Aldred, C. R., Green, J., & Adams, C. (2004). A new social communication intervention for children with autism: Pilot randomised controlled treatment study suggesting effectiveness. *Journal of Child Psychology and Psychiatry*, *45*, 1420–1430.
- Aldred, C. R., Green, J., Howlin, P., Le Couteur, A., Barron, S., Beggs, K., Collino, J., Colmer, R., Houghton, T., Randles, S., Slonims, V., & Taylor, C. (2011). *Intervention manual: Pre-school Autism Communication Therapy (PACT)*. Roundway Centre Publishing.
- Allgood, N. (2005). Parents' perceptions of family-based group music therapy for children with Autism Spectrum Disorders. *Music Therapy Perspectives*, *23*, 92–99.
- Bölte, S. (2014). The power of words: Is qualitative research as important as quantitative research in the study of autism? *Autism*, *18*, 67–68.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.
- Carr, T., & Lord, C. (2016). A pilot study promoting participation of families with limited resources in early autism intervention. *Research in Autism Spectrum Disorder*, *2*, 87–96.
- Carr, T., Shih, W., Lawton, K., Lord, C., King, B., & Kasari, C. (2016). The relationship between treatment attendance, adherence, and outcome in a caregiver-mediated intervention for low-resourced families of young children with Autism Spectrum Disorder. *Autism*, *20*(6), 643–652.
- Cheng, K. K. F., & Metcalfe, A. (2018). Qualitative methods and process evaluation in clinical trials context: Where to head to? *International Journal of Qualitative Methods*, *17*, 1–4.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Sage.
- De Greef, M., Pijnenburg, H. M., Van Hattum, M. J. C., McLeod, B. D., & Scholte, R. H. J. (2017). Parent-professional alliance and outcomes of child, parent and family treatment: A systematic review. *Journal of Child and Family Studies*, *26*, 961–976.
- Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics*, *134*, 454–463.
- Edwards, A. G., Brebner, C. M., McCormack, P. F., & MacDougall, C. J. (2018). From 'parent' to 'expert': How parents of children with Autism Spectrum Disorder make decisions about which intervention approaches to access. *Journal of Autism and Developmental Disorders*, *48*, 2122–2138.
- Freuler, A. C., Baranek, G. T., Tashjian, C., Watson, L. R., Crais, E. R., & Turner-Brown, L. M. (2014). Parent reflections of experiences of participating in a randomized controlled trial of a behavioural intervention for infants at risk of Autism Spectrum Disorders. *Autism*, *18*, 519–528.
- Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2011). Fatigue, wellbeing and parental self-efficacy in mothers of children with an Autism Spectrum Disorder. *Autism*, *17*, 465–480.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine De Gruyter.
- Green, J., Aldred, C., Charman, T., Le Couteur, A., Emsley, R. A., Grahame, V., Howlin, P., Humphrey, N., Leadbitter,

- K., McConachie, H., Parr, J. R., Pickles, A., Slonims, V., Taylor, C., & PACT-G Group. (2018). Paediatric Autism Communication Therapy-Generalised (PACT-G) against treatment as usual for reducing symptom severity in young children with Autism Spectrum Disorder: Study protocol for a randomised controlled trial. *Trials*, *19*, 514.
- Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., Le Couteur, A., Leadbitter, K., Hudry, K., Byford, S., Barrett, B., Temple, K., Macdonald, W., Pickles, A., & the PACT Consortium. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): A randomised controlled trial. *The Lancet*, *375*, 2152–2160.
- Green, V. A. (2007). Parental experience with treatments for autism. *Journal of Developmental and Physical Disabilities*, *19*, 91–101.
- Grindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based Applied Behaviour Analysis Programs for young children with autism. *Journal of Autism and Developmental Disorders*, *39*, 42–56.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*, 59–82.
- Hodgson, A. R., Grahame, V., Garland, D., Gaultier, F., Lecouturier, J., & Le Couteur, A. (2018). Parents' opinions about an intervention to manage repetitive behaviours in young children with Autism Spectrum Disorder: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, *31*, 165–178.
- Hudry, K., McConachie, H., Le Couteur, A., Howlin, P., Barrett, B., & Slonims, V., & the PACT Consortium. (2018). Predictors of reliable symptom change: Secondary analysis of the preschool autism communication trial. *Journal of Autism & Developmental Language Impairments*, *3*, 1–12.
- Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, *20*, 180–189.
- Kasari, C., Gulsrud, A., Paparella, T., Helleman, G., & Berry, K. (2015). Randomized comparative efficacy study of parent-mediated interventions for toddlers with autism. *Journal of Consulting and Clinical Psychology*, *83*, 554–563.
- Leadbitter, K., Aldred, C., McConachie, H., Le Couteur, A., Kapadia, D., Charman, T., Macdonald, W., Salomone, E., Emsley, R., Green, J., & the PACT Consortium. (2018). The Autism Family Experience Questionnaire (AFEQ): An ecologically-valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention. *Journal of Autism and Developmental Disorders*, *48*, 1052–1062.
- Lord, C., Risi, S., Lambrecht, L., Cook, E. H., Leventhal, B. L., DiLavore, P. C., Pickles, A., & Rutter, M. (2000). The Autism Diagnostic Observation Schedule – Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, *30*, 205–223.
- Mackintosh, V. H., Goin-Kochel, R. P., & Myers, B. J. (2012). 'What do you like/dislike about the treatment you're currently using?' A qualitative study of parents of children with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, *27*(1), 51–60.
- McConachie, H., Fletcher-Watson, S., & Working Group 4, COST Action 'Enhancing the Scientific Study of Early Autism'. (2015). Building capacity for rigorous controlled trials in autism: The importance of measuring treatment adherence. *Child: Care, Health and Development*, *41*(2), 169–177.
- Moore, G., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D., & Baird, J. (2015). Process evaluation of complex interventions: Medical Research Council guidance. *British Medical Journal*, *350*, h1258.
- Mullen, E. M. (1995). *Mullen scales of early learning*. Western Psychological Services.
- National Institute for Health and Care Excellence. (2013). Autism Spectrum Disorder in under 19s: Support and management. *Clinical Guideline*, *170*. <https://www.nice.org.uk/guidance/cg170>
- Nevill, R. E., Lecavalier, L., & Stratis, E. A. (2018). Meta-analysis of parent-mediated interventions for young children with Autism Spectrum Disorder. *Autism*, *22*(2), 84–98.
- O'Cathain, A., Thomas, K. J., Drabble, S. J., Rudolph, A., & Hewison, J. (2013). What can qualitative research do for randomised controlled trials? A systematic mapping review. *British Medical Journal Open*, *3*, e002889.
- Oono, I. P., Honey, E., & McConachie, H. (2013). Parent-mediated early intervention for young children with Autism Spectrum Disorders (ASD). *Cochrane Database of Systematic Reviews*, *8*(6), 2380–2479.
- Pickard, K. E., Wainer, A. L., Bailey, K. M., & Ingersoll, B. R. (2016). A mixed-method evaluation of the feasibility and acceptability of a telehealth-based parent-mediated intervention for children with Autism Spectrum Disorder. *Autism*, *20*(7), 845–855.
- Pickles, A., Harris, V., Green, J., Aldred, C., McConachie, H., Slonims, V., Le Couteur, A., Hudry, K., Charman, T., & the PACT Consortium. (2015). Treatment mechanism in the MRC preschool autism communication trial: Implications for study design and parent-focussed therapy for children. *Journal of Child Psychology and Psychiatry*, *56*, 162–170.
- Pickles, A., Le Couteur, A., Leadbitter, K., Salamone, E., Cole-Fletcher, R., Tobin, H., Gammer, I., Lowry, J., Vamvakas, G., Byford, S., Aldred, C., Slonims, V., McConachie, H., Howlin, P., Parr, J. R., Charman, T., & Green, J. (2016). Parent-mediated social communication therapy for young children with autism (PACT): Long-term follow-up of a randomised controlled trial. *The Lancet*, *388*, 2501–2509.
- Quintero, N., & McIntyre, L. L. (2010). Sibling adjustment and maternal well-being: An examination of families with and without a child with an Autism Spectrum Disorder. *Focus on Autism and Other Developmental Disabilities*, *25*, 37–46.
- Rahman, A., Divan, G., Hamdani, S. U., Vajaratkar, V., Taylor, C., Leadbitter, K., Aldred, C., Minhas, A., Cardozo, P., Emsley, R., Patel, V., Green, J., & Green, J. (2016). Effectiveness of the parent-mediated intervention for children with Autism Spectrum Disorder in south Asia in India and Pakistan (PASS): A randomised controlled trial. *The Lancet*, *3*, 128–136.
- Schreibman, L., Dawson, G., Stahmer, A. C., Landa, R., Rogers, S. J., McGee, G. G., Kasari, C., Ingersoll, B., Kaiser, A. P., Bruinsma, Y., McNerney, E., Wetherby, A., & Halladay, A. (2015). Naturalistic developmental behavioral interventions: Empirically validated treatments for Autism Spectrum

- Disorder. *Journal of Autism and Developmental Disorders*, 45, 2411–2428.
- Shire, S. Y., Chang, Y. C., Shih, W., Bracaglia, S., Kodjoe, M., & Kasari, C. (2016). Hybrid implementation model of community-partnered early intervention for toddlers with autism: A randomized trial. *Journal of Child Psychology and Psychiatry*, 58(5), 612–622.
- Stahmer, A., Brookman-Frazee, L., Rieth, S. R., Trigeiro Stoner, J., Feder, J. D., Searcy, K., & Wang, T. (2017). Parent perceptions of an adapted evidence-based practice for toddlers with autism in a community setting. *Autism*, 21(2), 217–230.
- Stahmer, A., & Pellecchia, M. (2015). Moving towards a more ecologically valid model of parent-implemented interventions in autism. *Autism*, 19(3), 259–261.
- Statista. (2019). Mean annual household disposable income in the United Kingdom (UK) from 2000 to 2019. www.statista.com/statistics/591342/united-kingdom-uk-average-yearly-household-income
- Tan, V. X., & Simmonds, J. G. (2018). Parent perceptions of psychosocial outcomes of equine-assisted interventions for children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48, 759–769.
- Taylor, C. A. (2015). *The quality of therapeutic alliance in a parent-mediated intervention for autism* [Unpublished doctoral dissertation, University of Manchester]. [https://www.research.manchester.ac.uk/portal/en/theses/the-quality-of-therapeutic-alliance-in-a-parentmediated-intervention-for-autism\(8ab65024-f956-4642-9c0f-40780924ffc7\).html](https://www.research.manchester.ac.uk/portal/en/theses/the-quality-of-therapeutic-alliance-in-a-parentmediated-intervention-for-autism(8ab65024-f956-4642-9c0f-40780924ffc7).html)
- Taylor, C. A., Emsley, R., Callery, P., Marshall, J., & Green, J. & the PACT Consortium. (2017, May). *Role and predictors of therapeutic alliance in a parent-mediated intervention for autism* [Poster presentation]. Poster presented at the International Society for Autism Research, San Francisco, CA, United States.
- Yoder, P. J., & Warren, S. F. (2001). Intentional communication elicits language-facilitating maternal responses in dyads with children who have developmental disabilities. *American Journal on Mental Retardation*, 106(4), 327–335.

Appendix I

Interview schedule

The following questions were presented in a standard order. The response to each scripted question was followed up with further prompts and questions to elucidate further detail and clarity.

Initial questions

1. Tell me about how you came into the PACT Study?
2. What happened before you came into the study?
3. What was family life like at the time or just before coming into the study?
4. What did you know about PACT before you took part?

Intermediate questions

5. What did you hope for (expectations, thoughts and feelings) from taking part in the study?
6. What happened next?
7. Have your thoughts, feelings, hopes changed since your first impressions?
8. What happened with your child?
9. Who was involved with them?
10. What changes did you see take place in your child? (Behavioural, emotional, social, educational?)
11. What were the most important changes?
12. Did these changes make a difference to your family life?
13. What was a good day like before taking part in the study?
14. Would a good day be different in any way now you have finished the study?
15. What was a bad day like before taking part in the study?
16. Would a bad day be different in any way now you have finished the study?
17. What has been most helpful?
18. What has been least helpful?

Ending questions

19. What changes have you made? (Prompt: helpful/unhelpful)
 20. What have you learned?
 21. Have you thought about anything in this interview that you had not thought about before?
 22. Is there anything else you want to tell me or expand on?
 23. Is there anything you want to ask me?
-