

PARENT EDUCATION IN AUTISM SPECTRUM DISORDER – A REVIEW OF THE LITERATURE¹

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Abstract: Families living with autism spectrum disorder (ASD) face many challenges, affecting not only the child with ASD and development but also family functioning and quality of life. Parent education (PE) in ASD has been identified as a priority intervention for this group both internationally and nationally. However, though there is a large body of literature regarding parent training (PT) in specific therapeutic approaches, a narrative literature review of databases found only 12 papers reporting on research into PE. Overall, PE is shown to be a positive intervention which can lead to reductions in stress and anxiety, improved coping, improved parent-child interaction and communication, improved understanding of ASD, efficacy and confidence and improved parental quality of life. Four key themes – impact, delivery, content and local/cultural issues – are discussed, weaknesses and problems within the literature are acknowledged, and the need is identified for further research into such interventions.

Key words: Autism spectrum disorder, parents, parent education

INTRODUCTION

Autism and the family

Autism spectrum disorder (ASD) is a lifelong developmental condition, identified by characteristic difficulties in social interaction and communication, the ability to think and act flexibly and the perception and management of sensory stimuli (American Psychiatric Association, 2013). It has a broad range of presentation and levels of severity, with a worldwide median prevalence of 62 per 10,000 (Elsabbagh et al., 2012), and a prevalence rate within Europe of about 1 per 100 or higher (Baird et al., 2006; Christensen, 2016).

It has long been established that the presence of ASD in the family can have a significant impact, and that the condition can lead to greater parental stress than other disabilities (Wolf et al., 1989). Families can face many challenges, affecting not only the child with ASD and development but also family functioning and quality of life. Difficulties can arise across a range of areas, including behaviour (Lecavalier et al. 2006), communication (Norton and Drew, 1994), sleep (Williams et al., 2004), eating (Ausderau and Juarez, 2013), personal care and independent living skills (Matson et al., 2009a). The child's sensory sensitivities and desire for routine can impose severe restrictions on the family's ability to perform typical activities of daily life, such as leaving the house, going shopping or

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visiting a restaurant (Schaaf et al., 2011; Vaughn et al., 2002); and activities such as addressing dental problems or going to hospital can cause severe distress and may be extremely difficult or impossible to undertake (Loo et al., 2009; Pratt et al., 2011).

Parent education and parent training in ASD

Dozens of treatment approaches and interventions – interpersonal, educational, and biomedical – exist within the field of ASD, with varying degrees of evidence and theoretical support (Simpson, 2005). Typing the words ‘*autism treatment*’ into the internet search engine Google brings up over 43 million ‘hits’, while the words ‘*autism cure*’ bring up over three million. Many approaches promoted on the internet are unsubstantiated (Fitzpatrick, 2009; Offit, 2008), and they may sometimes be dangerous, as in the case of chelating agents or bleach being marketed as a cure for ASD (US Food and Drug Administration, 2014). However, it can be difficult for parents and family members to identify fact from fiction in autism, and to discriminate between what is ‘good autism practice’ and what is unsupported. Parent education (PE) regarding ASD has therefore been identified as an important component within the spectrum of support for families living with the condition. The World Health Organisation has identified it as a priority for action (World Health Organisation, 2014), while the Autism Education Trust in the UK states that “*high on the agenda of parents/carers and professionals alike is providing knowledge and information on the autism spectrum...to parents/carers and other family members* (Jones et al., 2008, p102).”

A growing body of highly diverse literature is being published which is identified as dealing with PE or ‘parent training’ (PT) in ASD. Much of this focuses on specific intervention models or programmes: e.g. Applied Behaviour Analysis (ABA) (Ingersoll and Dvortcsak 2006), DIR/Floortime (Solomon et al., 2007) Pivotal Response Therapy (Coolican et al., 2010) or TEACCH structured teaching (Turner-Brown et al., 2016). A number of articles consider particular methods of delivery, such as distance learning (Wainer and Ingersoll, 2012), home teaching (Elder et al., 2011) or online training (Vismara et al., 2013); while others investigate the application of generic ‘par-

enting’ approaches with families living with ASD (Whittingham et al., 2009).

Bearss et al. (2015a) draw a distinction between PT and PE. They define the former as comprising child-focused training, where the individual child is the direct beneficiary of the intervention, and the parent is being trained to act as a therapist within a defined programme. On the other hand, PE is identified as being a more general parent-focused psychoeducational approach, with a focus on sharing knowledge, information and skills with the parent/family member, and where the child with autism is the indirect beneficiary. This type of psychoeducational PE seems particularly important for a number of reasons. Some specific therapies may be costly or locally unavailable, and therefore may be out of reach for large numbers of families living with ASD (Keenan et al., 2010). Some therapies may assume a certain basic understanding of ASD as a given, while others may prey on a lack of such knowledge to sell fallacious treatments (Travers et al., 2016). Simply to feel that they are trying to do something, parents may be tempted to spend large amounts of money (as well as time and energy) on ineffective or potentially dangerous approaches (Zane et al., 2008). Providing families with accurate information and introducing them to the use of effective approaches through PE has been shown to increase family adaptation and acceptance, and improve personal, educational and social outcomes for individuals with ASD and their families (Preece and Almond 2008; Green et al., 2010).

However, in a separate article, Bearss et al. (2015b) refer to both child-focused and parent-focused interventions as PT. Furthermore, Schultz et al.’s (2011) review of ‘parent education programs’ considers a high proportion of articles concerning PT interventions. It is clear that many authors use the terms PE and PT interchangeably, which can make navigating the literature difficult.

So how is PE in ASD being provided and what does the literature tell us regarding how such knowledge and information can best be transmitted to families? In this paper, we seek to review the literature on PE regarding ASD, discuss the main findings, and identify key issues or factors to be considered regarding to the provision of such education.

Method

Much of the literature on this topic is based upon small sample sizes or may feature single subject designs. The decision therefore was made to reject a systematic review approach, which might preclude the use of much of the existing literature, and to instead use a narrative review methodology with steps undertaken

to ensure rigour. Clear inclusion and exclusion criteria were established before the review began (Torgerson et al., 2012). These are shown in Table 1 below.

Results and discussion

Key word searches – using combinations of the words *autism*, *autism spectrum disorder*, *parent*

Table 2. Summary of journal articles meeting inclusion/exclusion criteria

Author(s)	Research design	N	Setting and education delivery	Participants
Al-Khalaf et al. (2014)	Exploratory case study	10	2 x private disability clinics in Jordan. 4 x weekly 4 hr sessions.	Parents of preschool children.
Bearss et al. (2015b)	Randomised controlled trial	180	6 x autism centres at US universities. 12 sessions (1-1.5 hrs) + 1 home visit over 24 weeks.	Parents of children aged 3-7 years
Birkin et al. (2008)	2 interlinked studies: a) telephone survey b) interviews	a) 77 b) 12	3 x urban and rural areas in New Zealand. 8 x 3 hr sessions + 3 home visits over 12 weeks.	Parents and caregivers of children 0-6 years
Chiang (2013)	Pre- and post-intervention design	9	Community centre in New York. 10 x weekly 2 hr sessions	Families of Chinese-American children 3-11 years
Cutress & Muncer (2014)	Evaluation of post-training survey tools	120	25 parent training courses in north of England. 8 x 3 hr sessions + 2 home visits over 10 weeks.	Parents of children 5-9 years
Farmer & Reupert (2013)	Pre- and post-intervention design	98	Early intervention setting in rural Victoria, Australia. 6 x weekly 2 hr sessions.	Parents and family members of children 2-6 years
Ji et al. (2014)	Quasi-experimental	42	2 x autism centres in Hunan Province, China 8 x weekly 1.5 hrs sessions	Parents and caregivers (mean age of children = 5.27 years)
Lecavalier et al. (2016)	As Bearss et al. (2015b) above.			
Tonge et al. (2006)	Randomised, group-comparison design	105	2 x rural and 2 x urban regions, Australia. 10 x 1.5 hrs small group sessions alternated with 10 x 1 hr individual family sessions over a 20-week period.	Families with children aged 1-5 years
Tonge et al. (2014)	As Tonge et al. (2006) above.			
Wang (2008)	Evaluation	27	City in north eastern China. 4 x weekly 4 hr group sessions + 4 x weekly home visits (maximum combined total = 20 hrs).	Family members of children 3-9 years
Yucel & Cavkaytar (2007)	Pre- and post-intervention design	72	Istanbul, Turkey. Distance education model via 5 x 20 Minute presentations on CDs + 5 handbooks.	Family members of children aged 3-15 years

training and *parent education* – were conducted using the following databases: Education Research Complete (EBSCO), Google Scholar, Ingenta Connect, Science Direct and Web of Science. Over 120 journal articles included the words parent training, parent education and reference to autism spectrum disorder in the key words and/or abstract. Application of the inclusion/exclusion criteria led

to twelve journal articles being identified (describing ten research studies or interventions) which met all inclusion and no exclusion criteria. These articles are summarised below in Table 2. Eleven articles related to group education models and one to a distance education programme. In two papers (reporting on the same study), parent education was compared with specific parent training. The studies

Child diagnosis	Outcomes/findings
Autism spectrum disorder	Following the education program, the mothers reported a statistically significant reduction in stress levels, an increase in coping skills, and an improvement in mother-child interaction. Compared to fathers, mothers' stress levels were significantly higher and their coping skills were significantly lower.
Autism spectrum disorder + disruptive behaviour	Study compared impact of providing direct training in behaviour management with parent education. Parents who undertook direct training reported greater reduction in behavioural problems than those undertaking parent education (55% compared to 34%) though this was not statistically significant.
Autism spectrum disorders	Approximately 85% of families eligible for the program do not participate. Non-membership of Autism New Zealand (the agency responsible for administering the program), ethnicity, and length of wait time were significant factors in non-participation.
Autistic disorder, Asperger Syndrome or PDD-NOS	After receiving the 10-week program, parents of Chinese American children with ASDs showed significant reduction in parenting stress, improvement in parental confidence, and improvement in quality of life in physical health and environment domains.
Autism spectrum disorder	Participants' reported increased understanding of autism and improvements in communication with their child and managing their child's behaviour. Parents valued the opportunity to meet other parents, and the programme seemed acceptable to the majority of parents who attended.
Autism	Analysis showed significant increases in parental understanding of autism and understanding of their own child, and in understanding communication, sensory, social, learning and behavioural features of autism. Significant increases in parental confidence and significant reduction in parental anxiety were also shown. Parents valued learning about the general nature of autism and sensory processing, and reported feeling less alone.
Autism spectrum disorders	At the end of 8-week multidisciplinary parent education program, significant improvements were observed in the mental health-related quality of life, family functioning, self-efficacy and positive coping style.
	Parent training was superior to parent education in decreasing disruptive and noncompliant behaviors.
Autism spectrum disorder	Comparison between 20-week manual-based parent education and behaviour management intervention (n = 35), a parent education and counselling intervention (n = 35) and control group (n=35). Both treatments resulted in improvement in overall mental health at follow-up and mental health significantly improved over time in the 54% of principal caregivers who had the highest levels of mental health problems. The parent education and behaviour management intervention was more effective at reducing anxiety, insomnia, and somatic symptoms/family dysfunction than parent education and counselling at 6-month follow-up.
	Parent education and behaviour management was superior to parent education and counselling in improving child adaptive behaviour and symptoms of autism for low-functioning children.
Autism	Post-training, parents in the training group were more sensitive to their children's interests, responded to their children's behaviour more appropriately, were more accepting of their children and their behaviour, showed more enjoyment of interacting with their children, and expressed more warmth toward their children.
Autism	Significant positive differences were found between pre- and post-test scores of the experimental group.

Table 1. Inclusion and exclusion criteria

<p>Inclusion criteria</p> <ul style="list-style-type: none"> • Studies which focus on psychoeducational parent education. • Participants: parents/family members of children with ASD. • Study design: quantitative and/or qualitative designs; small sample sizes included; case studies; studies without control groups. • Training models: group-or distance-based parent education models. • Content based on eclectic understanding of ‘good autism practice’ (for this reason the NAS EarlyBird (Shields, 2001) is included). • Outcomes: outcomes relating to child’s behaviour/ learning, family quality of life, family wellbeing. • Published in English since 2000.
<p>Exclusion criteria</p> <ul style="list-style-type: none"> • Anecdotal or descriptive accounts with no evidence relating to outcomes • Training with regard to single issues (either re child e.g. sleep, toileting, eating or parent e.g. mindfulness, stress management) • Training in a specific intervention method (e.g. TEACCH, ABA, Son Rise, DIR Floortime, SCERTS) • Participants: families of children with other learning disabilities • Outcomes: outcomes unrelated to the topic

were undertaken in Australia (n=2), China (n=2), Jordan (n=1), New Zealand (n=1), Turkey (n=1), the UK (n=1) and the USA (n=2, one specifically with Chinese Americans).

DIVERSE NATURE OF STUDIES

A significant difficulty in undertaking this review has been the highly diverse nature of the

studies reported on within this literature. Research designs have ranged from exploratory case studies to randomised controlled trials. While some studies reported on parental stress (Al-Khalaf et al., 2014; Chiang, 2013; Farmer & Reupert, 2013; Tonge et al., 2006), others focused on quality of life (Ji et al., 2014), level of knowledge (Cutress & Muncer, 2014; Yucel & Cavkaytar, 2007) or parent-child interaction (Wang, 2008). Even where studies reported on similar outcomes, the degree of diversity in the ways that data has been analysed and studies reported makes it impracticable to confidently make assertions regarding the impact of factors such as specific content, group size, or course duration on parent outcomes. This is illustrated by the summary of the four studies reporting on parental stress (see Table 4). Nonetheless a number of key themes can be identified within the literature – regarding impact, process, content and the need to take account of local considerations – and these are explored below.

Positive impact of parent education

No negative impacts of PE were identified. By contrast, a range of positive impacts were identified, including reductions in stress and anxiety, improved coping, improved parent-child interaction and communication, improved understanding of ASD, efficacy and confidence and improved parental quality of life. While some studies focused only on identifying knowledge or skills acquired, others reported on social benefits of attendance at PE session. For example, providing parents with the opportunity to meet other parents and to devel-

Table 3. Summary of studies reporting on parental stress

Study	Setting	Duration of training	Group size	Impact on reported parental stress
Farmer & Reupert (2013)	Rural Australia (early intervention centre)	6 x 2 hrs	5-16 parents per cohort (the study reports on multiple cohorts over time)	P<.001
Al-Khalaf et al. (2014)	Urban Jordan (private clinic)	4 x 4 hrs	5 mothers per cohort	P<.005
Chiang (2013)	Urban USA (community centre)	10 x 2 hrs	9 families (7x mothers only, 2 x 2 parents)	P<.05
Tonge et al. (2016)	Australia (2 x urban & 2 x rural regional assessment centres)	10 x 1.5 hrs small group sessions + 10 x individual family sessions	4-5 families per small group session	No significant difference with control group

op mutual support networks was explicitly identified as a desired outcome and supported within the EarlyBird programme (Cutress & Muncer, 2014). Families living with autism are at high risk of isolation and social exclusion (Banach et al., 2010) and we would recommend that PE programmes consider outcomes across a range of domains relating to knowledge, wellbeing and socialisation.

Programme delivery

There was considerable diversity regarding the manner in which the various education programmes were delivered. All but one programme – the Turkish distance education course – were taught face to face. Delivery typically included both lecture and group aspects, and active participation is reported positively. Some programmes explicitly provided parents with opportunities to share stories and knowledge and explore experiences (Chiang, 2013; Farmer and Reupert, 2013). Such activities can support the development of self-efficacy and confidence as well as providing mutual support.

Programmes ranged from 12 to 25 hours in length, half including home visits or individual activities in addition to the group sessions. Typically, sessions were held on a weekly basis. Group sizes ranged from 5 to 16 participants per course. The majority of groups comprised 10 participants or fewer. Participation in small, regular groups was judged positively and valued by parents; conversely larger groups were felt to offer fewer opportunities for effective learning and discussion, especially where individuals tried to monopolise the sessions (Farmer & Reupert, 2013).

Birkin et al. (2008), writing about courses in New Zealand, state that session times clashing with parents' work or wider family commitments was the most commonly given reason for non-participation in programmes, particularly with regard to families from minority ethnic communities. Long wait times for programmes, lack of information and access issues (e.g. transport, distance) were also identified as leading to families not attending programmes. All of these factors should be taken into account, and steps should be taken by programme providers to facilitate attendance. Distance education models utilising CDs and handbooks, such as

that reported on by Yucel and Cavkaytar (2007), may be of particular value where populations are widely dispersed and where access to the internet may be problematic.

Content

Though delivery methods varied greatly, the various parent education programmes dealt with a similar range of topics. Understanding ASD, the impact of the core areas of difficulty – social and communication issues, the impact of restricted/repetitive interests and sensory issues – and behavioural issues were common across all PE programmes. In the majority of the programmes there was a focus not only on knowledge and information, but on the development of practical skills to develop their child's play, socialisation and communication, and on understanding and managing behaviour. These topics were also identified as being of central importance in a survey of south-east European parents' priorities regarding PE in autism (Preece et al., 2017).

Some programmes devoted sessions to specific issues that were significantly impacting upon family life, including eating and sleeping difficulties. Negotiating local systems and services was also identified as being of importance, and this was an area where sharing knowledge and learning from other parents' experiences could be particularly helpful (Chiang, 2013; Farmer and Reupert, 2013). Overall, programmes that focus on the practical application of learning seem particularly valued by parents.

Local and cultural considerations

In common with research regarding PE more broadly (e.g. Turner et al., 2007), the studies reviewed here identify the need for 'cultural tailoring' when providing PE in autism. A wide range of factors need to be considered, including issues such as language, gender, social customs, autism awareness within cultural groups and the 'fit' between the pedagogic style of those delivering the programme and the cultural assumptions and expectations of the target audience (Birkin et al., 2008; Chiang, 2013; Perepa, 2014). Programmes need to be advertised in ways and via media that

are culturally accessible to all families. PE courses may need to be provided in a range of languages, not just in that of the majority, which can be particularly challenging in countries with ethnically diverse populations. Terminology used by those delivering the training needs to match and align with that used by the families, which can be difficult in some cultures and languages, where for example they may be no word for autism (Carroll, 2009).

While it can be argued that it is important not to waste limited time and resources on “*reinventing the wheel*” (Wang, 2008, p102), attempting to adhere to delivery procedures developed elsewhere for different populations can be problematic. Birkin et al. (2008) identify that the EarlyBird model, initially designed for delivery in the UK, was inappropriate for a country with a low population density such as New Zealand. Strict adherence to the original programme design led to courses running too infrequently or being locally unavailable, and it was therefore necessary to modify the programme to make it fit for purpose. While the Jordanian mothers in the study by Al-Khalaf et al. (2013)

were able to attend sessions during the working day, such a delivery model would not be suitable in, for example, south-east Europe, where parents reported a preference for weekend and evening courses (Preece et al., 2017).

CONCLUSION

This article has reviewed the literature regarding PE in ASD. It was surprising that so few articles have been published on PE in comparison to the relatively large body of literature on PT in ASD. Nonetheless, the studies reviewed here clearly identify that such programmes can have a positive impact on the lives of families with children on the autism spectrum. There is a clear need for further research in this field, and particularly for longitudinal studies to identify the impact of content and delivery variables on outcomes, and to monitor how training impacts over time. Further research is also needed to investigate how local and cultural differences can be addressed within PE programmes.

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EDUKACIJA RODITELJA O POREMEĆAJIMA IZ SPEKTRA AUTIZMA – PREGLED ISTRAŽIVANJA

Sažetak: *Obitelji koje žive s poremećajem iz spektra autizma suočavaju se s mnogim izazovima koji ne utječu samo na dijete s tim poremećajem i njegov razvoj, već i na funkcioniranje obitelji i kvalitetu njezina života. Edukacija roditelja o poremećaju iz spektra autizma identificirana je kao prioritetna intervencija u području ove problematike, kako na nacionalnoj, tako i na međunarodnoj razini. Dok je, s jedne strane, literature o osposobljavanju (treningu) roditelja u okviru specifičnih terapijskih pristupa opsežna, pretragom baza podataka pronašli smo svega 12 članaka koji izvještavaju o istraživanjima edukacije roditelja. Ukupno gledajući, ta istraživanja pokazuju pozitivne učinke edukacije roditelja: ona može doprinjeti redukciji stresa i anksioznosti, boljem nošenju s teškoćama, poboljšanju interakcija i komunikacije između roditelja i djeteta, boljem razumijevanju poremećaja iz spektra autizma, učinkovitosti, povjerenju i poboljšanju kvalitete života roditelja. Razmatraju se četiri ključne teme: utjecaj, provedba, sadržaj i lokalna/kulturna sporna pitanja edukacije roditelja, a također i slabosti i teškoće zamijećene u dosadašnjim istraživanjima, kao i potreba za daljnjim istraživanjima na području ovih intervencija.*

Ključne riječi: *poremećaji iz spektra autizma, roditelji, edukacija roditelja*