
Systemic relational dynamics between autism practitioners and clients in professional care settings

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Context to this study

- The facilitation of therapeutic relationship is the cornerstone of most contemporary models of “talking therapy” (eg. Beck, 1979; Rogers, 1957).
- Systemic therapy models explicitly acknowledge the social dimension to human distress, focusing on how relational “systems” might maintain poor mental health (Alilovic & Yassine, 2010; p. 270).
- Systemic approaches locate mental distress outside the “identified patient”, facilitating explanations of distress which take account of social context (Bor & Legg, 2003).

lessons from therapy

- Distress around distortions of meaning and “self” experiences is a common theme in therapy.
- A developmental perspective on the role of nourishing relationship in how we construct our social and emotional selves; eg. Intersubjectivity (Trevarthen).
- The common role of inter-personal relationship in therapy
- Carl Rogers’ person-centred therapy. Empathy, unconditional positive regard and congruence.
- Beck (1979) cognitive behavioural therapy. Warmth, accurate empathy and genuineness.
- *Any person* can offer therapeutic relationship. Any professional (Sommerbeck, 2011). Not just professional therapists.

The practitioner as therapist?

- Marlis Portner (2007) advocates a person-centred approach to daily interactions by *all* staff in disability settings, in an argument derived from Carl Rogers' (1957) thesis that *any* relationship possessing crucial relational ingredients can promote client growth and wellbeing.
- Such perspectives invite consideration of the nature of relational interactions between client and staff in autism care settings and whether such relationships might have *quasi therapeutic* qualities.

The study framework

- A qualitative study of the experience of 6 practitioners examining the nature of the practitioner/client relationship in autism care settings.
- The idea of qualitative research is to attempt to capture the richer sense of unique meaning and experience; appropriate perhaps to relational interactions in an autism service.
- The accounts of the participants suggested that professional and diagnostic imperatives often compete with practitioner desire to be “emotionally available” to the people they support.

Theme 1: The Importance of “Emotional Availability”

- Participants conveyed a feeling that the onus was on staff to create the necessary conditions in which the person could cope and feel heard. There is here a similarity in how the therapist might consider therapeutic relationship as something offered or facilitated by the therapist (eg. Rogers, 1957).

This “therapeutic” aspect of the staff/client relationship was perhaps illustrated by participant Gail, who linked “challenging behaviour” by clients to frustration at a lack of understanding by support staff:

“I suppose they probably just feel that they’re not being heard and that ehmm, that maybe that they’re not being properly cared for that they’re not being listened to. (Gail).”

Theme 2: Professional Barriers to Relationship

- Participants identified discrepancy between their desire to offer transparency in relationship and the reality that their ability to respond naturally and authentically was conditional upon professional policy and procedure.

I suppose in one way you'd feel kind of good maybe in a sense that that's how they would see you and that they are not seeing you as like the staff, but then in the other sense it's so ingrained in us like from (name of organisation) like that you are not friends, you are not family, you are not their you know you are there to support lives. (Gail).

Theme 2: Professional Barriers to Relationship

- Three of the six participants also made reference to the potential for staff interactions with clients to be negatively influenced by historic incident report forms within the client file
- Tension between engagement with clients and “paperwork” was also cited, while Peter went further suggesting that the humanity of the client was often smothered by a client’s reputation for engaging in “challenging behaviour”.

“You’re looking at you know behaviour support plans you’re looking at (...) all of the bad stuff is always written down and a lot of the good stuff isn’t so heavily documented (Gail).”

Theme 3: The “Grip” of Normality

- Four of the participants reflected upon an uncomfortable attempt to balance acceptance of the client and their desire to change unusual social behaviour.
- The “grip of normality” caused discomfort for Mary, Alice and Gail, and they each reflected on difficulty in standing by as the client made inevitable social “errors”. There is perhaps irony here in the discomfort of autism practitioners watching the people they support being “autistic”. Indeed all three participants laughed in a self deprecating way when discussing this theme, reflecting their dissonance around the futility of their attempts to change people who may be socially different.

Theme 4: The Dialectics of Power

- A recurring theme in participant interviews was reference to questions of power, with all participants expressing a desire for some form of fairness or balance in the relationship. However the qualitative method illuminated participant tension around this question of balance of power. For example, three of the participants seemed, to some extent, unaware of the existence of contradictions within their account. Steven discussed his hypothesis, that while on the one hand he treated the client as an equal, he had a sense that his imposing physical stature was in some way helpful to the client.
- *“maybe there is a mutual respect there from him or whether there's a fear from him or what I don't know but ... I'm not complaining (laughs).”*

Support for focus on relational dynamics in caregiver interventions.

- All participants conveyed a sense of warmth about clients together with a belief that how they *were* with clients really made a difference. A predominant idea which emerged was an association between the quality of the practitioner/client relationship and client ability to cope.
- note the small print in the DSMV about systemic stress. *“Symptoms must be present in early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies later in life”.*
- On that note, a transactional model of stress is the heartbeat of the low arousal model (see McDonnell, McCreadie and Dickinson, 2018 in press).
- Moving away from narratives of caregiver blame while acknowledging the potential value of change in caregiver behaviour. It may instead be helpful to focus on “relational mis-attunement” (Helps, 2016).

Implications for practice?

- Links between alexithymia, atypical sensory function and intolerance of uncertainty have been explored in research (South & Rogers, 2017).
- Perhaps securing **relational certainty** (rather than functional certainty) is an area where services might focus?
- A role for “**relational mindfulness**” (Hughes) in the sense of not what is happening for you, but what is happening between me and you?
- The practitioner **developmental agenda** (Mearns) ?
- The value of professional **supervision** and the **reflective practitioner** model (Schon).

Growing focus on caregiver interventions.

- Both parental conflict and individual depression and anxiety predict increased levels of “autism symptomology” (Kelly, Garnett, Attwood & Peterson, 2008).

Autism Spectrum Symptomatology in Children: The Impact of Family and Peer Relationships

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Abstract This study examines the potential impact of family conflict and cohesion, and peer support/bullying on children with autism spectrum disorder (ASD). While such impacts have been established for a range of non-ASD childhood disorders, these findings may not generalize to children with ASD because of unique problems in perspective-taking, understanding others' emotion, cognitive rigidity, and social reasoning. A structural model-building approach was used to test the extent to which family and peer variables directly or indirectly affected ASD via child anxiety/depression. The sample ($N=322$) consisted of parents of children with ASD referred to two specialist clinics. The sample contained parents of children with Autistic Disorder ($n=76$), Asperger Disorder ($n=188$), Pervasive Disorder Not Otherwise Specified ($n=21$), and children with a non-ASD or no diagnosis ($n=37$). Parents completed questionnaires on-line via a secure website. The key findings were that anxiety/depression and ASD symptomatology were significantly related, and family conflict was more predictive of ASD symptomatology than positive family/peer influences. The results point to the

different meanings of family cohesion and conflict for children with ASD relative to children without ASD.

Keywords Autism spectrum disorder · Asperger's syndrome · Autism · Family · Peers · Conflict · Support

Introduction

Early prevalence studies based on small samples indicate that ASD affects between 36 and 48 children per 10,000 (Ehlers and Gillberg 1993; Kadesjo et al. 1999), however recent reviews are more conservative (2.6 per 10,000; Fombonne 2007). ASD often produces difficulties with conversation and formation of friendships (Asperger 1944, 1979). Children with ASD have particular difficulty understanding and using the rules governing social behaviors (Wing 1981, 1992) and with using and interpreting nonverbal social and conversational cues (Ehlers and Gillberg 1993; Gillberg and Gillberg 1989; Szatmari et al. 1989). Children with ASD may be over-literal in interpre-

Growing focus on caregiver interventions.

- The “PACT” parent-mediated social communication intervention for children aged 2-4, encouraged parents to optimise parent-child communication in an effort to reduce the severity of “autism symptoms” (Pickles at al. 2016; p. 2507)

Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial

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Summary

Background It is not known whether early intervention can improve long-term autism symptom outcomes. We aimed to follow-up the Preschool Autism Communication Trial (PACT), to investigate whether the PACT intervention had a long-term effect on autism symptoms and continued effects on parent and child social interaction.

Methods PACT was a randomised controlled trial of a **parent-mediated social communication intervention** for children aged 2–4 years with core autism. Follow-up ascertainment was done at three specialised clinical services centres in the UK (London, Manchester, and Newcastle) at a median of 5.75 years (IQR 5.42–5.92) from the original trial endpoint. The main blinded outcomes were the comparative severity score (CSS) from the Autism Diagnostic Observation Schedule (ADOS), the Dyadic Communication Assessment Measure (DCMA) of the proportion of child initiations when interacting with the parent, and an expressive-receptive language composite. All analyses followed the intention-to-treat principle. PACT is registered with the ISRCTN registry, number ISRCTN58133827.

Findings 121 (80%) of the 152 trial participants (59 [77%] of 77 assigned to PACT intervention vs 62 [83%] of 75 assigned to treatment as usual) were traced and consented to be assessed between July, 2013, and September, 2014. Mean age at follow-up was 10.5 years (SD 0.8). Group difference in favour of the PACT intervention based on ADOS CSS of log-odds effect size (ES) was 0.64 (95% CI 0.07 to 1.20) at treatment endpoint and ES 0.70 (95% CI –0.05 to 1.47) at follow-up, giving an **overall reduction in symptom severity over the course of the whole trial and follow-up period** (ES 0.55, 95% CI 0.14 to 0.91, $p=0.004$). Group difference in DCMA child initiations at follow-up showed a Cohen's d ES of 0.29 (95% CI –0.02 to 0.57) and was significant over the course of the study (ES 0.33, 95% CI 0.11 to 0.57, $p=0.004$). There were no group differences in the language composite at follow-up (ES 0.15, 95% CI –0.23 to 0.53).

Interpretation The results are the first to show **long-term symptom reduction after a randomised controlled trial of early intervention in autism spectrum disorder**. They support the clinical value of the PACT intervention and have implications for developmental theory.

Growing focus on caregiver interventions.

- Parents participating in music therapy sessions with their children gained insight into ways to share relational experience moving from “teaching” to sharing emotional space (Thompson and McFerran, 2015).

“We’ve got a special connection”: qualitative analysis of descriptions of change in the parent–child relationship by mothers of young children with autism spectrum disorder

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Young children with autism spectrum disorder face many developmental challenges, most notably in the area of reciprocal social interactions with family and peers. Collaborating with the families of these children in therapy sessions is fast becoming best practice in many countries. This paper presents a qualitative analysis of semi-structured interviews with 11 mothers who participated in family-centred music therapy sessions along with their child. The interview questions focussed on changes to the nature of the parent–child relationship. Analysis of the interviews identified three aspects of positive change to the parent–child relationship, namely: the quality of the relationship; the parents’ perception of the child and the parents’ response to the child. The changes in the relationship with their child were valued and cherished by all of the mothers, and understanding the impact a family-centred approach might have on the nature of the parent–child relationship needs further exploration.

Growing focus on caregiver interventions.

- Links between caregiver synchronisation to a person and developmental trajectory in autism (Siller & Sigman, 2002). This study identified superior joint attention and communication skills in children whose early year caregivers had displayed higher levels of “synchronisation” in shared play activities (in the sense of caregiver attunement to objects which were *already in* the child’s focus of attention).

The present study focused on behaviors that caregivers of children with autism show during play interactions, particularly the extent to which the caregiver's behavior is synchronized with the child's focus of attention and ongoing activity. The study had two major findings. First, caregivers of children with autism synchronized their behaviors to their children's attention and activities as much as did caregivers of children with developmental delay and caregivers of typically developing children, matched on language capacities. Second, caregivers of children with autism who showed higher levels of synchronization during initial play interactions had children who developed superior joint attention and language over a period of 1, 10, and 16 years than did children of caregivers who showed lower levels of synchronization initially. These findings suggest a developmental link between parental sensitivity and the child's subsequent development of communication skills in children with autism. Implications for parent training interventions are discussed.

KEY WORDS: Autism; attention; communication; parent; language.

Idiosyncratic experience of relationship and emotion.

- Children with autism who have higher cognitive ability can form typical attachments with caregivers (Rutgers, Bakermans, Kranenburg, Ijzendoorn & Berckelaer & Onnes, 2004).

Autism and attachment: a meta-analytic review

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Method: Sixteen studies on attachment in children with autism were reviewed, and ten studies with data on observed attachment security ($N = 287$) were included in a quantitative meta-analysis. **Results:** Despite the impairments of children with autism in reciprocal social interaction, the majority of the studies found evidence for attachment behaviours in these children. In four samples using the Strange Situation procedure the average percentage of secure attachments amounted to 53% ($n = 72$). Meta-analytic results showed that children with autism were significantly less securely attached to their parents than comparison children, and the combined effect size for this difference was moderate ($r = .24$). Children with autism displayed less attachment security than comparisons without autism, but this difference disappeared in samples with children with higher mental development, and in samples in which autism was mixed with less severe symptoms of autistic spectrum disorders. **Conclusions:** It is concluded that attachment security is compatible with autism and can be

Idiosyncratic experience of relationship and emotion.

- Mothers rate their feelings towards the child significantly more positively than they perceive is reciprocated (Orsmond, Seltzer, Greenberg & Krauss, 2006). This study also found however that parents felt that children were more trusting of their mother, than mothers in turn felt towards the child.

Mother–Child Relationship Quality Among Adolescents and Adults With Autism

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Abstract

The mother–child relationship in families of 202 adolescents and adults with an autism spectrum disorder living at home and its association with maternal caregiving gains and strains were examined. Findings indicate a wide range of variability in the quality of the mother–child relationship, although most were characterized as positive across multiple measures. Characteristics of the son or daughter with autism (less severe maladaptive behaviors, better health, and less social impairments) and characteristics of the mother (lower levels of pessimism) were predictive of more positive mother–child relationships. In turn, specific aspects of the mother–child relationship (greater positive affect and warmth), along with other child and maternal characteristics, predicted fewer maternal caregiving strains and, to a lesser extent, greater caregiving gains.

Idiosyncratic experience of relationship and emotion.

- Why are so many people with autism anxious? Links between alexithymia, atypical sensory function and intolerance of uncertainty have been explored in research (South & Rogers, 2017). This paper links emotional understanding, sensory perception and cognitive style as factors mediating anxiety. Perhaps this is also a model for social anxiety and social withdrawal.

Sensory, Emotional and Cognitive Contributions to Anxiety in Autism Spectrum Disorders

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Severe symptoms of anxiety add substantial additional burden to many individuals diagnosed with Autism Spectrum Disorder (ASD). Improved understanding of specific factors that contribute to anxiety in ASD can aid research regarding the causes of autism and also provide targets for more effective intervention. This mini-review article focuses on emerging evidence for **three concepts that appear to be related to each other and which also strongly predict anxiety in ASD samples**. *Atypical sensory function* is included in the diagnostic criteria for ASD and is likely an important contributor to anxiety. Difficulties in understanding and labeling emotions (*alexithymia*), although a co-morbidity, may arise in part from atypical sensory function and can lead to confusion and uncertainty about how to respond to social and emotional situations. **Intolerance of uncertainty (IU)** describes people who have a particularly hard time with ambiguity and is known to be a key mechanism underlying some anxiety disorders. While evidence for linking these ideas is to date incomplete, we put forward a model including each concept as a framework for future studies. **Specifically, we propose that IU is a critical mediator for anxiety in ASD, and explore the relationships between sensory function, alexithymia and IU**. We further explore the role of the medial prefrontal cortex (mPFC) in

Idiosyncratic experience of relationship and emotion.

- Research suggests that children who have autism report experiencing loneliness more intensely and frequently than typically developing children. They appear however to have a different construct of “loneliness” linked to social exclusion rather than emotional loneliness (Bauminger & Kasari, 2000). The researchers suggest that it may be that autistic children evaluate loneliness based on prior social experience and social comparison with others and may have difficulty linking feelings with that experience.

Loneliness and Friendship in High-Functioning Children with Autism

Nirit Bauminger and Connie Kasari

Loneliness and friendship were examined in 22 high-functioning children with autism and 19 typically developing children equated with the autistic children for IQ, CA, gender, mother's education, and ethnicity. Children between the ages of 8 and 14 were asked to report on both their understanding and feelings of loneliness and the quality of their friendship. Compared to typically developing children, children with autism were both lonelier and had less complete understandings of loneliness. Although all children with autism reported having at least one friend, the quality of their friendships was poorer in terms of companionship, security, and help. Fewer associations were found between loneliness and friendship for the autistic than for the non-autistic children, suggesting less understanding of the relation between loneliness and friendship. Implications of these results are discussed for conceptualizing the social deficits in autism.