Advances in Mental Health and Intellectual Disabilities

Number 5/6

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In partnership with Estia centre
Impact of challenging behaviour on siblings of people with Autism

Evan Yacoub, Michael Dowd, Leigh McCann and Lydia Burke

Abstract
Purpose – Despite being largely supportive of their sibling with an autism spectrum disorder (ASD), some siblings without ASD also feel the effects of the disorder particularly in relation to challenging behaviour and lack of empathy. The purpose of this paper is to explore the experiences adults who have a sibling with ASD and intellectual disability (ID) with challenging behaviour.

Design/methodology/approach – Interviews were conducted with 11 capacitous adult siblings of service users who have ASD and ID as well as a history of challenging behaviour. A modified version of the autism Parenting Stress Index was used to assess the impact on those siblings. thematic analysis was utilised to analyse their responses.

Findings – Four main themes emerged from the interviews, which highlighted that challenging behaviour can cause emotional losses and can impact upbringing and the sibling relationship. Despite the siblings making adjustments, they continue to have concerns for the future.

Originality/value – Chronic challenging behaviour can impact on siblings, and it is important to support entire families, and not exclusively parents.

Keywords Intellectual disability, Impact, Challenging behaviour, Autism, Family supports, Siblings

Paper type Research paper

Introduction
Emerson (1995) defines challenging behaviour as “culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities”.

Prevalence
Prevalence studies that have looked at a wide range of challenging behaviours have indicated that such behaviours often coexist and that sizeable minority of people with intellectual disabilities (ID) show severe and multiple forms of challenging behaviour (British Psychological Society, 2004).

Prevalence of challenging behaviour was examined in the total population of people with ID in the UK (Emerson et al., 2001). The authors took their sample from a range of environments; residential facilities, village communities, day services, adult placement services, nurseries, special schools and peripatetic support teams. They found that challenging behaviours were shown by 10–15 per cent of people with ID. Similar prevalence levels were found by in Scotland (Cooper et al., 2009) and in North America (Borthwick-Duffy, 1994).

Impact
Challenging behaviour can both impact on the quality of life of the person exhibiting the behaviour and present difficulties for carers (Emerson, 1995). Doubet and Ostrosky (2015) report four key areas of impact on families.
Choosing activities. The parents surveyed discussed how having a child who is engaged in challenging behaviour changed typical and planned family activities.

Siblings. Parents reported that their attempts to help other children understand their absences from sibling extracurricular activities were compounded by the knowledge that despite the sibling understanding, they still wished they could be there.

Increase in family stress. At home, parents reported that the pressure of repeat incidents of behaviour impacted on their stress levels and that of other family members.

Questioning parental competence. The final theme in the research was that parents reported diminished feelings of competence in relation to their parenting approaches.

Siblings show less satisfaction with their sibling relationship in adolescence, as peer relationships become more important and there is less contact with siblings (Cicirelli, 1994). During adult years, sibling relationships increase in satisfaction and contact (Cicirelli, 1994).

In a study by Orsmond et al. (2009), the authors found that despite decreased contact with their siblings, adult siblings reported the same degree of positive effect in the relationship as adolescent siblings which suggests there may be a stability over time in the closeness of the sibling relationship when one has an autistic spectrum disorder (ASD).

While closeness in relationships between siblings where one has an ASD seems to be stable over time, the sibling relationship can have an effect on the sibling with no ASD. It is apparent that, despite their largely supportive attitude towards their sibling with an ASD, some of the non-autism spectrum disorder (NASD) (or neurotypical) brothers and sisters of those siblings also feel the effects of the disorder due to challenging behaviour and impaired empathy exhibited by their siblings (Hastings, 2003). Some evidence would suggest that NASD children and adolescents who have a sibling with an ASD are more likely to be distressed than their peers whose siblings do not have an ASD diagnosis (Hastings, 2003).

The effects of having a sibling with ASD can also have effects on the NASD siblings’ role in adulthood. Siblings with ASD become more reliant on their non-disabled siblings in later life (Davys et al., 2011). While research suggests there is a willingness to assume the role of primary support for the sibling with ASD (especially among sisters), this can be emotionally taxing for non-disabled siblings as they “worry for the future” as well as struggle to manage other competing demands with this new responsibility such as careers, children and aging parents (Davys et al., 2011).

Gender can influence the feeling of responsibility for the sibling with ASD as female NASD individuals reported their lives were more influenced by their sibling with an ASD than male NASD individuals reported (Hastings, 2003). There is also some evidence that NASD sisters of a sibling with an ASD are significantly more anxious and depressed than NASD brothers of a sibling with an ASD (Orsmond and Seltzer, 2009).

Hastings (2003) reported that the impact of autism on younger siblings and from a male sibling was more severe. Even within the ID population, challenging behaviour exhibited by those with ASD has more impact on siblings than other subgroups. For example, siblings of individuals with down syndrome seem to fare better than those who are siblings of individuals with autism. Compared with siblings of brothers/sisters with autism, siblings of brothers/sisters with down syndrome showed closer, warmer sibling relationships, along with slightly better health and lower levels of symptoms of depression (Urbano and Hodapp, 2007).

Much of the research is applied to child studies. There is limited research on adults’ reflections on growing up with a sibling with ASD; therefore, literature is limited on the opinions and needs of adult siblings of brothers/sisters with ASD and this is why this research is so important.

Study aims

This study set out to gain the perspectives of siblings of individuals with ASD and ID and to learn about how their experiences growing up have impacted them. In particular, the impact of challenging behaviour on siblings was explored.
Methodology

Design

Prior to interviewing the participants, ethical approval was obtained from the research ethics committee for Brothers of Charity, a community service for people with intellectual disabilities in the West of Ireland.

A qualitative approach using in-depth interviewing was chosen as it is less likely to constrain the material that participants contribute to the project. However, as part of the process of development, we modified and used the autism Parenting Stress Index (Silva and Schalock, 2012) to assist us in identifying areas of enquiry and in devising prompts for the interviews. The interview questions were as follows:

- Tell me about who is in your family.
- Overall how would you describe growing up in your family?
- What have been the happiest moments of growing up in the family?
- Who in your family has autism?
- Is x different from other people socially? If so how and does this affect you?
- Is x’s communication different from other people socially? If so how and does this affect you?
- Does x have tantrums/meltdowns? If so how and does this affect you?
- Does x have aggressive behaviour? If so how and does this affect you?
- Does x have self-injurious behaviour? If so how and does this affect you?
- Does x have difficulty making transitions from one activity to another? If so how and does this affect you?
- Does x have sleep problems? If so how and does this affect you?
- Does x have problems with his diet? If so how and does this affect you?
- How close are you and x? Tell me more about this.
- What is your prediction for x’s future? Tell me more about this.
- What help do you think x and the family need to do well in the future? Who do you think should provide this?
- Do you have any questions for me?

We used an iterative approach to develop our interview (Srivastava and Hopwood, 2009). The interview was piloted on the first two participants from each of the three interviewers. As anticipated, some small adjustments were made to the interview questions, for example:

- There needed to be more focus on getting relevant information without leading participants.
- There needed to be a comment before “what were the happiest moments growing up?”
- For each specific question, for example, “socially different”, “communication difficulty”, etc., it was necessary to seek both positive and negative examples.
- We replaced “tantrums/meltdowns” with “Can you remember a time when s/he was very distressed”.
- Before asking about what supports might be useful, we needed to first ask “what supports have you received to help you to live with XXX […]”.

The 11 interviews were carried out by a consultant psychiatrist (4), a senior clinical psychologist (3) and a then psychologist in clinical training (4). Participants were able to conclude the interview whenever they wanted and were offered further support at the end of the interview. They were given contact details for the interviewer in case they have any queries at a later date.
Interviews, which lasted 40 minutes on average (range 20–60), were transcribed verbatim before analysis. Once the data analysis was completed, a triangulation and feedback meeting was offered to the participants and three siblings attended.

Participants

Participants were capacitous adult siblings of service users with ASD and ID known to the Brothers of Charity Galway service who present with challenging behaviour, and where the sibling:
1. still lives at home either full time or when not attending term time further education; and
2. left the family home within the last year.

Also, participants were included where their sibling either lives at home full time with or without respite access or has moved out (e.g. to supported accommodation) but spends five days or more per month at the family home. This was to ensure that all interviewees were familiar with their siblings’ current behaviour patterns whilst giving informed consent to discussing current and previous behaviour patterns.

Child siblings were excluded as the interview process may be stressful for a child. We consulted with multidisciplinary team (MDT) members supporting the family prior to inviting siblings to participate but did not interview staff. Where siblings did not have the capacity to take part in the research, they were excluded. We consulted with MDT staff supporting the families to help us decide whether siblings meet our inclusion and exclusion criteria.

After potential interviewees were contacted by the professional involved, they were given at least 24 hours to reflect before being approached to give consent. To increase the reach of the study (Ely et al., 1991), we purposively recruited participants whose siblings had a range of functional abilities, ages, backgrounds and challenging behaviours. The final sample size was determined by continuing to interview participants until the data became “saturated” (Lincoln and Guba, 1985) and little new information emerged during coding. In previous qualitative projects, we have worked on, a total of 10–15 interviews were sufficient to saturate data.

Data analysis and storage

Thematic analysis (Braun and Clarke, 2006) suits questions related to people’s experiences, views and perception, and this approach was adopted to analyse the interview transcripts. Specifically, inductive thematic analysis was utilised, where the coding and theme development are directed by the content of the data. Patterns of meaning were identified through a rigorous process of data familiarisation, data coding, and theme development and revision.

We will store data for the period specified by the ethics committee, which is ten years. All data are stored at the community ID team electronic files, and only the researchers have access to it. Community ID team database has data protection registration, and we ensured that we complied with Data Protection Act guidance.

Ethics and consent

All sibling responses remain anonymous. All those interviewed were adults who can provide informed consent. Before commencing the project, Ethics Committee approval was sought and granted from the Brothers of Charity Galway.

Findings

Using thematic analysis method, we identified four consistent themes. The quotes from various participants are organised under these themes below and a narrative and model are suggested at the end.
**Differences – gains and losses**

The losses in people’s lives are identified as “being different” where the sibling with ASD often dictates both the mood and activities in the home. This involved not doing things other families do especially in relation to social interaction.

A number of siblings described the family mood being dictated by the ASD siblings’ behaviour, for example, when describing happy times “I suppose when we’re all together and when A was in good form” (P1).

The siblings also noted that compromises and sacrifices were necessary in order to get by “It would have been B first. Which I think my sister and me accepted, I don’t think we begrudged it […] in one way, he’s not independent. We are and sometimes that’s the price you have to pay” (P2).

One prevalent difference they noted was what might be described as a state of hypervigilance in the house “I think that it probably did impact you know. Although we had a standard upbringing […] you would have higher levels of anxiety, than you know other kids” and “having to keep everything secure in the house, locking all the doors […]. He would try and run away a lot” and also “I was kind of always preparing myself, you never kind of switch yourself off, especially like when he’s going through a tough time […] you’re always on alert” (P3).

In general, the losses experienced were associated with negative emotional impacts including fear, anxiety, guilt, frustration and embarrassment. The anxiety was personal to the sibling but also in the broader family. The fear was multi-faceted, including fear of meltdowns, fear of aggression and fear for safety of self and others. It also elicited feeling of care, concern and compassion for many people.

A number of families reported finding it very difficult to relax, and a constant feeling of tension. One sibling described the complexity of going away for a short time “If we went on holidays, and he was in respite and knowing that he’s doing well, we could relax more” (P1).

Family members also described feeling guilty at times. Perhaps when the ASD sibling is distressed or when they feel they should help more “To see him cry, that puts guilt on you but like it’s a natural guilt” (P2) and “I’d like to go abroad for a while, but like I’d feel a bit guilty, coz id be leaving my mother on her own, like” (P4).

On a positive note, some siblings found their experiences as carers from an early age inspiring “I think that I have good patience because of the experience of being his brother. I am now studying social care as a result” (P5), “thank god that I do have him, and he’s made me a better person” (P6), and finally “I did nursing I’m a psychiatric nurse” (P11).

One sibling talked about feeling powerless to affect the impact of ASD on his brother which completely took over his personality “I think he’s a slave to the autism” (P2) and “It was never about myself, it was always – I wish I could take that away from him […] It’s as if […] he’s locked in the autism” (P6).

**Impact on upbringing**

Many of the siblings described initially described a “normal upbringing”. There was a sense that this may have been because their situation was the only one they had encountered. “I always say it’s the only way I know, I’ve never been exposed to a normal functioning family” (P3) and “at times it was difficult […] I guess just dealt with it anyways, whatever […] didn’t know any different” (P4).

However, when pressed they identified many differences in practices “ […] because I was the eldest, I kinda did grow up a lot quicker than say my friends would have […] as in like I was given a lot more responsibility, a lot more […] I was like a lot more mature, and I kinda […] my parents depended on me a lot and I depended on them. So I was very involved with C growing up” (P3) and “If he was up everyone was up […]” (P11).

There was also a sense of parents compensating in some cases “mum especially always made a point of making sure that we got the opportunities that every other siblings would get. Doing things with friends” and “[They] never took their focus off me either so I was always very much included in everything. Still brought places, they’d still come to all my school plays, sports
days anything like that […] it was not like we have C to focus on now and I had to take a back seat. I had a great childhood” (P3).

The task of identifying triggers was discussed in detail as this led to family members having to adopt a detective type approach in dealing with incidents “Sometimes when he acts out, there has to be a trigger under it. You can spend all day trying to work it out” (P2).

**Impact on sibling relationships**

Siblings described questioning their own competence, which led to additional emotional distress at their lack of coping “There are times when I feel useless as I can’t do something” (P7) and “There are times when everyone is stressed and we don’t know what to do” (P8).

Whilst siblings were understanding and even accepting towards their ASD sibling’s aggression, there were times when they reacted angrily “he didn’t have the communication skills or verbal skills to tell us that he was having tantrum” (P3) and “my coping mechanism is to like accept that he will never be normal functioning whatever that even is” (P6) and “He hit my elbow a month ago, and it really hurt. I got angry with him” (P7).

Siblings described having positive relationships whilst clearly outlining that despite the impact of ASD on this relationship was evident “Me and him are very close. I can always direct him if needs be. He looks up to me” (P5), “I care for him in a dutiful kind of way” (P9) and, finally, “I think we get on very well but it’s just a weird relationship” (P2).

Siblings described having to withdraw at times in order to protect themselves physically and emotionally “Yeah, he’s given me a few slaps. I kind of have pulled back”. “You don’t want to isolate him either because that won’t help the relationship either” (P1), “I’d make an excuse not to call out to him” (P1) and “I had to kind of dehumanise him to be able to deal with […] him trying to hurt me, or trying to hurt himself. So it was almost like I had to numb myself, and then like I’d […] once that was dealt with […] I’d go and I’d cry for like 2 days” (P6).

**Future directions**

Siblings reported their aspirations which at times contrasted sharply with their reality or anxieties due reported failures of care “My vision for X is that there should be a community around him […] and sometimes you ask, is he happy where he is? But where do you put him? Out in the community? I just read an article in the Sunday Times yesterday. So we’re in a catch 22 situation; I don’t trust the community. If we’re in a community care thing. If they’re having staffing crisis where he is and that resulted in reduced staff so he can’t get out […] where’s the roadmap for B? They just deal with crises” (P2) and “I don’t want him to just be given a bedroom and he just watch TV all day, he’s a very intelligent boy. He needs to […] like he does work experience in Charlie Byrnes, or Fat Tony’s like for an hour, like sweeping the floor, like he’s a very bright child, […] well young adult” (P6).

Some siblings reported that the family did not receive sufficient help, which increases their anxieties about what to expect from services in the future “I felt that we could have got more help in June. Mum felt under pressure. Some months there would only be one night respite per month” (P10) and “I have a lot of support from my family, but as in the outside world, there is no support for […] I have never gotten any other support. I’ve kinda had to manage it on my own as well” (P6).

One sibling commented on service shortfalls being a national policy and legislation issue rather than a local service issue “There needs to be a change of mind-set. Change of mind-set from government as well as the [local service]” (P2). There was also a comment on the need to educate the public and “I think the acid test always is when you’re in a shop and have that kid staring at him. Might be 4 or 5 years of age, just notices that there’s something wrong. I had this situation where I was in a shop and this child goes ‘Mummy, is that guy drunk? She was putting shoes on her child, she was mortified, she took the shoes off the child, like just didn’t know what, and she said there’s something, the child kept pointing because he B, was making noises and the mother was like just dig me into a hole and get me out of here. She put the child’s shoes on and ran her out of the place” (P2):

Siblings discussed the chronic nature of their concern about their ASD sibling’s welfare and their potential ongoing role as a carer “I try not to think about I’s [sic.] future because of the idea of
growing old and frail and looking after (P9) and “It worries me for the future. My parents are getting older and I can see it. Like they’ve won the battle but they’ve lost the war. They’ve won a few battles for him but the overall war we’re losing” (P2) and finally “I’m scared of his future. Where he is now, is, I wish I could keep him there forever, because they’re just so amazing and I’m afraid of what services are out there [...] but he only has like two years left in the school that he’s in, and I remember like when I was younger, like two years ago, I was like he’ll live with me forever, and like that’s ok, [...] no, I’ll take him in, he will be part of my little family, and he’ll live in my house, he’ll have his own room and all that, but that’s not realistic. So I don’t know, I am quite scared of the future” (P6).

Discussion
The present study sought to explore the experiences of adult siblings of individuals with ASD with challenging behaviour. From the 11 transcribed structured interviews, a strong consistent narrative emerged from the data. This narrative is based around four identified themes which is summarised as follows:

First, the theme of differences – gains and losses; while many siblings reported life as being “normal for them”, they also reported many differences from those around them. There have been significant losses as the course of the siblings’ life has been dictated by my sibling’s ASD but there also were gains and positive experiences. Second, the theme of emotional impact was identified; these losses have resulted in predominately negative emotional impacts. Third, in the narrative, lies the theme of adjustment: “However, I have been active in making adjustments to cope and to take some control”. Finally, concern for the future was identified as the fourth theme: “I have thought about the future for my sibling and I see myself being involved but will require a lot of support, both individual and societal”.

Participants reported that their siblings’ challenging behaviour had a significant impact on them, the family unit, their upbringing and their relationship with their siblings. Whilst a number of stressful experiences were discussed, some siblings were able to make adjustments and encounter positive life events shaped by their experiences despite having ongoing worries for the future. Despite these positive experiences, previous research suggests that the struggle to maintain relationships with an ASD family member can have long-term detrimental effects.

As per previous research findings for family members and carers of people with ASD, siblings encountered significant difficulties. Despite these difficulties, participants have been active in making adjustments to cope and to take some control. Participants have been adopting a detective role, interpreting behaviour, trying to understanding communication by getting a greater knowledge and understanding of the condition. People struggled to develop and maintain a connection or relationship with their sibling particularly where there was aggression in relationships, although this sometimes led to withdrawal. Others adopted a role of an advocate.

Sibling attitude can be summarised as “I haven’t really thought much about the future for my sibling but I see me being involved but will require a lot of support. This support will be required for my sibling directly but there is also a need for a societal response”. The individual response will have to meet concerns for future placement whether it is full-time residential or involve respite. The participants see that this may also bring increased responsibility for them. The societal issues that emerged were the need to have social reform, change public perceptions and building social and community supports.

References


Further reading


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An open trial of psychodynamic psychotherapy for people with mild-moderate intellectual disabilities with waiting list and follow up control

Allan Skelly, Caoimhe McGeehan and Robert Usher

Abstract

Purpose – The purpose of this paper is to examine the outcome of psychodynamic psychotherapy for people with intellectual disabilities (ID), which has a limited but supportive evidence base.

Design/methodology/approach – The study is a systematic open trial of flexible-length psychodynamic therapy offered in an urban community to 30 people with mild and moderate ID, presenting with significant emotional distress on the Psychological Therapies Outcome Scale for people with intellectual disabilities (PTOS-ID). Allocation to therapy was made according to an established stepped care approach according to need, and the mean number of sessions was 22.03 (range 7–47). Treatment fidelity was checked via notes review and cases excluded from analysis where there were other significant psychological interventions.

Findings – On both self-report (PTOS-ID) and independent ratings (Health of the Nation Outcome Scales-Learning Disability (HoNOS-LD)) recipients of therapy: did not improve while waiting for therapy; improved significantly during therapy, with large pre–post effect sizes; and retained improvements at six-month follow-up.

Research limitations/implications – While it is important to conduct further controlled trials, the findings provide support for previous studies. High rates of abuse and neglect were found in the sample, suggesting that more trauma-informed and relational approaches should be explored for this client group.

Originality/value – No other study of this size has been completed which used dedicated standardised outcome measures, with this therapy type, with both waiting list and follow-up control and with account of model fidelity.

Keywords Psychotherapy, Psychodynamic, Intellectual disabilities, Follow up, Open trial, Waiting list

Paper type Research paper

Introduction

The practice of psychodynamic psychotherapeutic interventions in people with intellectual disabilities (ID) is the subject of a small but supportive literature. Prosaic early attempts at psychoanalysis with people likely to have ID date back as early as Clark (1933), without clear definition of the disability, clarity on the mechanics of treatment or systematic quantification of outcome. Sinason’s (1992; Revised, 2010) Mental Handicap and the Human Condition described several people who seemed to make better sense of their worlds during psychotherapy, and felt less distressed following this process.

A small evidence base has since developed. A range of studies now exist, including case studies with outcome data (Newman and Beail, 2002; Kellett et al., 2009; Alim, 2010), case series reporting outcomes (Frankish, 1989; Newman and Beail, 2005), and open trials of groups of people with pre–post comparison data (Beail, 1998; Beail et al., 2005, 2007).

Recipient experience seems to be positive. Merriman and Beail (2009) evaluated the views of individual participants in long-term psychodynamic psychotherapy. Using interview transcripts received 14 April 2018
Revised 20 May 2018
Accepted 29 May 2018
and Interpretive phenomenological analysis, most clients indicated feeling positive about their therapist and therapy itself, and stated that positive changes in emotions and behaviour took place during therapy. Munir Khan and Beail (2013) adapted the Experience of Service Questionnaire and the Satisfaction with Therapy and Therapist Scale (STTS-R), and found that recipients showed high “consumer satisfaction” with therapy: 95 per cent of participants reported that therapy had made life better. However, only 75 per cent of these participants received a psychodynamic therapy.

A systematic review by Shepherd and Beail (2017) demonstrated that some 13 quantitative studies supported the use of psychodynamic therapy for people with ID. While supporting effectiveness, these studies do not establish efficacy of the specific therapy techniques, though Alim (2010) has proposed a methodology using Malan’s triangles of conflict and persons. A review by Prout and Browning (2011) suggested that all models of psychological therapy appeared to be moderately effective in patients with ID, relative to no-treatment controls and in pre–post comparisons, but more controlled trials were required.

To date, no study has examined outcome of psychodynamic psychotherapy in a sizeable UK sample of people with mild to moderate ID, using four data points, from referral→ assessment→ discharge → follow-up. Beail et al. (2005) had considered outcome of individual psychodynamic psychotherapy of 20 recipients by using the symptoms checklist (SCL-90-R), the Inventory of interpersonal problems-32 item version (IIP-32) and the Rosenberg self-esteem scale at three separate points; assessment, discharge and follow-up (three months). All measures demonstrated significant change with large pre–post effect sizes between assessment and follow-up. The mean number of sessions was 13.2 with 65 per cent of participants completing their treatment in 16 sessions.

Skelly et al. (2017) considered the outcome for 66 recipients of routine psychodynamic interventions using the Health of the Nation Outcome Scales (learning disability; HoNOS-LD). This study included a limited attempt at waiting-list (15 recipients) and follow-up control (17 recipients). The study reported using only research assistants “blinded” to outcome measurement, by way of strict interview protocol. Again, mean number of sessions was relatively low (13.7). The obvious limitations were that the control groups were only subsets of the treatment group, and the lack of self-reported outcomes. Only 35 of the 66 participants (53 per cent) received individual therapy. However, the pre–post effect sizes across treatment for HoNOS-LD total and factor scores were significant, with total scores demonstrating a large effect size. For the 17 people who were followed up, there was maintenance of improvement.

The current study reports on the outcomes of a systematic use of psychodynamic therapy for people with mild-moderate ID within a community team setting. A standard triage session offers an opportunity for a “baseline” time point prior to assessment, allowing a waiting list control. All recipients of the therapy are followed up at six months, to test whether the improvements were maintained. We have attempted to assign clients to formal psychotherapy according to the stepped care model as described by Jackson and Beail (2016). We utilise both independent HoNOS-LD ratings and the Psychological Therapies Outcome Scale for people with ID (PTOS-ID, Vlissides et al., 2017) which involves two scales for client self-rating: distress, and well-being. We also consider therapeutic fidelity by way of notes review. We exclude recipients from data analysis where changes to psychotropic medication or occupational therapy were concurrent with the therapy. For homogeneity of therapy, only individual psychotherapy is considered.

With these hitherto unused methodological features, this study is intended to examine whether individual psychodynamic therapy in community team settings is associated with positive outcomes.

Method

Ethical status of the Study

All data were collected as part of routine clinical practice, and no additional information was requested from patients or others. The study was registered as a local service evaluation with Northumberland, Tyne and Wear NHS Trust, prior to data analysis.
**Therapy process**

Cases were allocated using a stepped care approach (Jackson and Beail, 2016). A triage (baseline) session clarified whether “caseness” was determined on the standardised measures, a personal history was taken, and then a joint decision made with the person as to whether:

1. No further intervention was required, they did not require psychotherapy but required other forms of intervention (no caseness determined on standardised measures/indication of the need to be provided information/or identification of alternative, fixed treatment, e.g. healthy lifestyles group, desensitisation programme).

2. To progress to a psychodynamic assessment of four sessions, with a view to either time-limited psychodynamic intervention, or extended work if necessary. The approach to length of treatment was flexible; previous studies and clinical experience suggest that only a small proportion of clients require longer-term work (e.g. Skelly et al., 2017).

We noted that of 47 referrals where psychotherapy was requested, six cases did not progress as there was no discernible symptom (HoNOS-LD scores all < 2 and PTOS-ID Distress < 16; n = 6). Only a small minority of people were diverted for psychoeducation (n = 3) or to cognitive-behavioural interventions provided as a lower step by an external service (n = 2). All patients triaged to psychotherapy were then seen within six weeks, and then seen weekly for treatment, subject to therapist leave or patient availability. Two further recipients were excluded from analysis due to receiving substantial occupational therapy intervention involving behavioural activation. One received a significant change to their psychoactive medication during therapy, and two had not received a full scale IQ. The mean number of sessions for the remaining 30 people was 22.03 (median 20.5, range 7–47, SD = 11.43). The psychologist held a doctorate in clinical psychology, and a Diploma in Counselling. Supervision was provided monthly by a psychoanalytic psychotherapist who held United Kingdom Council for Psychotherapy (UKCP) registration.

**Patient characteristics**

In total, 16 men and 14 women with mild to moderate ID (WAIS-IV Full Scale IQ mean 62.83, range 50–69, SD 5.69) were included in the data analysis. They were of working age, from 20 to 57 years (mean 35.3, median 34, SD 11.01). Only patients with complete data sets were included in the data analysis. Psychological treatment was provided by a clinical psychologist between 2015 and 2017. The recipients had a high incidence of adverse childhood experiences. Ten people (33 per cent) had been subject to UK statutory child protection proceedings under the category of sexual abuse, four (13 per cent) for physical abuse, six (20 per cent) for emotional abuse and seven (23 per cent) categorised under neglect. These are only the primary reasons for safeguarding, and many of the patients had complex and traumatic histories. Only two (7 per cent) of the therapy recipients had never been subject to child protection.

**Measures**

Patients were asked to complete the PTOS-ID (Vlissides et al., 2017), and were also independently rated on the Health of the nation outcome scales for people with ID (HoNOS-LD; Roy et al., 2002). Ratings were made by clinical assistants who were independent of any clinical intervention, following an interview protocol to minimise knowledge of the person’s current stage of intervention. Both instruments are well-validated outcome measures that have been factor analysed to determine their underlying structure and allow the construction of composite factor scores, which do not rely on diagnostic systems of classification. The PTOS-ID provides a score for: psychological distress; and psychological well-being, and the HoNOS-LD provides scores for: disturbance of behaviour, mood and relationships (BMR); loss of adaptive functioning (LAF); and internal dysregulation (IDys); as well as a total (difficulties) score. The HoNOS-LD also yields a cognitive and communicative competence score but this is not included in the analysis as it is not expected to change during therapy, though there may be conditions were it is expected to change (e.g. dementia).
**Fidelity to psychodynamic model**

We examined model fidelity for the 30 recipients included in the analysis by review of clinical record, as part of a routine quality standards audit facilitated by the electronic clinical records system, and its word search facility. To address affiliation or other bias, we attempted to measure fidelity via review of the clinical record and set criteria matching the features of psychodynamic therapy that were described by Shedler (2010). There was notable variation in adherence to the model on only one criterion, the explicit use of dreams and daydreams. This may be because people with ID may sometimes have a limited ability or opportunity to explain their dreams and fantasies, thinking and communicating in relatively concrete terms. The other criteria were consistent, suggesting that the therapist was indeed practicing psychodynamic psychotherapy (Table I).

**Results**

Having identified that the model was largely adhered to from examination of case notes, we considered waiting list effects, change during therapy and maintenance of any change at six-month follow-up.

A one-way repeated measures ANOVA was used to analyse normally distributed data. Normality was established by way of Shapiro-Wilk test, skewness and kurtosis score within $z = \pm 1.96$ and by visually inspecting histograms, dot box plots and Q-Q plots. Differences between outcome scores were tested (PTOS distress, PTOS well-being, HoNOS-LD BMR, LAF, IDys and total scores) over time, from screening/triage, through assessment and discharge, to follow-up. For non-normally distributed data, or data with unequal variance (determined by Levene’s test $p < 0.05$), the more appropriate non-parametric Wilcoxon signed-rank test was used. The following variables were identified as covariates during ANOVA and Wilcoxon analyses; IQ score, age, trauma type and the number of sessions attended.

To analyse the effects of subject variables (IQ score, age, trauma type and number of session attended) on PTOS and HoNOS outcome scores, multivariate analyses of covariance (MANCOVAs) were performed on data with equal variances (Levene’s test $= p > 0.05$). We used a generalised Poisson regression model for data which was not normally distributed data and/or with unequal variances in outcome scores (Levene’s test $= p < 0.05$).

The criterion for statistical significance throughout was a $p$ value of $< 0.01$ due to the multiple comparisons made, and all data are expressed as means. All statistical tests were performed using IBM® SPSS® Statistics 23.

**Self-report outcome: PTOS-ID**

Psychological distress. A Wilcoxon signed-rank tests assessed change in distress scores. There was a trend towards worsening of scores prior to therapy ($p = 0.04$), but a large decreasing effect

<table>
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<th>Table I</th>
<th>Fidelity to model by notes review</th>
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<tbody>
<tr>
<td><strong>Criterion (adapted from Shedler, 2010)</strong></td>
<td><strong>% concurrence</strong></td>
</tr>
<tr>
<td>Emotions and its expression as a source of information for therapist are explicitly named in at least 50% of sessions</td>
<td>100</td>
</tr>
<tr>
<td>Notes confirm that client freely chooses topic of conversation in all sessions and therapist does not set agenda</td>
<td>100</td>
</tr>
<tr>
<td>Exploration of attempts to avoid distress in thoughts/feelings, e.g. “triangle of conflict” formulation shared with client</td>
<td>97</td>
</tr>
<tr>
<td>Identification of recurring patterns of relating from childhood to adulthood in formulation</td>
<td>100</td>
</tr>
<tr>
<td>Notes/formulation specifies an account of past positive, traumatic and loss experiences</td>
<td>100</td>
</tr>
<tr>
<td>Notes/formulation specifies focus on at least one key relationship that cause distress or confusion</td>
<td>100</td>
</tr>
<tr>
<td>Notes/formulation specify that therapy is a re-working of past relationships (e.g. Malan “triangle of persons”)</td>
<td>93</td>
</tr>
<tr>
<td>Explicit interpretation of defences as a method of reducing anxiety in formulation</td>
<td>97</td>
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<tr>
<td>Reference to dreams, daydreams and associations as an attempt to explore fantasy life</td>
<td>76</td>
</tr>
</tbody>
</table>

Source: Shedler (2010)
of distress during therapy ($p < 0.001$, Cohen’s $d = 2.19$). Improvements were maintained until follow-up ($p > 0.05$). A MANCOVA was conducted to examine the relationships between patient demographics (IQ, age, the primary trauma type and number of sessions attended) and PTOS-ID distress score over the four data points (triage, assessment, discharge and follow-up). There was no interaction between IQ (Wilk’s $\lambda = 0.161, F(64, 41.424) = 1.336, p > 0.05$), age (Wilk’s $\lambda = 0.406, F(80, 26.090) = 1.099, p > 0.05$), primary trauma type (Wilk’s $\lambda = 0.265, F(16, 61.739) = 1.240, p > 0.05$), or the number of session attended (Wilk’s $\lambda = 0.333, F(84, 22.199) = 1.358, p > 0.05$) and PTOS-ID score. Therefore, on our primary measure of “caseness” (PTOS-ID distress), we found significant and large improvement, with no interaction with IQ, age, primary trauma type or the number of sessions attended (Figure 1).

Psychological well-being. A repeated measures ANOVA assessed change in well-being scores. A slight increase in mean well-being scores was not significant. There was a large increasing effect on well-being during therapy ($p < 0.001$, Cohen’s $d = −0.82$). This had not changed at follow-up ($p > 0.05$).

A MANCOVA revealed that change in well-being scores was not associated with primary trauma type (Wilk’s $\lambda = 0.215, F(16, 61.739) = 1.319, p > 0.05$), age (Wilk’s $\lambda = 0.184, F(80, 26.090) = 1.369, p > 0.05$) or the number of sessions attended (Wilk’s $\lambda = 0.380, F(84, 22.199) = 1.810, p > 0.05$). A Poisson regression analysis was performed to examine the effect of IQ on well-being scores. Whilst patient IQ did not affect well-being scores during triage (Wald’s $\chi^2 = 0.365, p = 0.546$), assessment (Wald’s $\chi^2 = 0.765, p = 0.386$) and discharge (Wald’s $\chi^2 = 0.380, p = 0.051$), IQ had a relationship to well-being scores during follow-up (Wald’s $\chi^2 = 8.180$, IRR = 2.0 per cent, $p = 0.004$).

Independent rating of outcome: HoNOS-LD

Total score. The total score of the HoNOS-LD comprehensively measures generic symptoms. A Wilcoxon signed-rank test was used to assess change. There was no change in scores between triage and the end of assessment ($p > 0.05$). However, there was a large decreasing effect during therapy ($p < 0.001$, Cohen’s $d = 1.3$), and a further fall to follow-up also approached significance ($p < 0.05$). Change in total HoNOS-LD score did not interact with IQ (Wilk’s $\lambda = 0.075, F(64, 41.424) = 1.524, p > 0.05$), age (Wilk’s $\lambda = 0.137, F(80, 26.090) = 1.483, p > 0.05$),
trauma type (Wilk’s $\lambda = 0.579$, $F(16, 61.739) = 0.894$, $p > 0.05$), or the number of sessions attended (Wilk’s $\lambda = 0.141$, $F(84, 22.199) = 1.498$, $p > 0.05$) as determined by MANCOVA. Figure 2 demonstrates the change in mean total HoNOS-LD scores.

**Behaviour, mood and relationships (BMR).** The BMR score encapsulates aggressive, self-injurious and property-destructive behaviours, observable signs of low mood, and breakdown/worsening of relationships. The Wilcoxon signed-rank test was used to assess change. There was no change from triage to assessment ($p > 0.05$), but a large decreasing effect during therapy ($p < 0.001$; Cohen’s $d = 1.1$) and a further decrease to follow-up ($p < 0.01$, Cohen’s $d = 0.78$). These changes in BMR scores were not related to patient demographics; IQ (triage and assessment, Wilk’s Lambda $= 0.541$, $F(64, 41.424) = 0.977$, $p > 0.05$; discharge, Wald’s $\chi^2 = 0.44$, $p = 0.829$; follow-up, Wald’s $\chi^2 = 3.016$, $p = 0.082$), primary trauma type (Wilk’s $\lambda = 0.335$, $F(80, 26.090) = 1.169$, $p > 0.05$), age (triage, Wald’s $\chi^2 = 0.266$, $p = 0.606$; assessment, discharge and follow-up; Wilk’s $\lambda = 0.719$, $F(16, 61.739) = 0.763$, $p > 0.05$) and the number of sessions (triage and assessment, Wilk’s $\lambda = 0.130$, $F(84, 22.199) = 1.524$, $p > 0.05$; and follow-up, Wald’s $\chi^2 = 0.925$, $p = 0.336$) throughout therapy. However, the number of sessions attended demonstrated a possible relationship to BMR scores at discharge (Wald’s $\chi^2 = 4.809$, IRR = 1.9 per cent, $p = 0.028$).

**Loss of adaptive functioning (LAF).** The LAF score measures decline in personal care, community activity, acute physical illness and worsening daily activity levels. A Wilcoxon signed-rank test was used to assess change. There was no change from triage to assessment ($p > 0.05$), but a moderate decreasing effect during therapy ($p < 0.001$; Cohen’s $d = 0.78$) with no significant decrease at follow-up ($p > 0.05$). Change in scores was not related to IQ (Wilk’s $\lambda = 0.728$, $F(84, 41.424) = 0.847$, $p > 0.05$), age (Wilk’s $\lambda = 0.307$, $F(80, 26.090) = 1.200$, $p > 0.05$), trauma type (Wilk’s $\lambda = 0.494$, $F(16, 61.739) = 0.975$, $p > 0.05$), or number of sessions (Wilk’s $\lambda = 0.805$, $F(84, 22.199) = 0.769$, $p > 0.05$).

**Internal dysregulation (IDys).** The IDys score captures disturbance of sleep, hallucinations, delusions, disruptive idiopathic symptoms and loss of appetite/extreme eating behaviours. A Wilcoxon signed-rank test was used to assess change. There was no change from triage to assessment ($p > 0.05$), but a moderate decreasing effect during therapy ($p < 0.001$; Cohen’s $d = 0.78$) with no significant decrease at follow-up ($p > 0.05$). Change in scores was not related to IQ (Wilk’s $\lambda = 0.728$, $F(84, 41.424) = 0.847$, $p > 0.05$), age (Wilk’s $\lambda = 0.307$, $F(80, 26.090) = 1.200$, $p > 0.05$), trauma type (Wilk’s $\lambda = 0.494$, $F(16, 61.739) = 0.975$, $p > 0.05$), or number of sessions (Wilk’s $\lambda = 0.805$, $F(84, 22.199) = 0.769$, $p > 0.05$).

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**Figure 2** Change in mean total HoNOS-LD scores

![Change in mean total HoNOS-LD scores](image-url)
a continuing trend towards decrease at follow-up (p > 0.05; Cohen’s d = 0.32). IDys scores were not related to age (triage, discharge and follow-up, Wilk’s Λ = 0.494, F(80, 26.090) = 1.022, p > 0.05; Wald’s χ² = 1.592, p = 0.207), primary trauma type (Wilk’s Λ = 0.884, F(16, 61.739) = 0.583, p > 0.05) or the number of sessions (Triage, assessment and follow-up; Wilk’s Λ = 0.805, F(84, 22.199) = 0.769, p ≥ 0.05; discharge, Wald’s χ² = 0.588, p = 0.443). Whilst IQ did not associate with IDys scores during assessment (Wilk’s Λ = 0.169, F(64, 41.424) = 1.324, p ≥ 0.05), discharge or follow-up (Wald’s χ² = 1.902, p = 0.168), there was a relationship between IQ and IDys score during Triage (Wald’s χ² = 8.219, IRR = 6.9 per cent, p = 0.004), with more internal dysregulation apparent on initial contact in people with lower Full Scale IQ (Table II).

Discussion

The provision of psychodynamic individual therapy to individuals with mild to moderate intellectual disability, presenting with significant psychological distress, was associated with self-reported and independently-rated improvement, with a combined mean pre–post effect size of 1.1 across all measures. Presentation of distress was stable while waiting for therapy, and improvement was maintained at six-month follow-up. In this group, which only included those with IQ scores of 50–69, we could find no consistent association of IQ, gender, age or number of sessions with outcome scores. Case notes were clearly consistent with adherence to the psychodynamic model, consistent with our clinical opinion. The effect sizes observed were sizable, and similar to those observed in previous studies of people with ID (Skelly et al., 2017; Beail et al., 2005). The effect sizes were also in accordance with the finding that psychodynamic therapy is broadly effective for people in enduring emotional pain, as found by meta-analytic reviews in the USA, UK and Australia (respectively, Shedler, 2010; Yakely, 2013; Gaskin, 2012). There may have been a relationship of better-maintained well-being in people with more ability, and possibly more initial “internal” dysregulation of functioning on first meeting the clients with lower intellectual functioning; but these factors did not co-vary with therapeutic change.

What are we to conclude about the effectiveness of this approach? The comparative therapy literature in the wider population defies simple generalisation. Fonagy (2015) points out that there may be specific psychological states that are less suitable for psychodynamic intervention (acute psychosis, flashbacks), and that apparent superiority of long-term work may be attributable to the depth and length of the relationship. We do not argue that specific psychodynamic techniques are the active ingredients of therapy; it is well-known that common factors are very important (Lambert, 2013), and this applies to other therapies as well.

In the field of cognitive-behaviour therapy for people with ID, it has been suggested that higher IQ may be associated with better clinical outcomes (Taylor et al., 2008). “IQ effects” might be more likely within more formal approaches where the client is expected to learn formal skills, such as

<table>
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<th>Table II</th>
<th>Means (SDs) of outcome scores with pre–post treatment effect size</th>
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<tbody>
<tr>
<td>Scale</td>
<td>Standardised Score</td>
</tr>
<tr>
<td>Psychological Therapies Outcome Scale for People with Intellectual Disabilities</td>
<td>Psychological distress</td>
</tr>
<tr>
<td>Health of the Nation Outcome Scales—Learning Disabilities</td>
<td>Psychological well-being</td>
</tr>
<tr>
<td></td>
<td>Total score</td>
</tr>
<tr>
<td></td>
<td>Behaviour, mood and relationships</td>
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<tr>
<td></td>
<td>Loss of adaptive functioning</td>
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<tr>
<td></td>
<td>Internal dysregulation</td>
</tr>
</tbody>
</table>

Notes: n = 30. ES: Cohen’s d. Scores declining are consistent with improvement save psychological well-being, were rising scores indicate improvement. See main text for details on significant differences and ES for triage to assessment and discharge to follow-up.
with CBT, or dialectical behaviour therapy. However, some studies also include people with full scale IQ scores above the range associated with ID (i.e. scores > 70; Taylor et al., 2005; Brown et al., 2013), so their conclusions may not directly comparable to this study. All of our participants can be described as having an intellectual disability meeting the accepted definition, as defined by the British Psychological Society (2015). We also took care not to conflate pharmacological interventions and occupational (mostly behavioural activation) approaches with psychodynamic therapy as concurrent treatments. Two other studies of psychodynamic psychotherapy also found no effect of IQ on change on the HoNOS-LD during intervention, despite sample sizes of 40 and 68, respectively, with the enhanced power from utilising repeated measures (Skelly and Burman, 2015; Skelly et al., 2017).

It is possible to provide this therapy to people suffering significant and enduring distress within a CLDT setting. There seems no need to refer people with ID, traumatic histories and/or associated attachment difficulties, to more specialist diagnostic or treatment services. Community learning disability services should contain the skills and flexibility to offer therapy of flexible length, so as to meet the needs of the group who have experienced more trauma, neglect and repeated failure experiences. A recent guideline for UK psychologists (British Psychological Society, 2017) recommends due consideration of attachment difficulties in people with ID who present in distress. This includes acceptance that many people need to use services to achieve not only physical safety, but also emotional security—a safe space to consider their options. At a time when services may be under pressure to seek early discharge, therapy recipients may feel that short inflexible blocks of therapy are not enough, or in some recipients, further exacerbate feelings of rejection.

Any service-based outcome study of effectiveness cannot achieve the rigour of the double-blind cross-over randomised controlled trial to establish efficacy. This study did not examine the issue of therapist similarity or model similarity, or the effectiveness of different models of psychodynamic therapy, which may propose different practices. It was noted by the British Psychological Society (2016) that the number of different therapy approaches, available to people with ID, has proliferated in the last decade. Given the very limited number of psychodynamic therapists working with people who have ID, it would be ethical and practical to extend this method of evaluation to different models of therapy. Many still receive therapy according to the particular skillset of local psychological therapies staff, rather than following any particular triage or stepped care protocol; still less, by way of reference to evidence-based guidelines. In the sample presented here, one cause of potential bias might be the lack of lower step referrals, thus creating a “complex” subgroup of people with ID and severe distress, who may not represent everyone with an ID who could benefit from therapy. However, there is good evidence that people with complex interpersonal difficulties do benefit from psychodynamic therapy (Fonagy, 2015), and this study is additional evidence that this approach can be extended to people with mild to moderate ID.

References


**Further reading**


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Comparing psychopathology rates across autism spectrum disorders and intellectual disabilities

Martyn Matthews, Elliot Bell and Brigit Mirfin-Veitch

Abstract
Purpose – The purpose of this paper is to compare the rates and patterns of comorbid anxiety, depression and ADHD across people with: autism spectrum disorder (ASD) plus intellectual disability (ID), ASD/no ID (AS/HFA) and ID only.
Design/methodology/approach – Data were obtained using structured file review and two psychometric screening instruments. File reviews used a modified version of the Case Review Protocol from the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities. Screening employed the Reiss Screen for Maladaptive Behaviour and the ASD-Comorbidity-Adults scale.
Findings – Levels of anxiety, depression and ADHD were high for all three groups, and greater than in general population studies. Between groups, the AS/HFA sample had significantly higher anxiety, while the ASD/ID group had significantly greater ADHD. Groups did not differ on measures of depression or total psychopathology. Levels of ADHD, but not anxiety or depression, increased with severity of ID and ASD symptoms.
Research limitations/implications – More research is needed on the relationship between ASD and both anxiety and ADHD, particularly the identification of these comorbid conditions and their treatment.
Practical implications – Rigorous screening for comorbid mental health conditions is required to achieve the best outcomes for adults with ASD.
Originality/value – The study used a broader community-based sample than previous comorbidity research. Including adults with ID but without ASD enabled a comparison of types and rates of disorder across three distinct but related groups with neurodevelopmental disorders.

Keywords Comorbidity, ADHD, ASD, Autism, Depression, Psychiatric disorder

A comprehensive meta-analysis (Steel et al., 2014) indicates a 12-month prevalence for all common mental disorders of 17.6 per cent in the general population, and according to the latest World Health Organisation (2017) report on common mental disorders, the global prevalence rate of depression is 4.4 per cent and anxiety disorders 3.6 per cent. Whilst there is substantial literature on psychiatric comorbidity amongst children and adolescents with autism spectrum disorders (ASDs), research examining this issue amongst adults is relatively new (Matson and Williams, 2014a). Studies to date indicate that rates of psychopathology are significantly higher for adults with ASD than for the general population (Kannabiran and McCarthy, 2009; Matson and Williams, 2013; Moss et al., 2015), a finding which is also well established in people with intellectual disability (ID) (Cooper et al., 2007, 2015; Deb et al., 2001). However, results from studies of psychiatric comorbidity with autism vary greatly, depending on methodology and the source of the sample population.

There are now several studies which examine multiple comorbidities in adults, and many more on specific psychiatric disorders which can co-occur with ASD (see Table I). A number of neurobiological (Bachevalier and Loveland, 2006; Bellani et al., 2013), psychological (Cooper et al., 2007) and social (Cooper et al., 2007) explanations for the rates of increased prevalence of additional psychiatric disorders in adults with ASD have been proposed. A further
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample population</th>
<th>Assessment methodology</th>
<th>Disorder</th>
<th>Current (%)</th>
<th>Lifetime (%)</th>
</tr>
</thead>
<tbody>
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<td>Rydén and Bejerot (2008)</td>
<td>Clinic sample of adults with Asperger syndrome or PDD-NOS (n = 84)</td>
<td>Structured clinical interview</td>
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<td>Tsakanikos et al. (2006)</td>
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<td>Bipolar Disorder</td>
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<td>Anxiety</td>
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<td>Wing (1981)</td>
<td>Clinic sample of young adults with Asperger syndrome (n = 18 aged over 16)</td>
<td>Clinical interview</td>
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consideration is the impact of severity of ASD or ID; for example, Jang and Matson (2015) indicated that, in children and adolescents with ASD, increased ASD symptom severity is correlated with increased comorbidity and a review by Underwood et al. (2010) indicates a relationship between severity of ID (IDSev) and limited adaptive and social skills with comorbid mental health disorders.

The literature regarding prevalence of psychiatric disorders comorbid with ASD is subject to several significant challenges and limitations. First, there is no consensus regarding the assessment or diagnostic practices used to examine comorbid psychiatric disorders amongst adults with ASD. Methods used include file review, structured clinical interview, comorbidity assessment instruments or a combination of these methods (Underwood et al., 2010). Variability in methods may be due to ASD being a heterogeneous disorder (Volkmar and McPartland, 2014) occurring both with and without ID, therefore, different assessment approaches are required to take account of the range of presentations. An additional concern is that the majority of research into comorbid mental disorders amongst adults with ASD has focused on those without IDs, and has investigated only the most frequently occurring disorders, anxiety disorders and depressive disorders (Matson and Cervantes, 2014), with a small number of publications also exploring Bipolar Disorder. Finally, the majority of samples used in previous research were derived from psychiatric clinics rather than community settings (Tsai, 2014), which could have led to the reporting of inflated rates of comorbidity.

Anxiety and depression are common manifestations of emotion dysregulation, which has been identified as one possible explanation of higher rates of these disorders amongst adults with ASD (Mazefsky et al., 2013). ADHD is an important additional concern for this population as there have been high rates of ADHD reported in children with ASD, but limited research on rates in adults (Sizoo et al., 2014). Developing a better understanding of the rates and nature of these particular mental health conditions in adults with ASD in the community is important for two key reasons: to inform support service providers of clients’ mental health needs, and to help psychiatric services develop effective assessment and intervention practices.

This study builds upon previous comorbidity research amongst adults with ASD by using a broad, community-based sampling strategy that has not been previously been utilised. Based upon the findings from previous studies of psychiatric comorbidity amongst adolescents and adults with autism it was hypothesised that: adults with ASD and ID would have significantly higher rates of comorbid anxiety, depression and ADHD than those with ID or ASD only, rate and pattern of these comorbidities would vary depending on the degree of ID, increasing with severity of cognitive impairment, and the rate and pattern of the comorbidities would vary depending on severity of autism symptoms, increasing with severity of ASD. The study, therefore, attempts to answer two research questions:

RQ1. Is there a difference in rates of anxiety, depression and ADHD between groups?
RQ2. Are scale scores for anxiety, depression and ADHD associated with severity of ASD or ID, across the whole sample?

Method

Data were obtained using structured file reviews and two psychometric screening instruments. The current study is part of a wider study of comorbid psychiatric disorders in adults with ASD in which file reviews were undertaken by the first author using a modified version of the Case Review Protocol from the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD) (Royal College of Psychiatrists, 2001). This enabled the systematic collection of data on participants’ gender, age, IDSev, current psychiatric diagnoses, support needs, living situation, psychological therapies and medication use.

Screening for comorbid psychiatric disorders was undertaken using both the Reiss Screen for Maladaptive Behaviour (RSMB) (Reiss, 1989) and the Autism Spectrum Disorder-Comorbidity-Adults (ASD-CA) scale which forms part of the Autism Spectrum Disorder Assessment Battery for Adults (ASD-A) (Matson and Boisjoli, 2008).
The ASD-A (Matson and Boisjoli, 2008) was selected as it is an ASD-specific comorbidity screening tool designed for adult populations, and preliminary research shows it has significant utility (LoVullo and Matson, 2009; Matson and Williams, 2014b). It also has the added advantage of providing an ASD symptom severity measure (ASD-Diagnostic Adults Scale (ASD-DA)), in addition to comorbid psychopathology screening, enabling the influence of ASD symptom severity to be examined. Matson and Boisjoli (2008) reported robust psychometric properties for the ASD-DA. $\kappa$ coefficients for interrater reliability ranged from 0.30 to 0.77 with an average $\kappa$ for all items of 0.43. For test-retest reliability $\kappa$ values were in the range of 0.35 and 0.92 with an overall average of 0.59. Internal consistency was determined by computing KR-20 coefficients for the entire scale and each factor. Overall, the scale had a KR-20 value of 0.91, which is within the acceptable range of 0.70–0.95 defined by Terwee et al. (2007).

The RSMB was selected because it has been extensively used in previous studies and also has strong psychometric properties, with good internal reliability ($\alpha = 0.80–0.90$), test-retest reliability of 0.84 and inter-rater reliability at 0.86 (Sturmey et al., 1995; Sturmey and Bertman, 1994); and it has been used in a number of studies involving adults with a variety of developmental disabilities, including those with autism without ID (Ghaziuddin et al., 1995), providing a degree of conferred validity for this population.

Both the ASD-CA and RSMB give an overall total score and a range of subscale scores, and both also have clinical cut-off scores for total and subscale scores. This study reports on the ASD-CA total scale scores and subscale scores for anxiety, depression and ADHD, and the RSMB total score and the behavioural and physical symptoms of depression subscales.

Participants

Participants were receiving support services from one of three non-government organisations (NGOs). They were selected if they met criteria for the three diagnostic groups being studied, were over 18 years old and were living in the community. The three diagnostic groups included: ASD + ID ($n = 31$), AS/HFA ($n = 15$), and ID ($n = 22$). All participants in groups 1 and 2 had previous formal diagnoses of autism made by a psychiatrist or clinical psychologist. A range of methods had been employed including clinical judgement, standardised assessment tools and, for a small number of younger participants, multi-disciplinary assessment. As all diagnoses were made before 2013, they used DSM-IV criteria. Diagnosis and ID level for each participant was confirmed by reviewing diagnostic reports when undertaking the Case Review Protocol.

Ethical approval

Ethical approval was given by the Lower South Island Health and Disability Ethics Committee, approval number LRS/09/06/EXP. This is a regional committee of the New Zealand Health and Disability Committees, which are ministerial committees established under section 11 of the New Zealand Public Health and Disability Act.

Procedure

The screening instruments were completed by either the first author or a clinician who worked for two of the NGO service providers and had been trained in administration of the screening tools by the first author. Screening included rating participants using direct observation and by interviewing an informant who had known the individual for at least three months. Consistency in rating was examined through screening of ten participants (14.6 per cent) being completed by the first author and one of the trained clinicians, with agreement between raters being 83 per cent.

Data/statistical analysis protocol

Full scale and subscale scores were analysed using SPSS V22 for the total sample and the three main sample groups, AS/HFA, ASD + ID and ID. A one-way between groups ANOVA was used as the primary test of significance for all scale and subscale scores.

Two further variables were created to allow meaningful statistical analysis of the influence of ASD symptom severity and degree of ID, using Pearson’s $r$ correlations. ASD-DA scores, which are a
measure of the number of ASD symptoms present, were used to evaluate the impact of autism symptom severity on comorbidity. IDSev was ranked from 0 to 3, based on diagnostic data ascertained from file reviews, with 0 = no ID, 1 = mild ID, 2 = moderate ID and 3 = severe or profound ID.

In addition, the percentage of participants scoring above the clinical cut-off was calculated for total score and subscale scores for both the ASD-CA and RSMB.

All statistical testing carries a risk of Type I and Type II errors occurring. Completing multiple tests of significance on the same data set increases the likelihood of Type I family-wise errors and typically the Bonferroni method is used to control for this. However, the standard Bonferroni method has been described as overly conservative (Eichstaedt et al., 2013) and can potentially lead to the rejection of significant results. An alternative, the Holm–Bonferroni method (Abdi, 2010) has been proposed and was used to provide adjusted p-values in the current study. The p-values for the ANOVA results were treated as one series and the p-values for the ASD/ID severity correlations as a separate series as they were answering two different research questions. The Holm–Bonferroni method involves first ranking the p-values for each test from smallest to largest. The critical value α for each test of significance is adjusted with the general formula: adjusted α = α/(k−rank +1) (where α is the critical value for tests of significance, in this study α = 0.05; k = the number of planned tests; rank = the ranked position of each test ranked in ascending order of calculated p-values). This process stops as soon as the nth-ranked p-value exceeds the nth adjusted α.

In respect of the six planned ANOVAs, the critical value for the test with the smallest calculated probability (rank = 1) would be adjusted as: adj. α = 0.05/(6−1+1) = 0.008; for the second ranked test adj. α = 0.05/(6−2 + 1) = 0.010; for the third adj. α = (6−3 + 1) = 0.0125 and so on. Similarly, for the eight planned correlations, the critical value for the test with the smallest calculated probability (rank = 1) would be adjusted as: adj. α = 0.05/(8−1 + 1) = 0.006; for the second ranked test adj. α = 0.05/(8−2 + 1) = 0.007; for the third adj. α = (8−3+1) = 0.008 and so on.

Results are presented in the following sequence: first, the between groups ANOVA is reported as primary test of significance. Post hoc tests are then reported for any significant results. Finally, correlations between scale scores and ASD and ID severity are reported. Adjusted αs are reported for those tests in which the p-value is less than the adjusted α. The results of the one-way between groups ANOVA tests and the percentage of participants scoring above the clinical cut-off threshold for the ASD-CA and RSMB are contained in Table II.

Results

Total psychiatric comorbidity scores

A one-way between groups ANOVA was conducted to compare ASD-CA total scale scores across groups. There was no significant difference between groups for ASD-CA total score (F(2, 65) = 2.21, p = 0.118) or RSMB total score (F(2, 65) = 0.03, p = 0.974).

<table>
<thead>
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<th>Table II</th>
<th>Between groups ANOVA and percentage above the clinical cut-off threshold for all sample groups</th>
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<td>Between groups ANOVA</td>
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<td>ASD-CA</td>
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<td>Total scale score</td>
<td>2.21</td>
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<tr>
<td>Anxiety</td>
<td>5.35</td>
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<td>ADHD</td>
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<td>RSMB</td>
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<td>Total scale score</td>
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<td>Depression (Beh)</td>
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<td>Depression (Phys)</td>
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There was no statistically significant correlation between ASD-CA total score and either IDSev ($r = 0.140, p = 0.253$) or ASD-DA score ($r = 0.136, p = 0.269$) and no correlation between RSMB total score and either IDSev ($r = 0.068, p = 0.583$) or ASD-DA score ($r = -0.16, p = 0.194$).

**Anxiety**

A one-way between-groups ANOVA was completed to compare ASD-CA anxiety subscale scores across groups. The Holm–Bonferroni adjusted $\alpha$ was 0.010, meaning there was a significant difference between groups ($F(2, 65) = 5.35, p = 0.007$). Post hoc comparisons using the Tukey HSD test indicated that the mean for those with AS/HFA was significantly greater than the ASD + ID group ($M = 1.17, p = 0.006$) and the ID group ($M = 0.95, p = 0.044$), but there was no significant difference between the ASD + ID group and the ID group ($M = -0.22, p = 0.32$).

A small inverse correlation was found between ID severity and anxiety, $r = -0.27, p = 0.026$. There was no significant correlation between ASD-DA score and anxiety, $r = 0.111, p = 0.370$.

**Depression**

A one-way between groups ANOVA was conducted to compare rates of depression for those with ASD/HFA, ASD+ID and ID for both the RSMB Behaviour (DepBeh) and Physical (DepPhys) depression subscales. There were no statistically significant differences between groups for either RSMB DepBeh ($F(2, 65) = 0.02, p = 0.981$) or DepPhys ($F(2, 65) = 0.06, p = 0.941$) subscales.

There was no correlation between ID severity and RSMB DepPhys ($r = 0.04, p = 0.725$) or DepBeh ($r = 0.05, p = 0.689$) subscales, or between ASD-DA score and RSMB DepPhys ($r = -0.05, p = 0.685$) or DepBeh ($r = -0.19, p = 0.115$) depression subscales.

**ADHD**

A one-way between groups ANOVA was completed to compare ASD-CA ADHD subscale scores. The Holm–Bonferroni adjusted $\alpha$ was 0.008, meaning there was a significant difference between groups ($F(2, 65) = 16.54, p = 0.001$). Post hoc comparisons using the Tukey HSD test indicated that the mean for those with ASD + ID was significantly different than the ID group ($M = 2.07, p = 0.000$) and the AS/HFA group ($M = 2.29, p = 0.000$). There was no significant difference between the AS/HFA group and the ID group ($M = -0.80, p = 0.925$).

There was a moderate positive correlation between ADHD subscale score and both ASD-DA score ($r = 0.43, p = 0.001$, adj. $\alpha = 0.007$) and IDSev ($r = 0.49, p = 0.001$, adj. $\alpha = 0.006$).

**Discussion**

This project examined comorbidity in relation to primary and secondary research questions:

**RQ1.** Is there a difference in rates of anxiety, depression and ADHD between groups?

**RQ2.** Are scale scores for anxiety, depression and ADHD associated with severity of ASD or ID, across the whole sample?

There were two significant findings in relation to differences in the rate and type of comorbid disorder between groups. The ASD + ID group had higher rates of ADHD symptoms and the AS/HFA group had higher rates of anxiety. However, there was no significant difference in total scale score between groups for either the ASD-CA or RSMB. There were also significant findings regarding the relationship between comorbidity and IDSev or ASD. Moderate, but significant, correlations were found between ADHD symptoms and both IDSev and ASD-DA score (as a measure of autism symptom severity).

Comorbidity of ADHD with ASD is of increasing interest to researchers and clinicians. In this study, participants with ASD + ID had statistically significantly higher scores for ADHD symptoms than participants with AS/HFA or ID, and none of the ASD + ID participants had a previous diagnosis of ADHD. Furthermore, no participants in the AS/HFA group scored above the clinical
cut-off and only 4 per cent of those with ID did, compared with 41.94 per cent of those with ASD + ID. Skokauskas and Gallagher (2012) found similar results (44.78 per cent) in children with autism and the results of the current study indicate that this disorder may continue into adulthood at similar rates as in childhood for those adults with comorbid ASD and ID. Further, it could be postulated that as autism severity increases, so does the likelihood of hyperactivity and impulsivity in those who have ASD + ID.

The two most commonly researched disorders which are frequently associated with ASD are anxiety and depression. In the current project, those with AS/HFA had the highest number anxiety symptoms, while those with ASD + ID and ID had similar levels of symptoms. Previous estimates of rates of anxiety disorders amongst adults with ID and ASD have tended to be higher than general population estimates, but have varied widely: White et al. (2005) found a prevalence of anxiety disorders of 14 per cent within a large community sample of people with IDs of all types ($n = 533$), Melville et al. (2008) found a prevalence of 3.9 per cent in a community sample of adults with ASD + ID ($n = 77$) and Bakken et al. (2010) found a prevalence of 33.9 per cent in a clinic sample of adults with AS ($n = 62$). The rates found in the current study (ASD + ID (35.48 per cent), AS/HFA (60 per cent) and ID (31.81 per cent)) show higher levels than previous research, though the pattern is consistent with Gotham, Brunwasser and Lord (2015) who found higher rates of anxiety in those with AS/HFA compared to those with ASD + ID. It should be emphasised that the current study examined symptoms of anxiety as opposed to diagnosed anxiety disorders, which may also explain the higher rates found. In clinical settings, differentiation between atypical presentations of anxiety seen with autism (Ung et al., 2013; Wood and Gadow, 2010), or separately diagnosable anxiety disorders is problematic, particularly so for those individuals who have limited or no verbal communication abilities. Although the point at which behavioural changes become diagnosable anxiety disorders remains unclear, the use of instruments such as the ASD-CA can assist in the diagnostic process.

The presence of symptoms of depression was similar across groups, with all groups having substantially higher rates than those reported in general population surveys. Our findings are consistent with Melville et al. (2008) who found no difference in rates of depression in people with ID, with or without ASD and with the high rates of depression found in Asperger syndrome (AS) (Joshi et al., 2013; Lugnegård et al., 2011), and ASD + ID (Bakken et al., 2010). The fact that depression is commonly comorbid with both ASD and ID is an important factor to consider in clinical assessment. Screening tools such as the RSMB or ASD-CA can be very helpful in ensuring that atypical symptoms are considered when assessing for depression in people with ASD.

The use of adjusted significance values in research where multiple tests are performed on the same data set is commonplace, and as with all statistical testing, there is a chance of error. However, the Holm–Bonferroni procedure has been shown to be robust way to protect against Type I error, which reduces the likelihood of discounting a potentially significant finding when compared to the standard Bonferroni procedure. The results from this study indicate that in this sample population there were between group differences in comorbidity and that there was a likely effect of both ASD and ID severity. It is possible that with a larger sample that other significant differences in full scale or subscale scores would have been or found between groups.

**Strengths and limitations**

This study has a number of strengths in comparison with similar studies. The study design, particularly the participant recruitment strategy, successfully attracted a broader community-based sample than previous similar studies. It was also methodologically rigorous, combining the administration of two screening instruments with a structured review of existing clinical and support service data. Finally, the inclusion of a group of adults with ID alone enabled a comparison of types and rates of disorder in people with ASD, both with and without the additional variable of ID, and also with a sample with ID but without ASD.

A limitation of this project is the relatively small sample size, particularly in the AS/HFA group. However, the availability of a formal diagnosis process for adults with ASD but no other cognitive impairments is limited in New Zealand. Whilst the final sample size for this group (15 participants) was considered a compromise, it was the best achievable in the region for which ethics approval was granted.
Conclusions

From a clinical perspective, this study adds to the body of evidence indicating that people with ASD are at increased risk of comorbid psychiatric disorders, particularly anxiety, depression and ADHD. When assessing people with ASD, mental health clinicians should screen for underlying psychiatric disorder before concluding that the presenting issue is attributable to ASD or just behavioural in origin. Additionally, the study shows evidence of the utility of two screening tools for the assessment of mental health problems in this population.

Two important implications for future research were identified. The current results indicate that differentiation between autism symptoms and anxiety disorder remains problematic. Recent neurobiological research suggests that underlying dysfunction may be common between autism symptoms and what are currently described as anxiety symptoms. In order to resolve this and provide effective guidance for clinicians and people with ASD, further research is required to assist differential diagnosis and to inform the choice of treatment.

A second area for future research is the relationship between ASD and ADHD. The results of this study indicate that adults with ASD + ID have a high prevalence of hyperactivity, impulsivity and distractibility; the more severe the autism symptoms, the more severe ADHD symptoms are likely to be. This warrants more rigorous study to identify both neurobiological cause, and effective treatment, as neither is fully understood at this point.

References


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Significant therapy events with clients with intellectual disabilities

Sarah Wills, Lorna Robbins, Tony Ward and Gary Christopher

Abstract

Purpose – The purpose of this paper is to explore significant events in psychotherapy with clients with intellectual disabilities (IDs).

Design/methodology/approach – Four therapy dyads, each consisting of one client and one therapist, were recruited. Following the brief structured recall procedure (Elliott and Shapiro, 1988), semi-structured interviews focused on helpful events in psychotherapy, using video of particular sessions as a stimulus to help prompt recall of that session.

Findings – Using interpretative phenomenological analysis, five super-ordinate themes were identified: “The Uniqueness of the Therapeutic Relationship”; “Using adaptations to Express Emotions”; “Client Behaviour/Therapist Behaviour”; “Hope and Paternalism”; and “Meaning-Making”. The results provide additional evidence that significant therapy events occur for clients with IDs. Furthermore, the research enabled insights to be gained about the process of therapy for this client group and for exploration of therapeutic factors that may be involved in facilitating a significant therapy event.

Research limitations/implications – This study highlights the need for therapists to work in such a way as to facilitate significant events in therapy. Whilst this study was a necessary first step, owing to the non-existence of research in this area, the sample size and qualitative design may limit any wider generalisation of the findings.

Originality/value – Significant events have not previously been explored in psychotherapy with clients with IDs. This research could therefore make an important contribution to our understanding of the process of psychotherapy for this client group.

Keywords Mental health, Interpretative phenomenological analysis, Intellectual disabilities, Qualitative, Psychological therapy, Significant therapy events

Introduction

Development of psychotherapy for people with intellectual disabilities (IDs)

People with a disability face a number of challenges, such as the physical or organic aspects of disability, attitudes from society and self-stigmatisation (Becket and Taylor, 2016). Furthermore, the Learning Disabilities Mortality Review Annual Report (Norah Fry Centre for Disability Studies, 2018) identified the persistence of health inequalities for people with IDs, highlighting the need for further action in order to meet the health needs of this client group. Additionally, people with IDs experiencing mental health difficulties have historically been excluded from psychotherapies due to their degree of intellectual impairment (Bender, 1993). However, research has shown that individuals with IDs can recognise and experience emotions in a similar way to the non-ID population (Bermejo et al., 2014); this indeed suggests that this client group has the ability to gain insight and develop self-awareness, factors that contribute to therapeutic change (Lacewing, 2014). Since the publication of the psychotherapy and learning disability report (Royal College of Psychiatrists, 2004), the evidence base has steadily grown, and substantial case study evidence exists for a number of psychotherapeutic approaches. Throughout this paper, psychotherapy has been taken to refer to all psychological approaches as follows.
Psychodynamic therapy addresses the unconscious content of a client’s psyche. By helping clients become aware and bring unconscious feelings into their consciousness, the aim is to alleviate psychological tension. Whilst case study evidence exists (Jackson and Beail, 2013), in a review of the evidence, Beail (2016) found no randomised controlled trials (RCTs); only one further controlled trial conducted by Birchard et al. (1996) was identified in which a significant increase in emotional development in the therapy group compared to the control group was found. Skelly et al. (2018) conducted an open trial of psychodynamic psychotherapy in which treatment fidelity was checked and cases excluded as appropriate. They found that clients did not improve while waiting for therapy and significantly improved while attending therapy; large pre-post effect sizes were reported, and improvements were maintained at six-month follow-up.

Another psychotherapeutic approach adapted for clients with IDs is cognitive behaviour therapy (CBT). CBT aims to help clients manage overwhelming problems by changing the way they think and behave in order to improve their mood (Beck, 2011). A growing number of case studies exist evidencing positive improvements for clients engaging in CBT (Wright, 2013). In a review of the available evidence for RCTs, Jahoda (2016) found only one, which was conducted by Willner et al. (2013); however, no reduction in scores of self-reported anger was found.

Cognitive analytic therapy (CAT) involves clients exploring the underlying causes of their current difficulties. In doing so, patterns of relating to others are identified, enabling the client to move forward by discovering ways of doing things differently. In a review of the evidence base, Beard et al. (2016) found over 25 published papers predominantly made up of either case studies or reflective essays. Very few of these papers reported outcome data and none contained pre-post data; however, some did report evidence of client change in revising relational patterns (Wills and Smith, 2010).

Mindfulness and acceptance-based therapies draw upon meditation and Buddhism. Rather than attempting to change particular thoughts or behaviours, the aim is for clients to change how they experience the world by bringing their awareness to the present moment through being curious and non-judging. In a review of the evidence, Gore and Hastings (2016) found, in addition to case studies, one RCT in which clients were randomised to either meditation intervention or to a waiting list control group (Singh et al., 2013). The authors found that physical and verbal aggression reduced to zero levels at six-month follow-up, with a large effect size reported; although this shows encouraging data, this was conducted at feasibility level, with further research required.

Dialectical behaviour therapy (DBT) provides support for clients who experience intense emotions in certain situations. DBT involves supporting the client to identify and build upon their strengths, as well as learning different ways of thinking. Lippold (2016) reviewed the evidence base and found case studies, with some reporting on outcome data in which improvements were evidenced (Lew et al., 2006). Studies reporting pre-post data are lacking. Morrissey and Ingamells (2011) reported preliminary outcomes based on six clients who showed significant reductions in distress; however, the fidelity of the model is questionable with the impact of medication not being separated out.

Furthermore, solution-focused brief therapy (SFBT), which involves maintaining a focus on achieving the client’s vision of solutions, has case study evidence available, with some reporting on outcomes (Rhodes, 2000); however, it is difficult to rule out other factors that may have contributed to reported improvements. Lloyd et al. (2016) found one published controlled trial in which a group of clients receiving six sessions of SFBT were compared to a control group receiving care as usual (Roeden et al., 2014); intervention fidelity was assessed, and cases were excluded as necessary. The SFBT group improved significantly compared to the control group, and improvements were maintained at six-week follow-up.

Thus, it is clear that such psychotherapies have been the focus of investigation, illustrating how they have been adapted in services for people with IDs. There is certainly a growing evidence base, and the level of evidence for psychotherapies varies from case studies for less established studies, to small scale RCTs. There are a few studies that demonstrate ineffectiveness, and the controlled studies that exist suggest that therapy is beneficial compared to waiting list and “treatment as usual”. However, for many psychotherapy approaches, the evidence is preliminary, and further research spanning a range of designs is required rather than a reliance on case studies.
**Significant therapy events research**

The term “significant therapy events” was first coined by Robert Elliott in the 1980s; these are the segments of individual therapy sessions, typically lasting between 4 and 8 min, in which clients experience significant moments of help or change. Significant therapy events are an important area to explore since the occurrence of such events during the course of psychotherapy is linked to positive therapy outcomes for the client. Rather than relying on participants’ memories during an interview, a method called brief structured recall (BSR) (Elliott and Shapiro, 1988) is often used whereby clients and therapists separately watch a video-recording of the therapy session in order to identify and reflect on any significant events during the therapy session.

In a review of the significant therapy events research within the non-ID population, Timulak (2010) found that research has focused on a range of factors including, type of events, match between client and therapist perspectives of events, and significant events in different therapies. The impacts of client-reported significant events focused on contributions to therapeutic relationship and therapeutic outcomes. Moreover, the review revealed the complexity of the process involved in significant events, highlighting the vital need to use a more creative methodology to explore the therapeutic process. Many examples have been given regarding the different types of therapy within which significant therapy events occur, including psychodynamic therapy and CBT. This, therefore, seems to provide further evidence for the presence of common factors (Wampold, 2015), whereby significant therapy events can be thought of as representing such common therapeutic factors, but in greater levels of concentration. Given the many benefits of investigating significant therapy events, it seems important to consider how such events may manifest during the course of psychotherapy with clients with IDs, since little is known about the process of psychotherapy with this client group and how positive change occurs.

**Significant therapy events research: involvement of clients with IDs**

Lloyd and Dallos (2008) explored the experiences of families who have a child with IDs. Seven families engaged in an initial appointment using SFBT. Along with completing the Helpful Aspects of Therapy (HAT) form, participants were interviewed using structured recall. The following three super-ordinate themes were identified: SFBT brought to mind the idea of “making the best of it”; examination of wishful thinking; and therapeutic relationship. This suggests, that even with a one session approach, the therapeutic relationship is a key therapeutic factor, and indeed, seems to be associated with client-identified significant therapy events. However, although the authors employed a methodology resembling some aspects of significant therapy events research, it only explored accounts of therapy from the client; by not interviewing the therapist, an important aspect of the process of therapy was not explored. Furthermore, whilst some of the initial sessions involved the child with IDs, the research interviews were conducted only with the mothers; therefore, the experiences of clients with IDs were not explored using the significant therapy events research methodology.

In a feasibility study by Burford and Jahoda (2012), clients with IDs engaging in CBT had their therapy sessions video-recorded. In a qualitative interview, clients were asked to review tapes of their fourth and ninth CBT session. Clients reported a number of helpful aspects of their therapy sessions, including: they can express themselves in sessions; they can say how they are feeling; and they feel understood. Again, this research did not specifically follow the significant therapy events methodology, since the interviews focused more generally on clients reviewing their therapy sessions, and therapists were not subsequently interviewed. It does, however, provide evidence that this approach to interviewing clients with IDs is feasible.

A further criticism of the studies by Lloyd and Dallos (2008) and Burford and Jahoda (2012) is the absence of situating the findings within an attachment theory framework, despite identifying the quality of the therapeutic relationship as a super-ordinate theme, and identifying emotional expression and feeling understood as helpful aspects. Indeed, although developed for parents and children, the Circle of Security ® model (Cooper et al., 2015) is similar to the psychotherapy process and the therapeutic relationship; by the therapist “being with” the client during their experience of emotions, the client can learn to trust, move on and feel less overwhelmed by their emotions. In order to develop more comprehensive understandings of the psychotherapy process for clients with IDs, attachment theory is undoubtedly an important theory to draw upon.
Aims

Hence, to date, no research could be found that explores how clients with IDs may experience significant events during psychotherapy. It has become clear from the research that the exploration of significant therapy events has made a vital contribution to furthering our understanding of therapeutic change and positive treatment outcomes for clients engaged in therapy. This creates huge potential in terms of implications for future practice with regard to psychotherapy with people with IDs. The aim of the current study is to examine client-identified significant events in psychotherapy and explore the lived experience of psychotherapy with clients with IDs.

Methodology

Research design

Taking a phenomenological theoretical stance to understanding significant events in psychotherapy, the research is concerned with meaning and the perspectives of the client and therapist participants. From this theoretical perspective, it was necessary to adopt a qualitative strategy; through following a longitudinal design, data were collected by conducting qualitative interviews with each participant on two separate occasions.

The HAT form was completed by client participants at the end of each therapy session. The HAT form is a self-report measure, developed by Llewelyn (1988) as a means for identifying helpful and hindering events in psychotherapy. Following consultation with individuals with IDs, this form was adapted by simplifying the language used, including visual images and making the Likert scales clearer. These adaptations were made to maximise the ease with which client participants could complete the form.

The BSR procedure (Elliott and Shapiro, 1988) was followed. This involved the researcher watching the video of the therapy session with the client and therapist separately whilst asking further questions about the session; the emphasis was placed on the client identifying events to be focused on. Two different interview schedules were used; for the client participant interview, an adapted version of the Client Event Recall Form (Elliott, 1986) was utilised, containing sections on the context of the event, the participant’s experience during the event, the most helpful things about the event and the impact of the event. For the therapist participant interview, an adapted version of the Therapist Event Recall Form (Elliott, 1990) was followed, containing sections on therapist event intentions and feelings, the context of the event and the impact of the event.

Participants

A purposive sampling procedure was used to recruit participants to the study. The inclusion criteria for client participants included: identified as having mild to moderate IDs; able to give informed consent; and over the age of 18 years. The inclusion criteria for therapist participants included: working in a community learning disability team; qualified or trainee psychologist, counsellor or therapist; minimum of one year’s experience of offering psychotherapy to clients with IDs, or transferable skills.

Four therapy dyads, each consisting of one therapist participant and one client participant, were recruited to the study. Client Participant 1 completed therapy, however, withdrew from the research study, and therefore completed only one research interview. All other participants took part in two research interviews each, giving a total of 15 transcripts for analysis.

Procedure

The study commenced, following a favourable opinion from the NHS Research Ethics Committee and approval from the Health Research Authority.

Therapists matching the inclusion criteria were approached and consented in the first instance. Participants were then asked to notify the researcher when they were due to start therapy with a client matching the inclusion criteria. For each therapy dyad, once the therapist had been identified and a possible client had been found, the therapist was requested to ask the client during their
assessment session if they were happy to be contacted by the researcher about a study; a consent meeting was then arranged between the researcher and the client before therapy was due to start.

All therapy sessions with each therapy dyad were video-recorded, and at the end of each session, the HAT form was completed by the client. By referring to the completed HAT forms, therapist participants were asked to select one session out of the first few sessions on which to focus the first interview. A qualitative interview was then scheduled with the client participant, and the therapist participant interview followed shortly afterwards. Later in the therapy, therapist participants were then asked to select one session out of the final few sessions on which to focus the second interview; similarly, a second qualitative interview was then scheduled with the client participant, and the therapist participant interview followed shortly afterwards. Therefore, two therapy sessions for each therapy dyad were included in the study.

In accordance with the BSR procedure, the researcher played the recording of the session to the client until the event was located; the client was asked to describe the context of the event, the event itself and its impact. In a separate interview, the researcher played the identified event for the therapist, asking them to describe the context of the event, their intentions during the event and its impact on the client. This data collection procedure was then followed for each therapy dyad for each of the selected sessions. Because of the focus on the participants’ perspective and the need for interpretation to make sense of their perspective, interpretative phenomenological analysis was selected to analyse the interview data. The following procedure described by Smith et al. (2009) was followed: initial case familiarisation by reading and re-reading the transcript; initial descriptive, linguistic and conceptual comments made in the right-hand margin; preliminary theme identification written in the left-hand margin; emergent themes developed; search for connections across emergent themes; continue the analysis with the other cases; and looking for patterns across cases involving further refinement of the themes into a master table of super-ordinate themes and sub-themes.

Results

A total of 5 super-ordinate themes and 11 sub-themes were identified from the analysis.

**Theme 1: the uniqueness of the therapeutic relationship** – “[...] I’m saying things now that I would never say to anyone [...]” (CP3)

The first super-ordinate theme encapsulates participants’ experience of the relationship they had with one another at the point of experiencing a significant therapy event.

**Sub-theme 1a: “To talk and be heard”.** Client participants seemed to be alluding to the therapeutic relationship in their narrative by exploring what it was like to talk to their therapist. One participant reported “[...] it was just nice to talk to someone outside the family, to talk to a stranger how I was feeling” (CP1). Another participant explained “[...] she listened to every single word um [...] if she didn’t understand what I was saying she normally asked me anyway ‘so you’re on about this or are you on about this’, so I’d be like ‘no it’s this’ or ‘it’s that’ ” (CP3).

**Sub-theme 1b: “Importance of building trust”.** Building trust with the therapist seemed to be key for enabling clients to talk more easily and freely. One participant reported “[...] now I know [therapist] I don’t get so anxious” (CP1). Another participant described “[...] as I get to know you I trust you and then that’s when I start letting stuff out” (CP4).

**Sub-theme 1c: “Walking in the client’s shoes”.** The use of empathy was also spoken about in terms of helping to build the therapeutic relationship. One participant reflected “[...] trying to understand that actually yes he has been through quite a lot and there are people that will can make you feel angry […]” (TP2).

**Theme 2: using adaptations to express emotions** – “I wanted [therapist] to see it” (CP4)

This theme reflects how client participants were able to express their emotions to their therapist, and how therapist participants focused on describing the adaptations they made in order for their client to communicate.
Sub-theme 2a: “The process of expressing emotions”. This sub-theme reflects the importance client participants placed on expressing their emotions. One participant described “Um […] get getting out how I was feeling off my chest” (CP1). Another participant spoke about drawing in their therapy session as a way of being able to express themselves “[…] sometimes I like just drawing on my own and have no-one see you, but obviously I want at that time I wanted [therapist] to see it” (CP4).

Sub-theme 2b: “The shift in emotions”. Client participants reflected on noticing a change in their emotions from beginning to end of the significant therapy event. One participant reflected “[…] I was really angry, really annoyed, really fed up and as I talking about it and talking how I felt and yeah I reckon it is leads up to what I’m talking about […] I felt more happier um […] coz I let it out my feeling […]” (CP3). Therapist participants seemed to become more attuned to their client’s emotions; “[…] he did seem pleased to be able to to realise that there was something he could do” (TP1).

Sub-theme 2c: “Making adaptations”. Therapist participants spoke about adapting the therapy to suit the needs of their client. One participant described “[…] so, I’m just looking at her drawing and I’m just saying I need to go with this because she’s trying to communicate something to me with drawing with the with this people and what’s happening to them that um […] that she can’t put into words […]” (TP4). Another participant reported “Um […] trying to give him time to speak” (TP3).

Theme 3: client behaviour/therapist behaviour – “[…] and she just started spontaneously drawing and I went with it” (TP4)

This theme illustrates the behaviours of the client and therapist during the time surrounding the significant therapy event.

Sub-theme 3a: “Focus on coping strategies”. Learning about coping strategies to manage difficult emotions was spoken about by all client participants. One participant described “Um […] talk about strategies and how to calm down by listening to music and things” (CP2). However, some participants spoke about some of the difficulties of using coping strategies outside of therapy and how their dependence on others sometimes made it difficult; “[…] I was like I couldn’t walk away from it because I had to wait for mum to give me a lift […]” (CP2).

Sub-theme 3b: “Therapist approach”. Therapist participants spoke about the type of approach they followed when working with their client. Participants seemed to allude to taking more of a client-led approach; “[…] we had been using the big paper for the maintenance cycles and she just started spontaneously drawing and I went with it” (TP4).

Theme 4: hope and paternalism – “I always think like maybe she’s telling me, I might be wrong here, that you are not alone […]” (CP3)

This theme encapsulates the tension between hope and paternalism, with client participants reflecting on their experience of having hope, whilst therapist participants alluded to the need to manage more of a beneficence/paternalism balance.

Sub-theme 4a: “The message of hope”. All client participants spoke about experiencing hope during their therapy. One participant reported “Um […] it was helpful what she said and how she um […] said to how to get round it and that’s when I thought ‘yeah’ […]” (CP2). Another participant reflected “[…] I always think like maybe she’s telling me, I might be wrong here, that you are not alone, maybe there is loads of other people out there who feel exactly the same […]” (CP3).

Sub-theme 4b: “Worry and protection”. However, in contrast, some therapist participants spoke about a need to protect their client; such responses could be likened to that of a paternal response. For instance, one participant reflected “I was worrying about the risk at the same time because when he feels very low he does self-harm […]” (TP3). Another participant reported “[…] it had been helpful so I wanted to kind of draw that out um […] draw out all the positives to help keep him safe […]” (TP1).
Theme 5: meaning making – “[...] I want to be here. I want to be with [partner] for the rest of my life” (CP1)

This theme refers to making sense of the significant therapy event as well as the impact of the event.

Sub-theme 5a: “Client realisation – the shift”. Client participants spoke about experiencing moments of change during therapy in which they noticed a shift in the way they appraised a situation or the way in which they viewed themselves. One participant described their thought changing: “That I want to be here […] I want to be with [partner] for the rest of my life. I want to be there for my mum, because my mum’s not well […]” (CP1). Perhaps because this meaning-making process appeared to be internal, Therapist Participant 1 perceived their client to be passive: “Um […] I think he’s being a bit more passive in this session than he has been in in the last few sessions […]” (TP1). Client Participant 4 alluded to experiencing some acceptance of themselves: “[…] coz obviously my disabilities, I can’t get rid of it, all I can do is try and beat it, which is what I have been doing […]” (CP4).

Discussion

The purpose of this research was to explore significant events in psychotherapy with clients with IDs. Indeed, the results suggest that clients with IDs do experience significant therapy events. Furthermore, the research enabled insights to be gained about the process of therapy for this client group and for exploration of therapeutic factors that may be involved in facilitating a significant therapy event. Significant therapy events have not previously been explored in psychotherapy with clients with IDs; however, it has been possible to make comparisons with research focusing more broadly on the experience of psychotherapy, as well as make comparisons with research carried out within the non-ID population.

Clients spoke positively about talking in therapy, but more specifically they reflected on being heard and understood by their therapist. Framed within attachment theory, people with IDs may be at a greater risk of developing insecure strategies through not having their needs met as children; for instance, being emotionally rejected by carers may make them likely to expect such rejection from their therapist or the receipt of intermittent care is likely to make them anxious as to whether they will be heard by their therapist. Therefore, being heard and understood could be thought of as a new encounter, that contrasts to their everyday lives in which interactions are frequently marked by a lack of reciprocity and the presence of power imbalances (Jingree et al., 2005). Indeed, therapy itself is also not balanced in terms of the power dynamics, and this is especially true for clients with IDs. Clients spoke at length about being able to successfully express their emotions, which supports the existing literature (Burford and Jahoda, 2012). Clients also spoke about receiving the message of hope from their therapist. However, only one previous study involving clients with IDs could be found that referred to clients experiencing hope; Pert et al. (2013) found clients to be cautiously optimistic about the outcomes of their therapy. The absence of hope in previous research could be a reflection of past literature not focusing on significant therapy events. Indeed, significant therapy events research within the non-ID population has found hope to be implicated (McVea et al., 2011). All clients in the current study reflected on the impact that the significant therapy event had on them, noticing a shift in the way they appraised a situation or viewed themselves. This is consistent with findings in Cahill et al. (2013), whereby helpful impacts, included “problem clarification” in which clients gained an understanding of what needed to change through working on it in therapy. However, because therapists in the current study were not always aware of this meaning-making process for clients, it seems it could sometimes be an internal process that clients are not able to articulate. Indeed, internal meaning making is different for clients and therapists (Yalom, 1989), and whilst shared meaning making may not be expected, finding ways to open up this dialogue where it relates to the client’s meaning making could be a fruitful area to explore in future research.

Therapists spoke about building a strong therapeutic relationship with their client; this supports the existing literature on working collaboratively (Lloyd and Dallos, 2008), showing clients empathy and remaining attuned to the client’s frame of reference (Balmforth and Elliott, 2012).
Making adaptations in order for clients to communicate and express their emotions was also focused on by therapists, which supports existing literature in which adaptations to therapy are described (Willner and Goodey, 2006). Referring to their therapeutic approach, therapists alluded to being client-led; in a similar way to person-centred approaches, therapists alluded to focusing on their client and the way in which they perceived their world. Although therapists spoke about wanting their clients to experience hope during therapy, they also worried about their client and felt a need to protect them. It seems that therapists may have been holding on to worry in order for their clients to experience hope.

**Implications for clinical practice**

This study highlights the need for therapists to work in such a way as to facilitate significant events in therapy with their clients through building a strong therapeutic relationship, making appropriate adaptations to ensure their clients can express themselves, being mindful about instilling hope, and adopting a client-led approach to provide opportunities for clients to use their initiative. It is notable that most clients noticed a shift in the way they appraised a situation or viewed themselves, and it is therefore important to open up conversation around the experience of change. In addition, to echo the implications of the research conducted by Skelly *et al.* (2018), it may be helpful to have more flexibility within therapeutic contracts to enable clients with IDs to have more sessions in order for a strong therapeutic relationship to be built, as well as providing the space for a client-led approach to foster client independence and moments of insight. Furthermore, therapists could use supervision to reflect on balancing empathising, protecting and helping in order to promote the process of empowerment.

**Limitations of the study**

Whilst this research was a necessary first step, owing to the non-existence of research in this area, the sample size and qualitative design may limit any wider generalisations of the findings. It is also noted that all client participants had mild to moderate IDs; it is therefore not known whether such findings would apply to people with IDs who are less able to express themselves. A further limitation of the study is that, whilst adaptations to the HAT form were necessary in order for clients to independently complete, it was not possible to quantitively determine whether these adjustments improved the quality of responses. Furthermore, clients completed the HAT form in the presence of their therapist, which may have made them reluctant to identify any unhelpful events. In addition, if time allowed, it could have been interesting to look at clients’ perceptions across the range of recorded sessions and their perceptions of where the most helpful aspects were, rather than focusing on their identified helpful event within the session selected by their therapist.

**Future research**

This study has highlighted the need for further research of significant therapy events with a larger sample of clients with different degrees of cognitive impairment. Furthermore, new areas to explore, include examining the relationship between therapists holding worry during therapy sessions, while clients seemingly receive the message of hope. In addition, future research should seek to examine the internal meaning-making process for clients. If more were known about this process, therapists could become more aware of it and adopt strategies for exploring this change process with clients, which would be likely to strengthen the therapeutic relationship, indicate the direction that therapy sessions could helpfully take to meet client goals and improve therapy outcomes. It would also be important to thoroughly investigate the efficacy of a client-led approach and quantitively measure its impact on the prevalence of significant therapy events and therapy outcomes by means of an RCT.

**Conclusion**

The current findings provide additional evidence that significant therapy events occur for clients with IDs. Furthermore, the findings also support Bender’s (1993) critique of the historic
exclusion of people with IDs from accessing psychotherapy; indeed, the “therapeutic disdain” towards people with IDs has an increasingly questionable evidence base. In addition, using the significant therapy events methodology was shown to be feasible with this client group, and enabled insights to be gained about the process of therapy for clients with IDs, as well as exploration of the therapeutic factors that may be involved in facilitating a significant therapy event.

References


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“We can feel good”: evaluation of an adapted DBT informed skills programme in medium security

Sarah Ashworth and Natalie Brotherton

Abstract

Purpose – The purpose of this paper is to provide a routine evaluation of clinical effectiveness of an adapted DBT informed skills programme (“I Can Feel Good”; Ingamells and Morrissey, 2014), run on both male and female intellectual disability wards of a medium security psychiatric hospital.

Design/methodology/approach – A pre–post evaluation study of routine clinical practice was undertaken utilising staff report scales collected as the primary source of evaluation.

Findings – Findings show a positive shift regarding each module for both gender groups. Due to observed baseline differences between gender groups, data were separated and analysed separately. Non-parametric statistical analysis demonstrates statistically significant improvement across three modules for the male sample (managing feelings, coping in crisis and people skills) and two modules for the female sample (managing feelings and people skills).

Originality/value – There appears to be subtle outcome differences regarding this programme for both gender groups across modules. Potential reasons for this are discussed, along with clinical reflections regarding gender differences and adaptations. Reflections upon future revisions including the integration of the new DBT skills (Linehan, 2014) are made in light of these findings.

Keywords Intellectual disability, Mental health, Learning disability, Psychology, Forensic, Adapted dialectical behaviour therapy

Paper type Research paper

Introduction

This paper aims to provide an evaluation of routine effectiveness regarding the application of a skills-based programme designed for people with intellectual disability (ID) and difficulties managing emotions, run on male and female wards within a medium secure environment. It aims to address the question “does a skills programme adapted from the mainstream actually have any impact on skills and behaviour”.

Dialectical behaviour therapy (DBT)

DBT was developed by Marsha Linehan in an attempt to create an effective treatment for suicidal women presenting with such complex symptomatology (Linehan, 1993). Linehan reviewed literature exploring the efficacy of psychosocial interventions for multiple disorders (including anxiety and mood disorders) and concluded such evidence-based interventions were typically focused upon changing cognitions and behaviours. She identified that these approaches engendered the feelings of criticism, misunderstanding and invalidation which resulted in high attrition rates.

Patients diagnosed with borderline personality disorder (BPD) are particularly complicated to treat (Linehan, 1993). Such patients display high dropout rates, show little responsiveness to typical therapeutic attempts and make significant emotional demands of the therapist, particularly when they display suicidal and para-suicidal behaviours.
In an attempt to remedy this, Linehan considered inclusion of a dialectical philosophy within her treatment, whereby therapists attempt to synthesise acceptance and change-oriented strategies. This was intended to introduce the communication of acceptance and to encourage the patient to accept themselves, in addition to teaching the changed based principles of CBT. This she termed DBT (Linehan, 1993).

The standard DBT treatment package consists of four primary modes. This includes weekly individual therapy sessions lasting 1 h, a weekly 2 h group skills training session (containing four modules of mindfulness, emotion regulation, distress tolerance, and interpersonal effectiveness), a weekly 2 h therapist consultation team meeting and telephone contact (out of hours telephone contact with the therapist). Within inpatient treatment settings, a fifth treatment mode can also be considered, the development of a therapeutic milieu (Ashworth, Otter and Summers, 2017).

A systematic review highlighted that findings suggest that DBT in inpatient settings may have some effects in reducing symptoms related to BPD (Bloom et al., 2012). This was notwithstanding substantial discrepancy in the arrangement and length of DBT implementation for inpatients with BPD.

Reviews such as the Bloom et al. (2012) paper demonstrate that there is a growing body of research which demonstrates that DBT is an effective treatment for BPD and related problems (e.g. Linehan et al., 2006; McMain et al., 2009). As such, DBT is the recommended psychological intervention for women diagnosed with BPD and suicidal behaviours (The National Institute for Health and Care Excellence, 2009).

**DBT for ID**

Traditionally, interventions for ID populations have focused upon behavioural approaches (Sturmey, 2004). The lack of psychological exploration has been attributed to several factors including a general lack of interest in this population (Stenfort Kroese, 1998), queries regarding cognitive capabilities (Sturmey, 2005) and perhaps more concerning, therapeutic disdain (Taylor et al., 2008) and perceptions of unattractiveness (Bender, 1993).

However, more recently, research supporting the efficacy of “talking therapies” has become more prevalent within ID populations (Beail, 2016). This has included reviews of interventions such as psychodynamic psychotherapy (Beail, 2016), cognitive behavioural therapy (Jahoda, 2016) and most notably, third wave approaches such as mindfulness-based interventions (Gore and Hastings, 2016) including DBT (Lippold, 2016). This is in line with recommended practice as The National Institute for Health and Care Excellence (2009) guidance states that those with comorbid diagnoses of ID and BPD should have access to the same services as other people with BPD, which includes, as stated previously, DBT.

Literature evidencing the effectiveness of adapted DBT programmes specifically for ID populations appears to be growing. Lew et al. (2006) highlight individuals with ID are likely to have experienced the invalidating upbringing coupled with a biological predisposition outlined by the bio-social theory of DBT and, therefore, may be an appropriate intervention. However, research is limited and often focuses upon people who present with offending or challenging behaviours (Lippold, 2016). This includes case studies within secure environments (Dunn and Bolton, 2004; Ashworth, Mooney and Tully, 2017).

Chapman et al.’s (2013) systematic review highlights the effectiveness of mindfulness-based interventions (such as DBT) with ID populations regarding the reduction of aggression over a medium-long-term period. However, the authors acknowledge methodological limitations as the quality of many of the studies was rated as weak due to small sample sizes, sample’s differing cultural backgrounds or severity of ID, and lack of information regarding intervention.

From a review of the literature, there are limited studies which explore the effectiveness of adapted DBT within ID populations. Additionally, there are methodological limitations acknowledged with each which must be taken into account when discussing results. Lew et al. (2006) reported a gradual reduction in self-harm in women with ID and BPD following the completion of an adapted DBT programme; however, this reduction was slow. Sakdalan et al.’s (2010) pilot study of an adapted DBT for an ID population described the results as promising.
Brown et al. (2013) developed an adapted DBT-based skills programme which was most effective in reducing challenging behaviour in ID populations for individuals who were younger, had BPD and displayed self-harm or aggression, in a four-year longitudinal study. Perhaps, one of the most well-known adapted DBT informed group-based skills programme is that developed by Catrin Morrissey and Bridget Ingamells. The I Can Feel Good programme originally developed and delivered at high secure, which has shown promising results with male ID populations (Morrissey and Ingamells, 2011). A relatively recent systematic review (McNair et al., 2017) highlighted the work services are doing, adapting DBT for individuals with intellectual disabilities, across a range of settings. It must be considered that due to methodological limitations, evaluations of such programmes are limited in their ability to draw firm conclusions regarding intervention effectiveness. However, several studies highlight promising initial outcomes in addition to reflection upon clinical application and informative detail regarding adaptations. However, despite initially promising results, all studies acknowledge the small scale nature of such research, and the need to further explore adapted DBT programme’s effectiveness with ID populations (Lippold, 2016).

For those familiar with DBT, it may be apparent that the majority of the content is not suited to ID populations (Lew et al., 2006). Such examples include complex terminology, reliance upon acronyms for key concepts and written behaviour and emotion diaries. These are known potential areas of difficulty for ID populations (Willner, 2009). Whilst the structure, philosophy and target hierarchy approach may still be applicable, the content and delivery methods may need modification. Adaptations may include renaming skills modules (as with the I Can Feel Good programme; Ingamells and Morrissey, 2014), inclusion of more pictorial information, repetition of content and increased use of role plays. The application of supported role-play within psychological treatments has been advocated to facilitate the application of skills to everyday life which is a known potential difficulty for individuals with ID (Brown and Marshall, 2006).

Additional considerations, such the inclusion of staff and/or carers within the programme has been shown to increase the therapeutic progress of those with ID (Rose et al., 2002, 2005). In addition to this benefit, Lindsay et al. (2013), who advocate the importance of homework within many structured psychotherapies but highlight the potential difficulties regarding understanding and recall in ID populations, suggest that the inclusion of staff or carers to facilitate the completion of such tasks may support implementation of skills developed during the programme. All such adaptations may increase DBT’s effectiveness with ID populations, but as such, may decrease the programme’s adherence to formal DBT (Linehan, 1993) and, therefore, limit the ability to generalise findings.

The current study attempted to evaluate routine effectiveness of the adapted DBT informed group-based skills programme, the I Can Feel Good group (Ingamells and Morrissey, 2014), delivered on both male and female wards. This DBT informed skills programme was based upon the DBT skills group structure and principles, containing four modules (mindfulness, managing feelings, coping in crisis and people skills) mirroring the original content with skills adapted for ID populations. These groups ran separately but using the same format and manual and as such can be compared. The study’s aim was to provide a pre-post evaluation study of routine clinical practice. There is limited statistical analysis, as this study presents an initial evaluation and aims to make comment upon the therapeutic progress. Recommendations regarding possible future research are highlighted.

Methodology

Design

In order to evaluate routine effectiveness of the adapted DBT informed group-based skills programme, a pre-post comparison within groups design was utilised.

Participants

The module sizes ranged from 10 to 12 patients across two groups. Attendance was relatively consistent; however, natural attrition occurred due to patient progress. The numbers of participants for whom there were completed pre-intervention and post-intervention measures varied across the measures, ranging from a low of four to a high of seven; however, there was a
core of regular attenders across all modules for each of the male and female groups. Actual numbers per measure is reported in Tables I and II. All patients were detained under the Mental Health Act (1983) within a medium secure psychiatric hospital and all patients had a primary diagnosis of Mild ID with comorbid psychiatric diagnosis including mental illness, autism spectrum disorder and personality disorder.

**Intervention**

The I Can Feel Good group (Ingamells and Morissey, 2014) is an adapted DBT informed group-based skills programme. It contains four adapted modules which are: mindfulness (which aims to teach the skill of paying attention in the moment); managing feelings (which aims to teach the skills to recognise and manage emotions); coping in crisis (which aims to teach the skills to manage immediate distress); and people skills (which aims to teach communication skills, skills in relationships and assertiveness). Two separate programmes ran across two wards (male and female) facilitated by one qualified psychologist and healthcare workers who had received training in the “I Can Feel Good” group delivery (Ashworth et al., 2016). Both programmes lasted approximately 14 months, including breaks, and covered all four modules.

**Materials**

There is a lack of psychometric instruments developed and validated (Hogue et al., 2007) in addition to the associated issues with self-report (Finlay and Lyons, 2001) within ID populations. Due to this, the decision was made to develop staff rating scales as the primary source of evaluation. This was to provide a template to score the degree to which identified goals were achieved over the course of a specific treatment or intervention for an individual patient. They contained items which were standardised and rated on a consistent level, developed by the assessor.

The scales were developed regarding the treatment goals for each module and each domain was rated prior to commencing and post completion of each module. These were rated jointly by programme facilitators. The rating scale ranged from "Absence of (appropriate) skill in attitude or

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<tr>
<td>Mindfulness</td>
<td>6</td>
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<tr>
<td>Managing feelings</td>
<td>7</td>
</tr>
<tr>
<td>Coping in crisis</td>
<td>5</td>
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<tr>
<td>People skills</td>
<td>5</td>
</tr>
</tbody>
</table>

Note: *p < 0.05
behaviour Or Extremely unskilled” (0) to “Extremely skilled behaviour consistently, displaying insight and appropriate attitudes” (4), with a rating of 0 given for “Lacking of skill in attitude or behaviour”. The following domains were included regarding each module in the following list:

1. Mindfulness:
   - judging thought processes;
   - evidencing judgements behaviourally;
   - attention span;
   - impulsive behaviour; and
   - awareness of emotion mind states.

2. Managing feelings:
   - emotional intensity and liability;
   - label emotional experience;
   - communicate emotional experience;
   - emotion control;
   - emotional experiencing; and
   - explosive/impulsive behaviour.

3. Coping in crisis:
   - tolerance of distress;
   - acceptance of reality;
   - explosive or impulsive outbursts;
   - finding meaning for distress; and
   - using skills to cope.

4. People skills:
   - assertiveness;
   - interpersonal problem solving;
   - relationship maintenance skills;
   - recognition of own needs;
   - situational analysis skills; and
   - goal determination.

Results

Total scores for all participants were calculated for both pre and post each module. Data were then entered into SPSS-20 for analysis.

It was noted that the baseline scores varied considerably across groups, resulting in bimodal distributions. As such the groups were not comparable as combined statistics would not be representative and the decision was taken to analyse the group separately. Following a Kolmogorov–Smirnov test, it was apparent that data were not normally distributed, due to this, and the small sample sizes, data were analysed non-parametrically utilising related samples Wilcoxon signed rank tests (Field, 2013). These figures were then analysed statistically and are presented in Tables I and II for female and male groups, respectively.

No significant difference was found between pre and post mindfulness module scores, for both female and male samples.
A significant difference was found between pre and post managing feelings module scores, for both female and male samples.

A significant difference was found between pre and post coping in crisis module scores for the male sample. However, there was no significant difference between pre and post coping in crisis module scores for the female sample.

A significant difference was found between pre and post people skills module scores, for both female and male samples.

Discussion

This paper initially set out to provide an evaluation of routine effectiveness of an adapted DBT informed skills programme (“I Can Feel Good”; Ingamells and Morrissey, 2014), run on both male and female ID wards of a medium security psychiatric hospital. However, due to observed baseline differences, data were separated by gender and analysed separately. The benefits and limitations of this approach are later discussed. There appears to be subtle outcome differences regarding this programme for both gender groups across modules and comment is made regarding this.

Although preliminary, the findings from the statistical analysis overall are promising, with statistically significant improvement across three modules for the male sample (managing feelings, coping in crisis and people skills) and two modules for the female sample (managing feelings and people skills). However, neither gender showed statistically significant improvement in scores following the mindfulness module.

When we examine the scores, there appears to have been a positive shift regarding each module for both genders. The lack of significant results may be attributable to the small samples sizes due to the need to separate both groups due to baseline differences and subsequent lack of statistical power (Field, 2013). However, there appears to be subtle differences regarding outcomes regarding this programme within our two gender groups across the different modules. There may be clinical benefit in exploring potential reasons for these differences and similarities, in addition to considering clinical reflections and potential for future adaptations to increase effectiveness for varying populations.

The statistically significant findings regarding the managing feelings and people skills module suggest that the programme is effective in facilitating positive therapeutic change in both genders. This suggests that there is potential therapeutic benefit in delivering these modules of the adapted DBT skills programme in secure forensic services for males and females.

A gender difference is highlighted in the coping in crisis module outcomes, with males demonstrating a significantly positive shift from pre to post scores. Factors measured included distress tolerance, acceptance, impulsive outbursts, finding meaning in distress and application of coping skills. This gender difference may be attributable to different support seeking methods, with females tending to use more passive methods to whereas males tend to use more direct actions to solve their problems (Folkman and Lazarus, 1980; Stone and Neale, 1984). This may be attributable to the socialisation and reinforcement (Gilligan, 1982; Petersen et al., 1991) of certain characterstics for males (e.g. valuing autonomy and independence, viewing change as a challenge and being problem-oriented) and others for female (e.g. valuing social relations, responding to change in a resigned withdrawn way). As the programme was originally developed for efficacy within a male population, these factors may have led authors to include strategies tailored to a more stereotypically male style. As such, this approach may have integrated well with the more proactive, skills-based coping styles held by the male group members.

Despite the growing evidence suggesting the potential efficacy of mindfulness-based interventions with ID populations (Chapman et al., 2013; Hwang and Kearney, 2013), this study found that the mindfulness module was the least effective in engendering therapeutic change for both genders. It is acknowledged that mindfulness is essentially an abstract concept and, therefore, potentially inaccessible to individuals with ID due to difficulties with nonconcrete
ideas (Gore and Hastings, 2016). Therefore, the lack of any significant change following this module may have been attributable to insufficient material adaptation. Future adaptations may ensuring simple clear, and brief language is used throughout, adequate experiential exercises and concrete examples are utilised and additional mindfulness practice materials are developed as guided by the literature regarding increasing mindfulness interventions efficacy with ID populations (Chapman and Mitchell, 2013).

As previously stated, due to potential validity issues with self-report measures in ID populations (Finlay and Lyons, 2001), staff report scales were developed to measure therapeutic change. However, problems may have arisen when attempting to measure inherently internal constructs, such as inner experiences, thought processes and mindfulness. The lack of evidence for the effectiveness of the mindfulness module may, therefore, be attributable to problems with the measurements developed within the study.

However, when we examine the figures, although both gender groups improved, the pre to post module change was greater in the female ($\Delta = 0.75$) than the male sample ($\Delta = 0.13$). As this research is not completed in a therapeutic vacuum, we must acknowledge the constellation of interventions and treatments provided to patients at any one time. It would be impractical and possibly unethical to control all other sources of support and therapy. Alongside the I Can Feel Good programme, a timetable which included a mindfulness group was running concurrently which some of the female patients attended. This may have been a source of education, reinforcement and modelling of the mindfulness skill for the female patients, which the males were not provided, perhaps creating the greater change observed. However, it must be reiterated that this change was not statistically significant.

The lack of statistically significant change may also be attributable to the lack of repetition of the mindfulness module within the I Can Feel Good programme, as with the original DBT programme (Linehan, 1993, 2014). This may inform future development of the programme to include more of a focus upon repeating the key concepts of mindfulness throughout the programme or potentially developing an additional optional mindfulness booster module to increase effectiveness.

As it has been noted with much of the research examining the efficacy of adapted DBT programmes with ID populations (Lippold, 2016), especially female populations (e.g. Lew et al., 2006), the sample sizes reported here are small and potentially lack the power to draw generalisable and firm conclusions. The decision was taken not to combine the two groups’ data, which would have created a larger more powerful sample, due to observation of the differing baselines across the two genders. However, an attempt has been made to compare and contrast these groups, highlighting some interesting differences across gender group which warrant further exploration with larger, more representative samples from which statistical analysis may provide more insight from which more firm conclusions can be drawn.

Regarding the evaluation methodology, future research may attempt to utilise outcomes measures previously validated with ID populations which are found to be relevant to the treatment aims of the programme. This may increase the generalisability and reliability of the results obtained from a programme evaluation. It may also be beneficial to involve an independent clinician who was not involved in the development or delivery of the programme, to score each group member pre and post each module to ensure potential bias was limited. Additional sources of information could be sought for future evaluation, scales such as the Clinical Outcomes in Routine Evaluation – Learning Disability (Brooks et al., 2013) may be appropriate in addition to the assessment of behavioural data. Furthermore, no measure of readiness was obtained during this process which may have benefited subsequent conclusions drawn from the findings and should be taken into account in future research as has been done with the University of Rhode Island Change Assessment Scale in clinical practice (DiClemente and Hughes, 1990).

As DBT was originally developed for application with females diagnosed with BPD (Linehan, 1993), the majority of the evidence base regarding the effectiveness of DBT focuses upon female populations. It, therefore, seems surprising that conversely, the evidence base regarding and adapted DBT programmes, such as the I Can Feel Good programme (Ingamells and Morrissey, 2014), focuses mainly upon male populations. Despite the growing literature regarding the
experiences of females within inpatient mental health, there is a paucity of literature exploring women with ID in such settings (Fish, 2013). Hellenbach et al. (2015) also highlight the paucity of research regarding specific service provision for female offenders with ID and additional mental health needs. The I Can Feel Good programme was developed and piloted within a male high secure setting (Ingamells and Morrissey, 2014), with props, examples and pictorial aids being focused upon a male population in mind (e.g. pieces of armour, “Henry’s head”). These may not have transferred easily to a female population. However, attempts were made to ensure relevance and applicability of all examples provided to the patient mix; however, efforts to maintain treatment adherence may have limited this.

Of the research which has been reviewed within the introduction, three publications’ samples included female participants. Lew et al. (2006) is the only study reviewed here which reports a purely female sample; however, this is limited to a sample size of 8. Sakdalan et al.’s (2010) study reported one female (out of a sample size of six), and Brown et al.’s (2013) longitudinal study with a larger sample of 40 participants, contains five females. Additionally, both case studies reported previously focus on male cases (Dunn and Bolton, 2004; Ashworth, Mooney and Tully, 2017). This is perhaps attributable to the forensic focus of the research, which is heavily weighted towards male populations in general (Lippold, 2016).

Considering the promising outcomes in light of the limitations of the current programme and its evaluation, this paper has sought to reflect upon future revisions of the I Can Feel Good programme, including the integration of the new DBT skills (Linehan, 2014) and future evaluation. Future adaptations of the I Can Feel Good manual should acknowledge the more varied application of the intervention including more diverse populations across genders, and settings, and as such provide more varied examples and resources for tailored, gender specific application.

References


Further reading


About the authors

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