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Two ACT for ID Case Studies

Two cases of Acceptance and Commitment Therapy leading to rapid psychological improvement in people with intellectual disabilities

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Conflict of Interest

None

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Two ACT for ID Case Studies

Two cases of Acceptance and Commitment Therapy leading to rapid psychological improvement in people with intellectual disabilities

Purpose

The purpose of this paper is to show that Acceptance and Commitment Therapy (ACT) may have utility with this client group in routine clinical practice.

Design/Methodology/Approach

This uncontrolled double case study describes the targeting of ACT processes with people referred to a mental health service for people with intellectual disabilities because of distressing intrusive thoughts. It includes qualitative data to illustrate the opinions of the participants eight weeks after the end of therapy.

Findings

Both clients described rapid relief from distress, with some additional untargeted benefits emerging too. The participants provided follow-up qualitative data in which they described how the therapy had helped them as well as areas where it had not.

Research limitations/implications

This paper presents uncontrolled case studies selected from routine clinical practice. They were selected due to their similarity of outcome and will not represent the experience of every client treated this way.

Practical Implications

The practical implications are that a therapy often considered to rely on the use of metaphors and the manipulation of complex metacognitions may be useful for people with more limited verbal and cognitive ability if the therapy is adapted to meet their level of ability.

Originality Value

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There has been very little published on using ACT with an intellectual disabilities population. This paper has originality value in that it illustrates the application of the approach in routine clinical practice. Additionally the qualitative follow-up allows the participants' voices to be heard about their experience of this approach.

Keywords

Acceptance and Commitment Therapy

ACT

Relational Frame Theory

Mindfulness

Defusion

Anxiety

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People with ID experience psychological distress at least as much as the typically developing population (Buckles, *et al.*, 2013). A recent review document prepared for the British Psychological Society (Beail, 2016) identified that while evidence is beginning to be gathered for a number of therapeutic orientations, the literature is not as yet clear which approach is best suited to which presentations in this population. The review notes that evidence continues to come predominantly from routine clinical practice and that clinicians in the field should be “aspirational and seek opportunities to expand our research efforts” (p.206) and that innovations and adaptations should be evaluated as they are applied. One such innovation for this client group would be the application of Acceptance and Commitment Therapy.

ACT (Hayes, Pistorello and Levin, 2012, Hayes, Strosahl and Wilson, 2012) is a “third wave” behavioural therapy (Hayes, 2004) that has attracted a growing number of studies over recent years (Hooper and Larsson, 2015). ACT is an explicitly behavioural psychotherapy, drawing upon operant principles of verbal language acquisition and rule governance for theoretical support, principally Relational Frame Theory (RFT, Hayes *et al.*, 2001). The ability to relationally frame appears to correlate positively with performance on tests of cognition (Pelaez *et al.*, 2013). Furthermore training in RFT skills can lead to increases in cognitive ability in typically developing participants (Cassidy *et al.*, 2010, 2011). This suggests that there is a link between these two constructs, and by this notion, people with ID may also demonstrate a reduced ability to relationally frame.

Within ACT, ongoing psychological distress is understood to be a result of verbal processes that become inadvertently reinforced and overly dominant by the sufferer’s determination to not experience them. In other words, what would otherwise be a transient reaction to an environmental stimuli (a thought, memory, feeling etc) becomes, through its participation in verbal networks, functional for avoidance, distress, and emotional pain. Unlike most psychotherapies, which characterise distress as a deviation from healthy normality, ACT regards suffering to be universal and an almost inevitable consequence of the ability to use language. This universality of suffering makes it a transdiagnostic theory and therapy, and the ACT model has been applied successfully to an array of different issues (Hooper and Larsson, 2015). Success, in an ACT sense, does not equate to symptom reduction. ACT seeks to

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change the relationship of the individual to their own private events such that they are more able to pursue a life in accordance with freely chosen values. Symptoms may well reduce as a consequence of a life filled with more valued experiences, but it is a by-product, not the goal. The goal is to enhance a construct called psychological flexibility, which has been defined as “contacting the present moment as a conscious human being, fully and without defence, as it is and not what it says it is, and persisting or changing in behaviour in the service of chosen values” (Hayes, Pistorello, & Levin, 2012; p.985). Psychological flexibility is considered to be a unitary construct, but can for pragmatic purposes be considered as six interconnected and manipulable processes (Blackledge, 2015).

Six core processes associated with ACT

1. Present Moment Awareness

Present Moment Awareness is the ability to attend to what is going on around you and within you, often achieved through mindfulness exercises.

2. Defusion

Defusion is the ability to interact with private events as something your mind and body are giving you in that moment, not as things with a literal truth that needs to be acted on accordingly.

3. Acceptance

Acceptance is the ability to react to aversive private events in an embracing, welcoming way that allows them psychological space.

4. Self as Context

Self as Context is a complicated process to describe briefly but can be conceptualised as a way of positioning your psychological self such that you are able to adopt a perspective from which it is possible to view all of the events of your life as things that have happened *to* “you” but that are distinct from this “you-as-observer” position.

5. Values

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Values are freely-chosen, desirable, life directions that can be used as a guide for behaviour – they are open-ended so have an orienting function rather than being goal-directed.

6. Committed Action

Committed actions are simply behaviours taken by the person in the service of their values; steps in the right direction.

ACT typically seeks to effect change through the therapeutic application of metaphor, paradox, metacognitive processes, and counterintuitive advice around turning towards distress (Hayes, Pistorello and Levin, 2012, Hayes, Strosahl and Wilson, 2012). Many of these elements are cognitively complex and for the client require the sophisticated use of verbal language. For clients who are less cognitively and verbally able, ACT interventions may require significant adaptations to better meet their needs.

ACT and Intellectual Disability

There are theoretical reasons why it may be worth considering ACT as a therapeutic approach with the ID population (Hoffmann *et al.*, 2016). Positive Behavioural Support (PBS) and ACT both emerged from the behaviour analytic tradition (Gore *et al.*, 2013; Hayes, 2015), and are therefore closely aligned in their philosophical and theoretical assumptions. When people with ID are referred into services, both PBS and ACT see the current problematic position of the person with ID as both functional and as being as a result of behaviour that has been reinforced, not as due to problems or disorders within the person. Both models seek to improve quality of life, not to reduce behaviour that challenges (as in PBS), or to reduce symptoms of distress (as in ACT). Additionally, the therapeutic stance in ACT sees distress as a normal part of having verbal language and holds that there is nothing inherently different between the therapist and the client except for perhaps the degree of distress (Hayes, Strosahl, and Wilson 2012). This stance could be potentially helpful and acceptable for a group of people who have historically experienced stigma and discrimination (Gore and Hastings, 2017).

Despite the potential utility of this therapeutic approach, the published evidence base for using ACT with people with intellectual disability is small. Indeed as far as can be

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ascertained, there are only three published papers (see reviews by Robertson, 2011, Harper *et al.*, 2013; Hwang and Kearney, 2013; Leoni *et al.*, 2015; Gore and Hastings, 2016; Singh *et al.*, 2017).

Pankey and Hayes (2003) presented a case study of a young woman with intellectual disability and psychosis. She had a reported full-scale IQ of 58 as measured by the WAIS, which would be categorized as mild by ICD-10 classification standards (World Health Organization, 1992). The woman resided in an intensive supported living environment with 24-hour staff support to assist her with activities of daily living. Pankey and Hayes (2003) described a four session ACT intervention which produced increased medication compliance (the targeted outcome) and non-targeted improvements in sleeping, eating, and the dismantling of appliances.

Jackson Brown and Hooper (2009) reported an ACT intervention with a young woman who was presenting with anxious and obsessive thoughts. She had a reported full-scale IQ of 44 (moderate ID; WHO, 1992). The intervention was based on an ACT protocol which required adaptation to meet her needs. She experienced a reduction in distress as a result of therapy.

As there was no published evidence after 2009, a recent paper by Boulton *et al.*, (2018) is timely and welcome. Boulton and colleagues presented the results of a feasibility study in which six adults with ID participated in a six-session manualised intervention using photography to help them to clarify their values. The authors reported that using photography as a basis for identifying and reflecting on elements of importance in people's lives was well received by those participants who completed the programme.

The current paper

This paper outlines two case studies in which psychological improvement was described by individuals with intellectual disabilities; seemingly as a result of clinicians targeting a small number of core ACT processes (defusion and present moment awareness), although subsequently bolstered by others.

A note on the cases

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These two cases were simply routine clinical referrals and were never intended *a priori* to be presented to the wider field. The reader will accordingly note a lack of experimental control and of quantitative data. Formally measured IQ scores are not available for either client as access to specialist services was not contingent on a prior diagnosis of ID but rather based on pragmatic decisions using clinical information. It was not considered ethically appropriate to ask the two women to complete cognitive assessments purely for the purposes of this paper. Both women held diagnoses of mild intellectual disability based on clinical judgments of ability and level of support needed at time of referral. The cases are presented due to the rapidity of change following interactions with ACT-informed clinicians at initial assessment sessions, and are enhanced by the qualitative data given by the two clients at follow-up.

Follow-Up and Qualitative Data

Approximately eight weeks after their final sessions, the clients met with one of the authors who was at that time a trainee clinical psychologist and who had not been part of any of the previous intervention phases and who did not know any details of the therapy. The meetings lasted around 30 minutes and consisted of semi-structured interviews with the focus being “to see if you have found [the intervention] to be helpful in your progress.” Responses were written verbatim and subsequently reviewed for elements consistent with increasing psychological flexibility, i.e. could they be mapped on to the core ACT processes.

Anonymity

Both clients gave consent to have their cases presented as case studies, and both chose the pseudonyms used to ensure their anonymity. Biographical and identifiable details have been changed to protect client confidentiality.

Case Study 1: Nicola

Nicola was a 39-year old woman with a diagnosis of mild intellectual disability, living in a shared independent supported living (ISL) home in the community. The ISL had 24-hour support staff.

History

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Nicola had had a two-year history of intrusive thoughts that she would get angry, lose control and stab someone with a kitchen knife. She had not disclosed these worries to anyone until she attended a routine review meeting with her psychiatrist, during which she was asked if she had any thoughts that were bothering her. She disclosed her fears around stabbing people, and this led to the rapid imposition of risk management procedures that included revoking her access to kitchen knives, and the loss of her favourite job within her home (peeling the vegetables). She subsequently lost her supported part-time job preparing sandwiches in a local care-home kitchen, on the grounds of her being too high a risk to others.

Case Conceptualization

Although Nicola's problems were initially considered to be around anger, on investigation it seemed that she rarely got angry because she was afraid of what would happen if she did; i.e. that she would lose control and stab people.

The understanding was that Nicola had found herself trapped in a cycle of worrying about thoughts. As is the nature of intrusive thoughts, she found that the more she tried to push them away, the more they would reappear. She would increasingly spend her time monitoring her own mind to see if she was thinking these horrible thoughts, and of course she always was.

Before disclosing to her psychiatrist, she had found respite from the thoughts when she was actively engaged in her work doing food preparation in the kitchen. Unfortunately when she lost this job and was also prevented from preparing food in her home, the result was that she had little to do except check whether she was having her distressing thoughts and worry about them when she had them.

Formal risk assessment showed that Nicola had had access to sharp knives for her whole life, but had never lost control and used them against anyone. Indeed she was distressed by the presence of these thoughts. She had twice held a knife to her stomach during rows with her mother, some years previously, but did not hurt herself on these occasions. If Nicola had a history of physical aggression or assaultive behaviours, and especially if she had a history of using weapons, the formulation would have differed accordingly. As she did not have such a history, the

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understanding was that she was in a state of distress caused by fears about her own thoughts.

Intervention

Nicola was helped to defuse from her thoughts and was then taught some present moment awareness skills: focused attention on an object, focused attention on her breath, and focused attention on the sounds around her. These skills were supplemented with psychoeducation about the nature of thoughts, reinforcement of the moves she made towards valued living, and specific work with the system of support staff around her, who were fused with their own thoughts of Nicola being dangerous and untrustworthy.

Course of Treatment and Assessment of Progress

Nicola was offered an initial consultation clinic appointment (in which the above formulation was developed), followed a month later by six weekly home visits. At the initial consultation clinic, facilitated by two clinical psychologists and an assistant psychologist (see Selman and Oliver, 2018, for a description of the consultation clinic model) Nicola described the thoughts she had been struggling with. As the previous hour had been spent untangling Nicola's problem as one of "anger", the psychologists present reacted with surprise when it emerged that she actually never allowed herself to become angry and never showed anger.

This surprise showed itself with the psychologists saying to Nicola, in an impromptu, but nevertheless targeted ACT intervention "oh you have *thoughts*. We have thoughts too!" This led to a conversation with Nicola in which three people with titles of "psychologist" and "doctor" shared with Nicola that sometimes unpleasant and unacceptable thoughts occurred to them also.

When one of the authors met with Nicola again at her first individual session nearly four weeks later, she said she had not been bothered by the distressing thoughts at all since the clinic. She was able to point to a number of positive changes she had spontaneously made to her life as a consequence - she reported that her relationship with her mother had improved, she had been taking regular exercise; going to the gym

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and going out running. She had lost some weight and was feeling positive and relaxed. She had signed up to do a sponsored run to raise money for charity.

Within the ACT model this could be understood as a spontaneously enhanced level of psychological flexibility, following the defusion intervention. The subsequent intervention involved bolstering this by teaching Nicola a number of mindfulness / present moment awareness techniques, the aim of which was to enhance her ability to catch her thoughts and to experience them as “minds doing what minds do” and not something that she had to engage with unless she wanted to. Nicola was taught three present moment awareness exercises; focused attention on an object (the “raisin exercise”), focused attention on the breath, and focused attention on the sounds around her. These exercises were repeated in each of the six sessions, and a staff member usually a different one each time, was present in each one and took part in the exercises.

Systemic considerations

Staff continued to harbour evaluations of Nicola as dangerous, and were themselves fused with *their* thoughts that she was a highly dangerous and untrustworthy individual. Sessions therefore incorporated some orientation to the concept of thoughts-as-thoughts. One useful staff-level intervention was to engage staff in conversations about whether they had ever had thoughts about winning the lottery and quitting their job. All staff confirmed that they had. They were asked to reflect on how it would feel if they turned up for work on Monday morning to be met with surprise by their manager and be told that they’d been let go and replaced because they’d had thoughts about not coming in. This exercise was helpful in bringing staff into contact with the consequences of treating “thoughts” as reflections of reality.

Nicola was given her job back preparing sandwiches and regained access to kitchen knives in the home, despite the reluctance of some of the staff.

Qualitative data

Qualitative data provided by Nicola eight weeks after the end of therapy provided insights into how she had found the intervention more and less useful. Her reports can

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be mapped onto some of the core ACT processes, some of which were directly targeted, others more emergent:

Defusion

“[Clinician] has helped a lot he said “Nicola they are just thoughts, nothing bad” and I felt at ease. I asked “why am I getting them?” and he said “we are human, we are meant to get them” but it is horrible when they come”.

Present Moment Awareness

“[Clinician] came to see me and gave me some relaxing things to do. He told me to shut my eyes and listen to the world going on outside and if a bad thing comes into your mind hit your back and go back to what you are thinking. This one I’ve not done as much, it was not very helpful, I don’t know why, but I have done the other one more ... Shut my eyes, and imagine a room with lots of noise, block it out and think of something else, something good, and that helped”.

“One day I was sitting outside doing it and one of the staff said what is she doing? (Nicola then demonstrated the mindfulness exercise using an object) I was doing this, looking at it, touching it and noticing how smooth it is, and that seemed to work. One time I was sitting with my bare feet touching the carpet and one of the staff said “what’s she doing, that’s weird.” I came to and told them I was doing one of my mind things. I’ve started to go to my bedroom more at night to have “me time” and chill out”.

“(Was it important for staff to know about these exercises?)

Yes because they look [at me] and think it looks a bit strange”.

“One day [clinician] brought raisins and I had to study it and feel it and think about the softness and the colour and then put it in my mouth and bite it.

(What did you like about this?)

I got a raisin!”

Values and Committed Action

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“Me and my mum are getting on now, my attitude with her has changed and I am happier and help her more”.

Case Reflection

This case was noteworthy for how quickly and effectively a defusion intervention could provide relief from intrusive distressing thoughts in an adult with ID. She was able to defuse from difficult thought content much quicker than her staff who remained to varying extents fused with their own thought content around her being dangerous and a high risk. This highlights the importance of involving staff members in ACT work to the fullest extent that this is possible. ACT incorporates many counter-intuitive interventions and messages, such as the importance of being open to experiences, even if they are momentarily unpleasant. It is important that staff are somewhat familiar with this, as the dominant message they will be communicating at other times is likely to run counter to this – “push the thought away”, “distract yourself”, “have medication to make yourself feel better”. In this case (and even though many of the staff had participated in Nicola’s sessions) Nicola appears to have felt that staff regarded her mindfulness practise as weird and felt self-conscious enough to not want to engage in practise around them.

This qualitative data also raises issues around language and how it is used and received when working therapeutically in this way. In Nicola’s description of a mindfulness instruction, she said “if a bad thing comes into your mind hit your back and go back to what you are thinking”. In this case this was a misunderstood invitation along the lines of “when you catch that your mind has wandered, or when thoughts pop into your head, *pat yourself on the back* (i.e. congratulate yourself) and bring your attention back to your breath”. This at least is easily interpreted... it is not immediately clear what Nicola was referring to when she said “shut my eyes, and imagine a room with lots of noise, block it out and think of something else, something good”. This appears to refer to the “focused attention on the sounds around you” exercise, but misinterpreted with a clearly ACT-inconsistent message.

Case Study 2: Kelly

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Kelly was a 28-year old woman with diagnoses of mild ID, reduced mobility, epilepsy, and auditory verbal hallucinations. She lived with her husband and father who also acted as carers. She had no paid support staff involved.

History

Kelly discussed a situation in which due to her mobility problems, she tried out a mobility scooter. She rode it once round the estate and that night had a seizure. She thought that the vibrations from the mobility scooter had set this off and had found supporting evidence on the internet that this can happen. Since then she had had fears that vibrations of different types could set seizures off, and experienced auditory verbal hallucinations (AVH) which warned her not to do particular things for the same reason. Her auditory verbal hallucinations had been present from about age 15 and she described hearing them nearly every day for the previous 13 years. They commented on things around her that could hurt or threaten her. They bothered her less when she was around other people or was busy.

Kelly's epilepsy was generally well-controlled, and according to her father she averaged one or two seizures a year. When Kelly first met with one of the authors she described her hopes for therapy that it would be like tablets to remove her anxieties.

Case Conceptualisation

Kelly described a situation in which she was troubled by auditory hallucinations that told her not to do certain things as they were likely to trigger a seizure. Interestingly, her response was to do the thing anyway. Consequently she found it hard to outline any areas in which her life had become restricted as a result of her fears, with the exceptions of no longer using the mobility scooter (which she had decided she didn't want anymore) and the settings on her mobile phone (which she kept on a low-volume instead of vibrate). In all other areas, from worries about buses, to doing the hoovering, she confronted her fears quite spontaneously and her life was not unduly affected as a consequence. Kelly had her own excellent formulation of her problems; she understood the process as worries leading to voices, which circled back and lead to more worried thoughts. Her presenting problem therefore appeared to be the intrusiveness of her thoughts and voices.

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Intervention

Kelly was taught some present-moment awareness exercises designed to help her to change her relationship with her thoughts. The exercises were the same as those described in Nicola's case; focused attention on an object, focused attention on the breath, and focused attention on the sounds around her.

Course of Treatment and Assessment of Progress

Kelly required only three sessions in all, the first two a week apart, with the third following after a natural break of three weeks due to holidays.

Kelly experienced immediate improvement from the mindfulness techniques. In session two she reported that she was no longer troubled by thoughts that she would trigger a seizure. Quite unexpectedly, she had generalised this skill to an area that had not been directly trained: she found that this defusion and distancing was also effective in dealing with her voices. She described mindfulness as being the most effective technique she had found of managing her voices in all the time she had heard them.

As Kelly was no longer troubled by the voices, she was no longer concerned that she was going to have seizures.

Her father described how when they are out together, she would typically link his arm for support and he could usually feel her hand clenching with anxiety. He said he had noticed she hadn't been doing that since she started with the mindfulness exercises.

Kelly maintained her initial gains at three-week follow-up, with her father declaring that he was "over the moon" with her. At several points throughout the session Kelly pointed out to her father when *he* expressed a pessimistic or negative viewpoint - "that's just a thought". She was encouraged to continue to apply this same level of skill to her own negative or troubling thoughts.

Qualitative Data

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Qualitative data provided by Kelly can be mapped onto some of the core ACT processes:

Present Moment Awareness and Defusion

Dad – “the mindfulness has done her the world of good”.

(Kelly described the exercises that she had found helpful) “looking at raisins, and noticing things that I have not noticed before, like looking at the dog.”

“I also look at the bubbles when I am doing the dishes. If the voices come I say “no thank you, not today”, and I focus on different things”.

Dad: “She used to squeeze my hand because she was anxious, but she isn’t anxious anymore. She sits and looks at the fish; that helped her, she sat and noticed it as if it was for the first time”.

Kelly: “When the voices come on I do that for about 5 minutes and then they go away”.

Dad: “She says to the voices “go away, I’m busy at the moment” and it is very rare now that she mentions the voices”.

Values and Committed Action

Kelly: “I’m seeing my dad more now”.

Dad: “She is more confident and outgoing now. She stayed in a hotel and wasn’t frightened. We also went to Edinburgh zoo”.

A review of subsequent entries in our shared electronic patient record noted that she was still reporting symptom relief when reviewed in clinic by other colleagues some months later; eight months after her final session her psychiatric review identified that she was no longer hearing voices and she was discharged from mental health services soon after.

Case Reflection

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This case represents another indication that targeting ACT processes associated with enhancing psychological flexibility may be helpful for adults with intellectual disabilities. This case saw a generalisation of these skills to an untargeted domain; auditory verbal hallucinations. Kelly had had a thirteen year history of hearing voices and indicated that they were complicit in her anxieties in this case example specifically, but in other worries more generally. Through the bolstering of defusion skills aimed at thoughts, Kelly generalised to other private events leading to a reduction in believability and distress associated with the voices in the short term, and ultimately (according to psychiatric review eight months later) to the cessation of her auditory verbal hallucinations altogether.

Kelly also demonstrated that she could recognise cognitive fusion in others; telling her father when he was talking about his own anxieties that he was talking about “just thoughts, dad”.

Overall Discussion

These two cases were chosen for consideration because they share a rapid course of improvement as a result of ACT interventions. The two cases therefore raise a number of issues for consideration and discussion.

Nicola experienced immediate relief from a two-year history of intrusive and distressing thoughts about stabbing people with knives following a defusion intervention in which clinicians normalised the ubiquity of unpleasant private events and the lack of control humans have over them. She found that her support staff were more fused with *their* thoughts about *her* thoughts than she was which delayed her ability to make changes that could move her in the direction of valued living, but she made changes .

In Kelly’s case, a single session targeting defusion through experiential present moment awareness exercises provided relief from distress from intrusive thoughts, which generalised to other distressing private events in the form of Auditory Verbal Hallucinations. Kelly was not reliant on paid carers and was therefore freer to make values-consistent changes to her life and she subsequently maintained her level of

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improved wellbeing and was discharged from mental health services altogether eight months later.

The inclusion of follow-up qualitative data illustrates the areas of therapeutic influence from the clients' own perspective, shows which messages were learned well, and which ones took on an idiosyncratic form.

Theoretical Implications

ACT typically relies heavily on the use of metaphor to enact cognitive-behavioural change, it also draws upon sophisticated concepts regarding the relationship between people and their inner world that are initially counter-intuitive. This therefore presents a challenge to clinicians who wish to work in a way that is consistent with ACT principles with adults with intellectual disabilities; metaphor, sophisticated language and subtle reconsiderations of a person's inner world are likely to be more difficult for people with ID.

And yet, ACT considers human suffering to be ubiquitous and universal (Hayes *et al.*, 2012); *not* ubiquitous and universal only for people of typical cognitive abilities. ACT, drawing as it does on Relational Frame Theory, understands human suffering and distress to be universal because of the ability for verbal language to have functional effects due to participation in complex verbal networks. If there is the ability to relationally frame, then the theory suggests that distress is unavoidable. ACT therefore cannot apply only to people with an IQ of 70 and above. For ACT to be theoretically consistent it has to be applicable to people with more limited verbal ability. If ACT is the process of exploring how verbal processes have debilitating functional effects over the individual while helping them move to a more helpful psychologically flexible place using and developing the individual's own abilities, then working with people with more limited verbal repertoires could be potentially informative.

Clinical Implications

The first clinical implication of this work is that it supports and extends the small evidence base that ACT can be an effective intervention with adults with ID (Pankey & Hayes, 2006; Jackson Brown & Hooper, 2009, Boulton *et al.*, 2018). In particular if

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a person with ID is complaining predominantly of troubling and distressing thoughts, in the absence of any particular avoidant or safety behaviours (like Kelly) then ACT interventions targeting defusion should be a consideration.

Secondly, the other major component of an ACT approach is to make conscious changes in your life to be more consistent with valued living. People with ID face a challenge in this regard as they are frequently under the care of paid and unpaid people, are reliant on others to facilitate their access to things, and may find that their wishes are incompatible with the systemic requirements of their commissioned services. In other words, people with ID have fewer opportunities to be their own agents of change, and rely on others to facilitate it, either actively or by not obstructing it. Change was more rapid for Kelly possibly because she did not have to overcome risk-averse service provision. Nicola by contrast, did have paid carers and it was more difficult for her to recommence areas of her life that she valued but had no access to, and as noted, she defused from her own private events much quicker than her support staff were able to. People with ID under the care of services may therefore require more systemic thinking from the clinician, and some work with the staff will almost certainly be needed.

Limitations

This is case study material, selected due to the similar responses to seemingly common intervention elements. There were no attempts at experimental control in this, and there is no implication that all clients respond similarly, indeed it is the unusual rapidity of the change that links the cases and makes them theoretically and clinically interesting. The implications of the cases are limited to these clients in these settings. Although the clinicians involved felt that they were targeting ACT processes, it is difficult to know whether it was the ACT elements that facilitated change. While “symptoms” seemingly reduced, this is not the goal of ACT, but at present it is impossible to track changes in psychological flexibility as there are no adapted and accessible measures of this construct suitable for an ID population. This will be discussed further below.

Caution is also due around the qualitative interviews. Although care was taken to have them conducted by a colleague who had not been involved in the cases, both the

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clients and the interviewer were aware that the authors found these cases to be interesting. It was therefore not fully blinded and could potentially be open to bias.

Future research

There is a certain coherence between deliberately targeting elements of psychological flexibility and the subsequent psychological improvement seen, but symptom reduction is not the purpose of ACT (Herbert *et al.*, 2015), and at present there are no measures of psychological flexibility that are adapted for the ID population. Future research could involve the development of such a tool, which may be useful both for routine clinical practice and to enable more confidence to be had in future research with this population.

It would also be useful to consider what it was about the cognitive processes demonstrated by these two women that made them such seemingly quick responders to defusion interventions while other people remain fused with their private content despite much more intensive efforts. It is possible that for some people with ID, they have a long history of being corrected by the community about things they have misunderstood and are therefore potentially less fused with being the notion of being “right”. It is possible that they were therefore relatively open to the possibility of changing their mind on the basis of input from trusted professionals.

Conclusion

ACT is considered a transdiagnostic model of psychological distress (Herbert *et al.*, 2015), yet it has attracted little research attention in adults with ID. This paper represents only the fourth published consideration of ACT for ID and how it can be adapted. Two cases were discussed that showed improvement as a result of interventions targeting core ACT processes, particularly defusion and present moment awareness. Outcomes were encouraging, suggesting that change (sometimes very rapid) is possible when applying ACT to adults with ID who are in psychological distress, particularly if the distress is due to intrusive thoughts. More research is required into the processes of change.

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References

- Beail, N. (2016), *Psychological therapies and people who have intellectual disabilities*. British Psychological Society, Division of Clinical Psychology. London, UK.
- Blackledge, J.T. (2015), *Cognitive Defusion in Practice: A Clinician's Guide to Assessing, Observing, and Supporting Change in Your Client*. Context Press, Oakland, CA.
- Boulton, N.E., Williams, J. and Jones, R.S. (2018), "Intellectual disabilities and ACT: feasibility of a photography-based values intervention". *Advances in Mental Health and Intellectual Disabilities*, Vol. 12 No.1, pp.11-21.
- Buckles, J., Luckasson, R. and Keefe, E. (2013), "A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003–2010". *Journal of Mental Health Research in Intellectual Disabilities*, Vol. 6 No.3, pp.181-207.
- Cassidy, S., Roche, B. and O'Hora, D. (2010), "Relational Frame Theory and human intelligence". *European Journal of Behavior Analysis*, Vol 11 No.1, pp.37-51.
- Cassidy, S., Roche, B. and Hayes, S.C.. (2011), "A relational frame training intervention to raise intelligence quotients: A pilot study. *The Psychological Record*, Vol. 61 No.2, pp.173-198.
- Gore, N.J. and Hastings, R.P. (2016), Mindfulness and acceptance-based therapies. *Psychological Therapies and People Who Have Intellectual Disabilities*. British Psychological Society, Leicester, pp.44-54.
- Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, J.C., Baker, P., Hastings, R.P., Noone, S.J. and Denne, L.D. (2013), "Definition and scope for positive behavioural support". *International Journal of Positive Behavioural Support*, Vol.3 No.2, pp.14-23.
- Harper, S.K., Webb, T.L. and Rayner, K. (2013), "The effectiveness of mindfulness-based interventions for supporting people with intellectual disabilities: a narrative review". *Behavior Modification*, Vol. 37 No.3, pp.431-453.
- Hayes, S.C. (2015), *The Act in Context: The Canonical Papers of Steven C. Hayes*. Routledge, Hove.

Two ACT for ID Case Studies

- Hayes, S.C. (2004), "Acceptance and Commitment Therapy, Relational Frame Theory, and the third wave of behavioral and cognitive therapies". *Behavior Therapy*, Vol. 35 No.4, pp.639-665.
- Hayes, S.C., Barnes-Holmes, D. and Roche, B. eds. (2001), *Relational frame theory: A post-Skinnerian account of human language and cognition*. Kluwer Academic/Plenum Publishers, New York, NY.
- Hayes, S.C., Pistorello, J. and Levin, M.E. (2012), "Acceptance and Commitment Therapy as a Unified Model of Behavior Change". *The Counseling Psychologist*, Vol. 40 No. 7, pp.976-1002.
- Hayes, S.C., Strosahl, K.D. and Wilson, K.G. (2012), *Acceptance and Commitment Therapy: The process and practice of mindful change*. The Guilford Press, New York, NY.
- Herbert, J.D., Forman, E.M. and Hitchcock, P. (2015), Contextual Approaches to Psychotherapy. In: R. Zettle et al., eds. *The Wiley Handbook of Contextual Behavioral Science*, John Wiley & Sons, Chichester, pp.287-302.
- Hoffmann, A.N., Contreras, B.P., Clay, C.J. and Twohig, M.P. (2016), "Acceptance and commitment therapy for individuals with disabilities: A behavior analytic strategy for addressing private events in challenging behaviour". *Behavior Analysis in Practice*, Vol. 9 No. 1, pp.14-24.
- Hooper, N. and Larsson, A. (2015), *The research journey of Acceptance and Commitment Therapy (ACT)*. Springer.
- Hwang, Y.S. and Kearney, P. (2013), "A systematic review of mindfulness intervention for individuals with developmental disabilities: Long-term practice and long lasting effects". *Research in Developmental Disabilities*, Vol. 34 No. 1, pp.314-326.
- Jackson Brown, F. and Hooper, S. (2009), "Acceptance and Commitment Therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts". *Journal of Intellectual Disabilities*, Vol. 13 No. 3, pp.195-201.
- Leoni, M., Corti, S. and Cavagnola, R. (2015), "Third generation behavioural therapy for neurodevelopmental disorders: review and trajectories". *Advances in Mental Health and Intellectual Disabilities*, Vol. 9 No. 5, pp.265-274.
- Pelaez, M., O'Hora, D., Barnes-Holmes, D., Amesty, L., & Robinson, K.K. (2013), *Performance on WAIS-III Relates to the Ability to Derive Relations*. Retrieved

Two ACT for ID Case Studies

from

<http://digitalcommons.fiu.edu/cgi/viewcontent.cgi?article=1074&context=sferc> (accessed 15 April 2019).

- Pankey, J., & Hayes S.C. (2003), "Acceptance and Commitment Therapy for Psychosis". *International Journal of Psychology and Psychological Therapy*, Vol. 3 No. 2, pp.311-328.
- Robertson, B. (2011), "The adaptation and application of mindfulness-based psychotherapeutic practices for individuals with intellectual disabilities". *Advances in Mental Health and Intellectual Disabilities*, Vol. 5 No. 5, pp.46-52.
- Selman, M. and Oliver, M. (2018), "Systemic consultation clinics in a community service for people with intellectual disabilities". *Context*, Vol. 159, pp.21-24.
- Singh, N.N., Lancioni, G.E., Hwang, Y.S., Chan, J., Shogren, K.A. and Wehmeyer, M.L. (2017), Mindfulness: An Application of Positive Psychology in Intellectual and Developmental Disabilities. In Shogren, K.A., Wehmeyer, M.L. and Singh, N.N. (Eds), *Handbook of Positive Psychology in Intellectual and Developmental Disabilities*. Springer International Publishing, Cham, pp. 65-79.
- World Health Organization (1992), *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines (Vol. 1)*. World Health Organization, Geneva.

Further reading

- Bordieri, M.J., Kellum, K.K., Wilson, K.G. and Whiteman, K.C., 2016. Basic properties of coherence: testing a core assumption of Relational Frame Theory. *The Psychological Record*, 66(1), pp.83-98.