Experiences of dialectical behaviour therapy in a community setting for individuals with intellectual disabilities

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Background
There is growing interest in the application of dialectical behaviour therapy (DBT) for individuals with intellectual disability (ID) and recent qualitative studies have explored their experiences of DBT in inpatient and forensic settings. This article aimed to explore experiences of DBT in a community setting for people with ID.

Method
Eleven individuals recruited from two NHS Trusts were interviewed about their experiences of DBT. Interview data was analysed using interpretative phenomenological analysis (IPA).

Results
Four superordinate themes and eight subordinate themes emerged from the data. The first superordinate theme ‘experience of power’ captured participants experience of power within DBT. The second theme ‘differences in therapy contexts’ highlighted how participants had made sense of different therapeutic contexts. The third theme ‘the experience of a positive therapeutic relationship’ focused on the qualities and attitudes of the therapist. The fourth theme ‘a new way of being’ described the impact DBT had on participants’ everyday lives and the shift in their sense of self.

Discussion
This study provides insight into the lived experiences of people with ID receiving DBT. Therapeutic processes including the interplay between factors unique to DBT and features common across therapies are discussed.

Keywords: Intellectual disability, learning disability, dialectical behaviour therapy, DBT, interpretative phenomenological analysis, community

Introduction

Dialectical behaviour therapy

Dialectical behaviour therapy (DBT) (Linehan 1993) is a well-established and evidence-based treatment for Emotionally Unstable Personality Disorder (EUPD) (Chapman 2006). The DBT model draws on Biosocial Theory and posits that individuals experience the difficulties associated with EUPD (i.e. cognitive, emotional and behavioural dysregulation, interpersonal difficulties) as a result of the interplay between ‘biological vulnerabilities’ and growing up in an ‘invalidating environment’ (Feigenbaum 2007). Individuals with EUPD have often not been able to develop effective skills in regulating their emotions and tolerating distress and may therefore engage in impulsive behaviours (e.g. parasuicidal acts) as a way of managing overwhelming feelings (Lippold 2016). DBT encourages the balance and synthesis of both ‘acceptance’ and ‘change’ principles; meaning an individual’s difficult experiences are validated, and they are also encouraged to develop more adaptive cognitive and behavioural coping strategies (Swales 2009).

Originally developed as an outpatient intervention, DBT utilises a multi-modal approach, including group skills training, individual therapy, 24-hour telephone coaching and team consultation (Linehan *et al.* 2015). Within the group component, individuals are supported to develop skills in: emotional regulation, distress tolerance, interpersonal effectiveness and mindfulness (Linehan 2015). ‘Standard’ DBT is usually 1-year in duration; one cycle of group skills training is around 24 weeks, and this is then repeated (Flynn *et al.* 2017).

The efficacy and effectiveness of DBT for individuals with EUPD has been supported by the research literature; in a meta-analysis by Kliem *et al.* (2010), a moderate effect size for a reduction in suicidal and self-injurious behaviours was found. Similarly, a meta-

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analysis conducted by Panos *et al.* (2014) concluded that DBT was an efficacious treatment in reducing suicidal and self-harming acts in individual's with EUPD.

DBT for individuals with intellectual disabilities

DBT has increasingly been adapted and utilised with a range of diagnoses, populations and settings (Lynch *et al.* 2007). In recent years there has been growing interest in DBT as a potential treatment for people with ID who present with emotional dysregulation and impulsive behaviours (Crossland *et al.* 2017). The current evidence base for DBT and people with ID is limited, however, the available studies have reported positive outcomes. Studies reported reductions in self-injury and aggression to others (Lew *et al.* 2006, Brown *et al.* 2013); individuals also required fewer hospital admissions (Brown *et al.* 2013) and were able to move to lower security settings following DBT (Morrissey and Ingamells 2011). Other outcomes included reductions in psychological distress (Crossland *et al.* 2017), a decrease in anxiety and depression symptoms (Hall *et al.* 2013), and improvements in global functioning (Sakdalan *et al.* 2010, Crossland *et al.* 2017). However, these studies had various methodological limitations, including small sample sizes and a lack of control groups. McNair et al. (2017) reviewed the available literature and concluded that DBT can be adapted for individuals with ID; however, conclusions about efficacy or effectiveness could not confidently be made, due to the quality of the available literature. Authors noted that more methodologically robust evidence was required, and they also suggested that it would be beneficial to carry out qualitative research, in order to explore individual's *experiences* of DBT. It could be argued that whilst quantitative research captures important information about psychological change following an intervention, it does not capture valuable information about the salient processes within client experiences of therapy (MacMahon *et al.* 2015). There is also developing evidence for the use of Interpretative Phenomenological Analysis (IPA) and other qualitative methodologies for people with ID (e.g. Merriman and Beail 2009, MacMahon *et al.* 2015, Anslow 2013, Rose *et al.* 2019).

Roscoe *et al.* (2016) conducted a qualitative study which used IPA to explore 10 participants' experiences of DBT in an inpatient setting. Participants reported experiencing difficulties in understanding parts of DBT; however, some developed personal understandings of the different aspects of the programme. Individuals found DBT to be helpful and beneficial; they spoke about applying the skills they had learnt to manage difficult situations more effectively and described having greater control over intense emotions. Participants highlighted factors that affected their engagement in therapy; this included the number of clients present in the group skills sessions and the development of a trusting therapeutic relationship. Thomson and Johnson (2017) used IPA to examine seven participants' experiences of DBT in a forensic setting. Participants described having a good understanding of DBT and the functions of the different modalities. They were able to develop skills which were personalised and meaningful to them. Individuals recognised the advantages of utilising DBT skills and were able to respond to difficult situations more effectively. Individuals experienced some skills as being more difficult to apply than others. Participants were able to generalise their skills outside of sessions on the ward; however, they experienced inconsistencies in the level of knowledge ward staff had about DBT.

Two other studies have used mixed-methods designs, which involved seeking qualitative feedback in addition to collecting quantitative measures (Hall *et al.* 2013, Crossland *et al.* 2017). In the study by Hall *et al.* (2013), five individuals were interviewed following attending a community-based DBT programme. Interviews focused on experiences of the group skills component specifically, and data was analysed using Thematic Analysis. Findings suggested that individuals observed positive changes in themselves following the group (e.g. reduction in self-harm) and benefitted from being with others who had similar difficulties. Crossland *et al.* (2017) interviewed four individuals and their support staff about a community-based DBT skills group, and results were analysed using Thematic Analysis. Participants described developing relationships with others in the group; they also spoke about the boundaries of the group, including the duration and number of sessions. Participants described generalising skills with differing levels of success.

Research aims

The two previous qualitative IPA studies cited explored experiences of DBT programmes within inpatient or forensic settings, whilst the two mixed-methods studies took place in community settings, gathering qualitative data about the DBT skills group component specifically, then analysed the results using Thematic Analysis. To date, there are no qualitative articles, which explore experiences of a multi-modal DBT programme in community settings for individuals with ID, which have been analysed using an in-depth analysis. This research therefore aimed to explore the subjective experiences of people with ID who received DBT in a community setting.

Method

Design

As this study aimed to explore individuals' experiences of DBT, a qualitative methodology which utilised a phenomenological stance was considered to be most appropriate; IPA was subsequently used (Smith 2011). The three main theoretical underpinnings of IPA are phenomenology, hermeneutics and idiography. Phenomenology is concerned with an individuals' subjective, lived experience of an event. The idiographic element of IPA means that it focuses on the 'particular', therefore a detailed analysis of individuals' accounts is required. Hermeneutics refers to the interpretative component of IPA, as it is concerned with how individuals *make sense* of their personal world. During IPA, the researcher attempts to make sense of how the individual made sense of their experiences; this process is referred to as the 'double hermeneutic' (Smith *et al.* 2009; Smith and Eatough 2007, Smith 2011).

Roscoe *et al.* (2016) suggested that it can be difficult to accurately represent the views of individuals with ID, therefore the interpretative element of IPA may be particularly relevant and appropriate when capturing the experiences of this population.

Participants

Eleven participants were recruited from two community-based NHS Intellectual Disability Teams. Nine of the participants were recruited from one team and two were recruited from the other. IPA typically requires a homogenous, small sample size, due to its idiographic commitment. Whilst three to six participants are generally seen as acceptable, the sample size may also depend on factors such as the richness of the individual cases (Smith *et al.* 2009). As individuals with ID may have difficulties expressing themselves verbally or telling their story (Beail and Williams 2014), a larger sample of participants were recruited to account for a potential lack of rich data. Purposive sampling was used, meaning participants were selected as they were considered to be experts in the phenomena being researched (Holloway and Wheeler 2010).

A description of participants is provided in Table 1. All participants were White British and were aged between 26–52 years old (mean= 38). Eight were females and three were males. Ten of the participants had mild ID and one had moderate ID. The majority had a diagnosis of EUPD or displayed EUPD characteristics. All participants received group skills training and individual therapy. Nine participants had access to telephone coaching. One ID Team did not provide telephone coaching; however, individuals ($n = 2$) were able to contact the service by telephone, if required. All staff involved with the delivery of DBT, attended the DBT Team Consultation. At the time of interview, all participants had completed at least one cycle of DBT group skills training, however, there were some variations in the stage of treatment participants were at.

Procedure

The research was granted ethical approval by a NHS Research Ethics Committee and by the Research and Development Department of the two NHS Trusts. Individuals who met the inclusion criteria were approached by a clinician known to them about the study. Those who were interested in the research were provided with an adapted information sheet, which the clinician supported them to read through.

Prior to the interview, the researcher asked participants some 'comprehension questions', to ensure that they had fully understood what the research involved and what their rights were (Arscott *et al.* 1998). Participants were then supported to read and sign the consent form, which had also been adapted to be more accessible.

Data collection

IPA advocates the use of open questions, where participants are encouraged to talk at length (Smith *et al.* 2009), however, some individuals with ID may struggle to respond to open questions and provide reflections (Holloway 2005). An interview schedule was therefore used flexibly throughout the interviews, with the researcher paying close attention to the participants' responses, adapting the style of questions and prompts accordingly, to support the individuals to provide a detailed account of their experiences. The researcher also sought supervisory feedback about the quality of the interviewing; this enabled adaptions to be made within subsequent interviews, to ensure that the researcher was noticing cues from participants and paying attention to their individual experience (Smith *et al.* 2009).

Participants were interviewed once in a private room at the service where they received DBT. One participant chose to have their DBT therapist present for the interview, whilst the other participants were interviewed by themselves. Interviews were audio-recorded and were between 23 and 48 minutes in length (mean = 38).

Data analysis

Interviews were transcribed verbatim, identifying information was removed and participants were assigned a pseudonym. The IPA process of analysis was carried out using the 6 steps described by Smith *et al.* (2009).

During the data analysis stage, the researcher engaged in credibility-checking of the emerging themes through the use of supervision. In order to further increase the plausibility, credibility and validity of the interpretations, the superordinate themes and accompanying subthemes were reviewed by clinicians independent of the study, who have experience of IPA.

Table 1. Participant demographics.

Pseudonym	Age	Sex	Ethnicity	ID	Diagnoses	Reason referred for DBT	DBT intervention received	Stage of treatment
Evelyn	43	Female	White British	Mild	EUPD	Self-harm behaviours, suicide attempts, emotional dysregulation	Group skills training (2 cycles). Individual therapy. Telephone coaching. Team consultation	Completed October 2017
Tess	40	Female	White British	Mild	EUPD	Self-harm behaviours, suicide attempts, emotional dysregulation	Group skills training (2 cycles). Individual therapy. Telephone coaching. Team consultation	Completed February 2017
Katherine	37	Female	White British	Mild	EUPD	Self-harm behaviours, service disengagement	Group skills training (2 cycles). Individual therapy. Telephone coaching. Team consultation	Completed February 2018
Harry	26	Male	White British	Moderate	Characteristics of EUPD	Suicide attempts, emotional dysregulation	Group skills training (1 cycle). Individual therapy. Telephone coaching. Team consultation	Currently engaged in treatment
David	52	Male	White British	Mild	EUPD	Self-harm behaviours, suicide attempts, aggression, emotional dysregulation	Group skills training (1 cycle). Individual therapy. Telephone coaching. Team consultation	Currently engaged in treatment
Sandra	45	Female	White British	Mild	Characteristics of EUPD	Suicide attempts, aggressive behaviour, calling emergency services	Group skills training (1 cycle). Individual therapy. Telephone coaching. Team consultation	Currently engaged in treatment
Roger	27	Male	White British	Mild	Characteristics of EUPD	Self-harming behaviours	Group skills training (1 cycle). Individual therapy. Telephone coaching. Team consultation	Currently engaged in treatment
Helen	26	Female	White British	Mild	Characteristics of EUPD	Self-harming behaviours, emotional dysregulation	Group skills training (1 cycle). Individual therapy. Telephone coaching. Team consultation	Currently engaged in treatment
Emily	43	Female	White British	Mild	EUPD	Severe emotional dysregulation, aggressive behaviours	Group skills training (1 cycle). Individual therapy. Telephone coaching. Team consultation	Currently engaged in treatment
Barbara	43	Female	White British	Mild	Depressive illness	Emotional dysregulation	Group skills training (2 cycles). Individual therapy. Team consultation	Completed December 2015.
Carole	37	Female	White British	Mild	EUPD, autistic features	Emotional dysregulation	Group skills training (2 cycles). Individual therapy. Team consultation	Completed December 2015. Currently receiving individual therapy

Reflexivity

A reflexive journal was kept throughout the research process in order to capture and reflect on the researchers' perceptions and experiences (Larkin and Thompson 2012). This helped the researcher to notice initial thoughts and feelings regarding participants' narratives, whilst also recognising how the researchers' beliefs and previous experiences may have impacted on their interpretation of the data. It was hoped that engaging in this process would reduce the presence of researcher bias.

Epistemological position

The researcher adopted a critical realist epistemological stance throughout the research process. This seemed appropriate as the theoretical roots of IPA are aligned with critical realism; moreover, the critical realist perspective has gained increasing acceptance within the social sciences research field (Hood 2016). Critical realism assumes that reality exists independently of 'human conceptualisation', and that there may be differences in the way individuals make sense of and assign meaning to their experiences, as they experience different 'parts of reality' (Fade 2004).

Results

Four superordinate themes and eight corresponding subordinate themes emerged during the analysis and are represented in Table 2. These themes capture the individuals lived experience of DBT and the impact this had on their lives.

Theme I—experience of power

There was a strong narrative regarding the experience of power throughout the interviews. Whilst some participants spoke about power more explicitly, for others, this was more implicit in their accounts.

Having a voice in therapy

A number of participants' accounts suggested that during DBT they made efforts to actively express their needs and subsequently get these needs met. For instance, when individuals found new concepts/skills difficult to understand, they appeared to take control of the situation and assert themselves:

> …I said "what we will have to do is try and explain it to me again". So they explained it to me again in more detail but slowly for me (Barbara)

By Barbara voicing what she needed, therapists were able to responsively adapt the content and delivery of the information described. Individuals seemed to become more confident in not only asking for information to be explained again, but for it to be explained at a more appropriate level:

> …if there is anything that you don't understand (…) now we are so upfront, we will just say to them, "can you talk in English please?" (laughs) (Emily)

Emily's account suggests that over time, individuals were able to openly and humorously, use their voice to communicate difficulties in understanding.

Most individuals displayed a sense of taking ownership and responsibility for their own learning; participants were not passive recipients of information, but instead were proactive agents in their learning. In the following exchange, Tess describes how she actively sought opportunities to be involved during sessions and she shows awareness of what helps her to learn most effectively:

> Tess: …I got up and done all the drawings on the whiteboard (…) And the writing on the whiteboard (…) I asked if I could get up and do some writing
>
> Interviewer: What made you want to do the writing and the drawing?
>
> Tess: …Listen more better if I'm doodling or writing words down (Tess)

A shifting position of power

Individuals seemed to view DBT as being a learning environment where they acquired new knowledge/skills. They appeared to experience learning within DBT as a *process,* which involved moving through different stages. Their narratives suggest that within this learning process, they experienced a shift towards being in a more powerful position.

When starting the programme, most individuals took on the role of a learner and placed themselves in a

Table 2. Superordinate and subordinate themes.

Superordinate theme	Subordinate theme
Experience of power	a. Having a voice in therapy b. A shifting position of power
Differences in therapy contexts	a. Openness and filtering b. Seriousness and playfulness c. Being in a group as challenging and rewarding
The experience of a positive therapeutic relationship	
A new way of being	a. Integrating DBT into life b. Change c. A shifting sense of self: old me and new me

learning position; comparatively, they put the therapists in the role of teachers- arguably a more powerful position.

> … it's a course that you go on to get help in learning about feelings, coping in a difficult situation and that sort of stuff (Helen)

> [the therapists] teach us, teach us how to like cope (Emily)

> They taught us a lot of things (Harry)

Some participants showed conscious awareness of the lack of knowledge and/or adaptive coping skills they previously possessed:

> So all my emotions … I didn't know what they were for (Emily)

> … if I was having a crisis, I would just shout and self-harm … because I did not know how to cope with it (Evelyn)

> I didn't know how to open up, I didn't know how to kind of express my feelings without kind of like going off on one, like overpowering myself (Roger)

Many recognised that there was a *need* to learn new skills in order to help them to manage better:

> I needed to know what skills I needed … and for other bits and pieces like my emotions … to sort them out … (Barbara)

> Because I need[ed] help and that with things … like learning skills (Carole)

Participants spoke about initially struggling to make sense of new information/skills, then moving towards a greater understanding. They appeared to move from a position of 'not knowing' to a more powerful position of 'knowing'. Moving to a 'knowing' position was a gradual process for most participants; David and Katherine both highlight the element of time involved in this process:

> At first, pretty hard … but … as time went on … they got pretty easy (David)

> When I first got told it, no I wasn't sure about it … but I think over time … I started to get used to it (Katherine)

In contrast, Barbara and Roger experienced the shift towards 'knowing' as more of a sudden 'eureka' moment:

> … I kind of went "whoa, I understand this more clearly now" (Roger)

> … all of a sudden it will just hit me, and I think "whoa I've got it now" (Barbara)

Some participants spoke about achieving mastery over the skills/ideas they had learnt. There was a real sense of accomplishment and pride around this:

> All my skills I've learnt I've now got mastered … I've got all the skills I needed to learn mastered (Barbara)

Several participants appeared to go a stage further in the learning process and move from being a learner to a teacher:

> … you learn how to deal with yourself in crisis and how to deal with your emotions. I'm teaching everybody else, like my staff, you know "you can't say that, you've got to do this … you can only do it one thing at a time". And they are saying "I can't do it" and I say, "there is no such word as can't" (Tess)

Tess seemed to have taken on a mentoring role, whereby she was not only applying the knowledge she had gained herself, but also using it to empower and motivate others. David also described the 'ego boost' he experienced at being able to 'teach' and help others, through 'passing the knowledge on'.

Theme II—Differences in therapy contexts

The format through which therapy was delivered (i.e. individual therapy, group), appeared to affect participants' experiences. This theme captures how individuals experienced DBT across the different therapeutic modalities. Interestingly, participants spoke at length about individual therapy and group skills training, but spent little time describing their experience of telephone coaching.

Openness and filtering

There was a strong narrative around the value participants placed on being able to talk openly and honestly. Individuals claimed that they were able to be 'more' open/honest and found it 'easier to talk' in a one-to-one setting, compared to when they were in the group. A number of individuals actively spoke about 'preferring' individual therapy as a result.

For some individuals, the presence of others hindered their ability to talk openly/honestly, moreover they seemed conscious of other group members 'listening in':

> Being honest, it's good (…) whereas if you are in the group you can't [be] (…) Because you've got … loads listening haven't you (Carole)

Participants described being able to 'talk about anything' in individual therapy; they experienced no limitations or boundaries around what could be discussed. Comparatively, they seemed to filter what they said in the group and showed greater awareness of boundaries. Moreover, they considered the impact of what they said on other group members:

> In one-to-one's you can talk about everything, like from back to when you were a child, to present… everything that's gone on in your life… but not like in the [group] sessions because you might upset someone else (Emily)

> One-to-one's you could talk… group skills you can't talk about your personal life… because you might upset other members and if they talk about it, they might upset me (Katherine)

Participants clearly differentiated between what could be spoken about in the different contexts; there was a sense that individuals had internalised rules and recognised the importance of adhering to them.

Seriousness and playfulness

The different therapy contexts appeared to meet different needs and serve different functions for the participants; this impacted on how the participants presented themselves, the emotions they experienced and how they made use of the sessions.

Tess described presenting a different version/part of herself when in a group setting, compared to when she was in a one-to-one setting:

> …I suppose it was two hats. One was the serious hat and one was the one that you could muck around in (Tess)

Many echoed this and described being more 'serious' when working individually and being more playful in the group. Participants described 'talking about more serious stuff' in individual therapy, including exploring and reflecting on current struggles and previous difficult life events. Most experienced the content of sessions as somewhat intensive and thought provoking:

> …you have got to think a bit in that hour (Harry)

For some clients, the nature of the sessions elicited uncomfortable feelings and emotional expression:

> …it was just upsetting… really upsetting (Katherine)

> …there were some sessions that I came out crying, I came out worse than before I came in (Roger)

For Roger, it seemed that expressing his emotions through crying during/following sessions had been a detrimental experience for him. Comparatively, other participants described emotional expression in sessions as a positive experience and there was a sense of relief associated with this:

> … we have talked about my emotions, I've even cried in front of her… I just could not hold it in no more… I said "oh sod it", and my emotions come. I let go of my emotions… It felt a weight lift off me (David)

In contrast to individual therapy, participants described the group as somewhere they could be playful and have 'fun'. They spoke positively about the engaging, enjoyable activities and games they were involved in as part of the group:

> I liked a lot of the group… the games we used to play in there, we used to play different kinds of games (Barbara)

Individuals seemed to appreciate the emphasis that was placed on maintaining a light-hearted environment and the use of practical activities to facilitate learning. It appeared important that individuals had the opportunity to be playful within DBT due to other components of the programme being experienced as more intensive.

Being in a group as challenging and rewarding

The majority of participants spoke about various challenges associated with the group component of DBT, however, many individuals also recognised the value of being *part of* a group.

When describing the difficulties experienced within a group setting, most individuals highlighted social challenges, in particular, difficulties with meeting new people:

> I'm not really a new people person. I don't really like talking to new people because it makes me feel anxious… It's alright when you know them but not when you don't (Helen)

Helen's perception of herself seemed to contribute to the experience of starting group sessions as being particularly difficult. Many participants were fearful of judgement from others in the group and this appeared to hinder their willingness to engage in the group activities.

> …the staff was doing the role play bit and they expected us to do it. And I thought "I'm not going to make a fool of myself" (Barbara)

Barbara appeared to avoid performance-based tasks, which seemed to be linked to a fear of ridicule or embarrassment.

When considering the value of being in a group, it seemed that the group component of DBT met certain needs, which the individual sessions were less able to. The group appeared to serve a social function for many, providing opportunities to interact and develop relationships. Sandra in particular spoke about how she was able to *'meet new friends',* and this was echoed by others:

> I'd never make new friends and coming to the group has made me do that… And that's built my confidence up, meeting new friends (Barbara)

Barbara appeared to directly associate coming to the group, with making new friends and a subsequent increase in confidence. Participants seemed to gain a sense of belonging and connectedness from attending the group; particularly benefitting from interacting with others whom they identified with:

> Interviewer: … what would you say you liked most about it?
>
> Harry: Being with other people living with the same mental health (Harry)

The above exchange highlights how significant it was for Harry to be with others whom he felt similar to. Individuals could relate to one another and seemed to find strength and unity from this. Interestingly, participants seemed to develop a group identity and there was a sense that they felt they were part of a special group:

> … the good thing is that whatever we say in the group, stays in the group, that is one of our group rules. And like things like social media, some of us are friends on Facebook, but we never discuss what went on. Like today for instance, we don't discuss what went on in that room, it doesn't go anywhere else than that room (Emily)
>
> … everything in the group has got to be kept in the group, you can't tell anybody outside the group, so I never did, I never discussed anything with the group outside the group (Barbara)

The way Emily spoke about the group created feelings of intrigue and curiosity around '*what went on'*. There seemed to be a shared agreement around the *'rules'* of the group and what was expected of its members. Similarly, the extract from Barbara emphasised this sense of being part of an in-group, whereby nobody outside of the group could be privy to what was discussed.

Theme III—The experience of a positive therapeutic relationship

A theme which emerged throughout the majority of narratives, related to the positive therapeutic relationship experienced. Individuals spoke at length about the various qualities and attitudes of the therapist which contributed to the development of this positive relationship.

Several individuals described feeling listened to and heard by the therapist, and there was sense of feeling genuinely understood. For Katherine, it seemed more evident to her that her therapist was *really* listening and understanding her, in comparison to her previous experiences of therapists:

> This time my therapists listened to me (…) just listening to me, much clearer and understooded much better (Katherine)

A number of individuals spoke about feeling able to trust the therapist. For Tess, trusting the therapist, being listened to and understood were all intrinsically linked:

> Tess: I can trust [the therapist]
>
> Interviewer: (…) So what did [the therapist] do that made you feel you could trust her?
>
> Tess: Listened. She understood (Tess)

Feeling able to trust another person felt particularly significant for a number of individuals, who drew on difficult past relational experiences.

Participants viewed the therapist as being flexible and adaptable in sessions, in that the therapist was led by the client, so their wants and needs were at the heart of how the session was conducted:

> [the therapist] would play it by ear, depending on what I wanted to talk about and what I didn't want to talk about (Tess)

Individuals felt that the therapist was attuned to them and responded appropriately to their cues:

> … It's like she knows if you're sad, she knows if you just want to sit there and be quiet, she'll just sit there and be quiet (Emily)

Participants experienced the therapist as being validating, accepting in their approach and they were perceived as having a non-judgmental attitude:

> … she doesn't judge what you say and that's where it works (David)

For David, there seemed to be a clear link for him between the therapist's non-judgmental attitude and how effective their relationship was.

Theme IV—A new way of being

This theme captures the impact DBT had on participants' lives. Individuals were able to implement the skills they had learnt and noticed numerous changes, not only in their everyday lives, but also in their sense of who they are as people.

Integrating DBT into life

Participants described being able to take the skills/knowledge that they had learnt in DBT, generalise these to other settings and integrate them into their day-to-day lives:

> I did like a sensory table, when I got candles and a lava lamp and other stuff… because in the group I learnt that if you have something to focus on, it takes your mind off what you are thinking about. So I set that up… and when we used to go for walks we used to notice stuff… so if I'm out and about I notice stuff more now, which helps. (Evelyn)

Evelyn seemed to have drawn on particular DBT ideas which were most useful/relevant to her and was implementing these outside of sessions. Participants commonly referred to utilising mindfulness-based exercises in their narratives. Individuals seemed to have adopted a mindful way of being when completing everyday activities:

> … you know like when you have a drink, like tasting … like when I have a hot chocolate, now before I drink it, I have a smell of it and that. It's good … And when I'm eating, like taste what you are eating (Carole)

The DBT ethos and exercises seemed to have become a part of life for most participants and arguably a 'new norm':

> I used to struggle doing it, but now I just do it, it's like a normal routine to me, it's like making a cup of coffee, it's just normal routine now (Barbara)

This excerpt suggests that Barbara experienced a shift from initially struggling, to integrating DBT into her life and simply seeing it as a *'normal routine'* now.

Change

Participants described the various changes they had experienced following attending the DBT programme. This included emotional, behavioural, cognitive and interpersonal changes, as well as greater feelings of empowerment.

In relation to emotional change, many participants noticed that they were not experiencing difficult emotions such as anger as intensely or frequently, and described feeling significantly calmer:

> I've noticed I'm a lot calmer … I'm not losing it every 5 minutes (Sandra)

> I am a lot calmer (Emily)

> I don't get angry so much now (Evelyn)

Some participants described developing a better understanding of emotions generally. Emily's narrative particularly, suggested that she experienced greater *acceptance* of her emotions:

> … I have learnt since coming here, that it is ok. Like its ok to be sad, its ok to be cross (Emily)

> … it's alright to be angry sometimes. It's alright to be cross, it's alright to be upset, it's alright to be sad (Emily)

Similarly, David appeared to have given himself permission to genuinely experience and express a wider range of emotions:

> Interviewer: And what's changed then, from then until now?
>
> David: (…) I can absolutely laugh and not feel ashamed of laughing (…) And … it's alright to cry and not be judged (David)

Participants also spoke about behavioural changes they had noticed. Some noted that they were engaging in fewer risk behaviours following DBT:

> I'm not self-harming now … That's a big step for me … Because I used to do it all the time when I got angry, but now I've realised it doesn't make life any easier by doing that, it just makes it worse (Helen)

Helen emphasised the personal significance of this change for her. She seemed to have come to a powerful realisation and recognised the negative impact self-harming was having on her life.

Some participants noticed a change in their thinking styles and the way they perceived situations. Evelyn gave an example of when she was able to interpret a situation in a more balanced and flexible way:

> … if … I send someone a text and they don't text back … I don't take it personally. I'm just like maybe they haven't got credit … maybe their battery has run out … maybe they haven't got a signal. It's just stuff like that now. I think I've noticed that more. (Evelyn)

Similarly, Roger described difficult situations where he has now *'thought about it differently'* compared to how he would have previously made sense of the situation.

Participants described a number of interpersonal changes they had observed following DBT. Many individuals noticed positive changes in their existing familial relationships:

> **…** before I started doing this, like my relationship with like my Mum and my dad was not good, because I was always angry, always cross, and now, its lovely. (Emily)

Emily attributed the previous difficulties in her parental relationship to her persistent anger and aggression. It seemed that by developing skills in managing emotions, this impacted on her interpersonal relationships. Tess appeared to have adapted her communication style following DBT and demonstrated assertiveness in her interactions:

> … when Mum tells me to do more than one thing, I tell her now that "I can only do one thing at a time. I can't wash up, do the dishwasher and make the tea at the same time. I have to do one thing at a time". (Tess)

Other individuals noticed changes in the development of *new* relationships. Participants described a previous lack of social support and difficulties with making friends; however, this appeared to have changed:

> … it don't take me long to make new friends now like I used to, because I never used to have many, but now I've only got to go out and they say "do you fancy a … " and then we are out, having a laugh and a joke (Barbara)

Some participants made reference to feelings of empowerment following DBT. Katherine reflected on what she had learnt in DBT, particularly in the context of the difficult previous life events she had experienced:

> … showed me … part what I put up with, and part what I wouldn't put up with and showed me … I got strength to do something about it instead of leaving it and I won't put up with it anymore (Katherine)

Katherine appeared to have found inner strength, where she felt more able to take control of her life and place herself in an empowered position rather than the submissive position she was previously in.

A changing sense of self: 'old me' and 'new me'

The various changes participants experienced, seemed to impact on their sense of self and who they are as individuals. Many referred to how they *used* to be as a person and the behaviours they used to exhibit (i.e. 'old me'); they also spoke about how they are now and the 'new' person they have become.

In relation to how they used to be, individuals predominantly spoke about previous aggressive feelings they experienced and dysfunctional behaviours they displayed:

> I used to kick doors and punch a hole in them (Sandra)

> I would have screamed … and just been really angry (Helen)

> … before I used to smack the walls and smack doors and put holes in walls in my temper … (Emily)

> I kept being angry all the time, I kept having a go at people (Roger)

There was a sense of feeling out of control, overwhelmed and frustrated with how things were. Participants previous sense of self appeared to be formed by the angry emotions and behaviours they experienced. In Emily's narrative, she referred to herself as *'that horrible person'* and spoke about *'that angry person that I used to be'*. Emily seemed to experience a shift away from identifying as that '*angry*' and *'horrible'* self, and moved towards seeing herself as '*this nice, calm person'*. She spoke explicitly about how significantly her sense of self had changed:

> I'm a totally different person to what I was … totally different person (Emily)

Similarly, David's sense of self was also previously made up of being an *'angry person'*. Interestingly, David spoke about how others around him had also noticed a change in him as a person following DBT:

> He goes "you're a different person. I don't know what you're doing, or where you are getting your personality from lately, but it's a good thing" (David)

Hearing this from another person felt particularly important for David and seemed to reinforce the changes he had made.

Discussion

This study aimed to explore individuals with ID experiences of DBT in a community setting; the analysis identified four main themes. Theme I highlighted that the empowering and validating environment created within DBT appeared to facilitate individuals *having a voice* in sessions, as individuals described asserting their needs, exerting control and showing agency around their learning. This suggests that they were 'active participants' rather than 'passive recipients' in therapy, which challenges previous perceptions about this population's ability to make use of or meaningfully take part in therapy (Handley *et al.* 2012). As individuals with ID often experience a lack of choice or control in their day-to-day lives (Finlay *et al.* 2008), becoming skilled in using their voices both within and outside of therapy feels particularly important.

Having the opportunity to learn new relevant skills has been associated with feelings of personal growth and empowerment for people with ID (Atkinson *et al.* 2015). The findings from this research support this notion, as participants seemed to value the skills/knowledge acquired through DBT and this appeared to be associated with a sense of empowerment. Participants seemed to experience a shift in their position of power, as part of the process of learning; they appeared to move from the arguably more subordinate position of a learner, towards mastery, and the role of a teacher. Individuals spoke with pride about the skills/knowledge they had been able to master; this echoes the findings by MacMahon *et al.* (2015) where individuals with ID were interviewed following attending a CBT-based group and were eager to share their expertise and sense of mastery. Experiential claims around taking on a teaching role, echoed the findings of Thomson and Johnson (2017), who highlighted that clients wanted to teach staff and peers on the ward about DBT.

The ‘conscious competence’ model of learning postulates that when learning a new skill, we progress through four stages (unconscious incompetence, conscious incompetence, conscious competence and unconscious competence) (Adams 2016). This model appears to reflect the learning process reported by participants, as they described awareness of the skills/knowledge they were lacking (*conscious incompetence*), then described developing greater knowledge/skills (*conscious competence*) and finally, they achieved mastery, used the skills habitually and were able to teach others (*unconscious competence*).

Theme II highlighted the differences participants experienced in therapeutic contexts. Thomson and Johnson (2017) similarly found that participants differentiated between the one-to-one and group modality, with individuals recognising the different functions of these therapeutic settings and what was expected of them. Participants emphasised the unique and valuable element of the one-to-one interactions, whereby they could talk privately and openly. This is consistent with other literature, which found that individuals with ID experienced being able to talk in therapy as helpful (Merriman and Beail 2009, Pert *et al.* 2013). However, these findings go beyond that, and emphasise that individuals highly valued the absence of boundaries and limitations of what could be spoken about within a one-to-one context. It also seemed that being with others in a group who had similar difficulties and shared struggles provided a sense of belonging for participants. Being in a group setting also provided social opportunities and the development of friendships. The group component of DBT may therefore be particularly important for this population, who often have limited social support (Lippold and Burns 2009).

Theme III highlighted that participants experienced a positive therapeutic relationship, where the relationship was characterised by trust, validation, attunement, availability, empowerment and a non-judgmental stance. Similarly, Roscoe *et al.* (2016) highlighted that the therapeutic relationship appeared to influence participants engagement in DBT. In the wider literature, the therapeutic relationship has repeatedly been associated with positive therapeutic outcomes, irrespective of the model of therapy being delivered (Ardito and Rabellino 2011). Individuals with ID often have fewer experiences of being genuinely listened to and accepted by others (Pert *et al.* 2013); this may provide some insight as to why the value of the therapeutic relationship emerged so prominently in the data.

Theme IV highlighted the various changes individuals experienced following DBT. Participants described utilising skilful behaviours and generalising these skills to other settings; these outcomes are in line with some of the ‘treatment functions’ of DBT (e.g. skill generalisation) (Dimeff and Linehan 2001). Moreover, many of the changes experienced by participants, such as a decrease in parasuicidal acts, greater regulation of emotions and improved interpersonal effectiveness, are aligned with the aims of DBT (Panos *et al.* 2014). This provides evidence for the efficacy of DBT with this population.

Participant’s narratives also suggested that they experienced a change in their sense of self. They referred to the person they *used* to be and the person they *are* now. This lends itself to the ‘old me’, ‘new me’ model developed by Haaven and Coleman (2000) for individuals with ID who have sexually offended. ‘Old me’ represents the previous attitudes, feelings and dysfunctional ways of behaving, whilst ‘new me’ reflects a new identity and positive lifestyle (Ward, Polaschek and Beech 2006).

Critique

The study utilised purposive sampling, meaning the sample was reasonably homogenous, in line with IPA recommendations; however, this sampling method may limit the extent to which we can generalise the findings beyond those involved. IPA is however, concerned with the *depth* rather than the *breadth* of the study (Pietkiewicz and Smith 2014), less importance is therefore placed on being able to generalise the findings.

The literature suggests that individuals with ID may be more likely to acquiesce during interviews (Baxter 2005, Hollomotz 2018); the presence of a therapist during one of the interviews may have also further influenced how this particular participant described their experience of DBT. To reduce the likelihood of acquiescent responding, the researcher was mindful of this during the interviews and adapted the style of interviewing (i.e. open-ended questions, use of prompts as needed, paraphrasing, summarising).

As previously noted, this study recruited a larger sample of participants to account for a potential lack of rich data. During data analysis, it was acknowledged that the richness of the data varied considerably across the interviews; this may indicate that the decision to recruit a larger sample of participants was justified and beneficial within the current study. However, it is worth noting that irrespective of the richness of the data, all interviews were included in the analysis, and quotations from all participants were included in the text; meaning the voice of every participant was heard. Whilst some of the extracts included were short, they arguably still capture the complex stories of the participants. This provides support to the application of IPA with people with ID, as analysis goes beyond what is being said and seeks to make sense of experience at an interpretative level.

It could be argued that the analysis was subjective, as the themes were developed based on the interpretation of the data by the researcher; it is therefore possible that another researcher may have interpreted the data differently. However, a strength of the study was the various credibility checks which were carried out during the analysis. Throughout the research process, the researcher made use of a reflexive journal, utilised supervision and attended IPA peer group meetings; additionally, the IPA themes were reviewed by clinicians who were independent to the study, thus increasing the plausibility, validity and credibility of the analysis, and minimising potential bias.

However, a limitation was that a credibility check was not conducted with the participants' themselves. It can be difficult to obtain participant validation, particularly when interpretative approaches are used; however, this may have been beneficial and in line with ethical principles (Beail and Williams 2014, Coons and Watson 2013). A further limitation is that individuals with ID were not meaningfully involved at the various stages of the research (e.g. idea conception, research design, developing accessible materials and dissemination). This was unfortunately beyond the scope of the current research article due to research delays and time constraints.

Clinical implications and recommendations

- **Delivering multi-modal DBT to people with ID**—This research highlighted the distinct contributions made by the different therapeutic modalities (i.e. individual therapy, group skills training). Whilst the DBT skills group has been provided as a standalone treatment with this population and has shown positive outcomes (e.g. Crossland *et al.* 2017, Sakdalan *et al.* 2010), it seems that participants benefitted from accessing the different modalities within DBT. Where possible, services should therefore aim to provide DBT within both individual and group contexts. As experiential claims about telephone coaching did not emerge prominently within the current data, it may be beneficial to develop a further understanding about the utility of telephone coaching for this population.
- **Skill generalisation**—Participants highlighted the value associated with acquiring new skills and knowledge. In order to support individuals to generalise their newly acquired skills/knowledge, it may be beneficial to involve support staff/families within the DBT process (Rose *et al.* 2005).
- **Meaningful involvement of people with ID in research**—Whilst it was unfortunately beyond the scope of the current article to meaningfully involve individuals with ID throughout the research process, the researcher recognises the importance of this. Future research should therefore endeavour to advocate a more inclusive approach, meaningfully involving individuals at each stage of the research process.
- **Synthesising the current qualitative research**—When considering future research, due to the growing qualitative research in this area, it may be beneficial to conduct a meta-ethnography in order to synthesise the available qualitative literature.

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