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Supporting people with intellectual disabilities in psychological therapies for depression: a qualitative analysis of supporters' experiences

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Abstract

Background: Clinicians suggest that including carers or others in a supporting role in the therapy is an important adaptation of psychological therapies for people with intellectual disabilities. This nested qualitative study from a larger trial explored supporters' experiences of supporting people with intellectual disabilities receiving behavioural activation or guided self-help therapies for depression.

Method: Twenty-one supporters were purposively sampled and interviewed after therapy completion. Framework analysis was used to analyse the semi-structured interviews, covering expectations of therapy, views of therapy sessions, relationships with therapist and participant, and perceived changes.

Results: Supporters were positive about both therapies and reported both therapy-specific and non-specific therapeutic factors that had significant positive impacts on people's lives. Most supporters reported their involvement contributed to the interventions' effectiveness, and helped establish closer relationships to the people they were supporting.

Conclusions: The presence of supporters within psychological therapies for people with intellectual disabilities can be an effective adaptation to therapies for this population.

Introduction

There has been a growing awareness of the mental health needs of people with intellectual disabilities. It has been reported that at least 20% of people with moderate intellectual disabilities experience depression (NICE, 2016). Depression amongst people with intellectual disabilities may be under-reported within primary care, with GPs reporting similar rates of depression for people with intellectual disabilities (13.9%) and people without intellectual disabilities (14.5%) (NHS Digital and Public Health England, 2016).

Despite the clear mental health needs of many people with intellectual disabilities, the evidence base for therapies addressing these needs is somewhat lacking, particularly compared to the general population (NICE, 2016). For example, a meta-analysis of psychological interventions with people with intellectual disabilities found only 14 studies (Vereenooghe & Langdon, 2013), with very few rigorous randomised controlled trials. This review found that variants of cognitive behaviour therapy (CBT) may be effective in the treatment of depression and anger in adults with intellectual disabilities (Vereenooghe & Langdon, 2013; see also NICE, 2016). It was also found that studies using individual therapies may be more effective than those using group-based interventions (Vereenooghe & Langdon, 2013).

There have been attempts to adapt psychological therapies for depression to increase their accessibility and effectiveness for adults with intellectual disabilities (Esbensen & Hartley, 2012; Lindsay *et al*., 2012a, b). These adaptations are designed to reduce the potential demands of CBT and other psychological interventions in terms of access, cognition, language and memory, which can pose potential challenges for effective interventions with people with intellectual disabilities (Dagnan *et al*., 2012).

One adaptation that has been suggested to make psychological interventions more accessible and effective for people with intellectual disabilities is to include significant others, such as paid or family carers, in the therapy as supporters. This can help the person get to therapy sessions and help to improve the information available to the therapist. Additionally, for therapies requiring the completion of homework, such as CBT or behavioural activation, assistance may be required due to lack of ability, confidence or resources to carry out the tasks alone. The presence of a supporter in the therapy may also prove helpful in providing more background information regarding life events and other important information in relation to the person with intellectual disabilities (Beail & Jahoda, 2012; Lindsay *et al*., 2012a).

Therapies such as behavioural activation, as designed for the general population, do not specify a role for supporters within therapy sessions. However, these therapies recognise the importance of getting support from others throughout the therapy, for reasons beyond the immediate practicalities of facilitating people's participation in the therapy. As Lejuez et al. (2011) state: "Specifically, contracts now involve the patient identifying (a) an activity that is difficult to accomplish, (b) up to three supportive individuals who might be able to assist/ support, and (c) specifically how and when each person might do this. This change in emphasis provides the patient with an opportunity to identify concrete needs and provides a specific plan on how to obtain the help needed" (pp. 119-120).

From the supporter's point of view, being part of therapy sessions may have the effect of increasing their confidence and effectiveness in supporting the individual to overcome their emotional difficulties (Lindsay et al., 2012a).

The authors have only been able to find one study concerning the inclusion of carers as supporters in therapy for people with intellectual disabilities, with the research focused on paid staff as supporters rather than family members. Rose et al. (2005) found that including staff alongside clients during group-based CBT for anger management was more effective in reducing anger than when staff did not attend the groups. Beyond this, it is unknown what impact the involvement of supporters has on the practice and outcomes of psychological interventions with people with intellectual disabilities, the potential feasibility of involving supporters in therapy, or how supporters experience their involvement.

In the current paper, we explore the experiences of carers supporting adults with intellectual disabilities randomised to one of two psychological interventions for depression; behavioural activation or guided self-help. There is substantial evidence for the effectiveness of both behavioural activation (e.g. Richards et al., 2016) and guided self-help (e.g. Williams et al. 2013) for adults with depression in the general population. The randomised controlled trial within which this qualitative study was nested was designed to evaluate the costs and effectiveness of adapted versions of behavioural activation versus an active control, guided self-help, for adults with mild-to-moderate intellectual disabilities and depression (see Jahoda et al., 2017 for costs and effectiveness findings). Neither of these adapted forms of therapy (which included a significant other as a supporter in all the therapy sessions) had previous evidence concerning their effectiveness with people with intellectual disabilities, beyond a feasibility study concerning adapted behavioural activation (Jahoda et al., 2015b). This paper describes findings from semi-structured interviews with supporters to garner their opinions and experiences of the intervention they were involved in, with a particular focus on understanding more about the supporter's role within these psychological interventions and the impact of supporters on the therapy process.

Method

The randomised controlled trial

This qualitative study was nested within a randomised controlled trial (RCT) whose primary objective was to compare the clinical and cost effectiveness of behavioural activation and guided self-help for the treatment of depressive symptoms in adults with intellectual disabilities (Jahoda et al, 2015a; Jahoda et al., 2017). For inclusion in the RCT, participants needed to report clinically significant depression, as assessed by an independent researcher using the Diagnostic Criteria for Psychiatric Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities (Cooper et al., 2003). In total, 161 adults with mild/moderate intellectual disabilities across sites in Scotland, Wales and England were randomised 1:1 to participate in either a 12-week behavioural activation intervention or an 8-week guided self-help intervention. Both interventions were structured and manualised and delivered through weekly face-to-face sessions with a trained therapist, with a supporter present at each session. For the RCT, quantitative data were collected from all participants at baseline, 4 months post-baseline (soon after the end of the therapy) and 12 months post-baseline. Qualitative data were collected separately from participants and supporters via face-to-face semi-structured interviews between 4 months and 8 months post-baseline, and focus groups were conducted with therapists and supervisors after all therapy had been completed.

The behavioural activation intervention, named Beat-It, aimed to work with the participant and their supporter to help them plan how to re-engage in meaningful and positive activities they may have withdrawn from related to their depression. Behavioural activation emphasises the link between activity and mood, whereby low mood decreases activity levels and withdrawal from regular activities leads to further decreases in mood. It focuses more on behaviour than cognition, and is therefore less reliant on verbal communication skills.

The guided self-help intervention, named Step-Up, focused on 4 self-help booklets, covering the nature of depression, sleep, physical activity and problem solving. These were developed by Melville et al. (2009) for use by adults with intellectual disabilities and depression.

Supporters

For inclusion in the trial, all potential participants needed to have an identified support person who could accompany them to therapy sessions and provide them with at least two hours of support each week. Whilst only one potential participant was excluded from the trial on this basis, researchers on the trial had to assist in the identification of supporters for 15 trial participants by liaising with referrers.

For the qualitative interviews, a purposive sample of 21 supporters (19 women, 2 men) was interviewed, all of whom had supported an adult with intellectual disabilities through either the behavioural activation or guided self-help intervention. One participant had supported two people through the therapy (both participants underwent Beat-It) – their interview was treated as one transcript for the purposes of the analysis, although different experiences relating to individual participants could be coded across more than one thematic category if warranted. Participants were purposively sampled (using matrices of supporter circumstances in each of the three sites to guide recruitment) to reflect diversity in: therapy type, living situation, location (England, Scotland or Wales), gender of the participant they supported through therapy, and supporter-participant relationship (family or paid staff).

Eleven supporters had supported someone through the behavioural activation intervention and 10 carers through guided self-help. Of the 21 carers, 14 were paid support workers (nine supporting people through Beat-It and five supporting people through Step Up) and seven were parents of the person with intellectual disabilities in therapy (two supporting people through Beat It and five supporting people through Step Up).

All interviews took place between 4 and 12 month post-baseline data collection. As therapy finished around the time of the 4 month post-baseline data collection, it was hoped that interviewing supporters as close to this time as possible would ensure their experiences and memories were still vivid.

All supporters had agreed to be interviewed when consenting to participate in the RCT. Those selected to be interviewed were contacted again by researchers before the semi-structured interviews to check they were still willing to take part. For participants with intellectual disabilities who did not wish for their support person to be interviewed, these supporters were not approached.

Materials

A semi-structured interview schedule was created in collaboration with members of the research team, as outlined in the protocol (Jahoda et al., 2015), to focus on supporters' experiences related to the therapy process. An initial interview schedule was piloted in three interviews, which was then revised by the project team to focus on exploring supporters' experiences of supporting the person with intellectual disabilities through therapy. The final interview schedule was divided into four general topics which could be followed up with questions or prompts: 1) supporters' expectations of therapy; 2) supporters' view of the therapy sessions; 3) working relationships with the therapist and person with intellectual disabilities; and 4) perceived changes and maintenance of change post-therapy. The use of a semi-structured interview format allowed the interviewers to explore these pre-determined topic areas whilst allowing supporters the flexibility to discuss other aspects of their experience which were important to them.

Procedure

Interviews were conducted either in the home of the adult with intellectual disabilities or in the workplace of the supporter, with interviews scheduled in times and places to encourage privacy. The interviews were conducted by three researchers in Scotland, England and Wales. The researchers conducted the interviews in alternative locations to where they were collecting the quantitative data for the wider study, to ensure they remained blind to the therapy type assigned to people with intellectual disabilities within their data collection areas. Interviews were audio-recorded and transcribed verbatim. Interviews were 20-80 minutes long. In two interviews, supporters opted for the interviewer to take written notes of the interview rather than have the interview audio recorded and transcribed. All supporters were assured by the researchers that their views would be kept confidential.

Data analysis

The qualitative analysis approach used in this study was framework analysis, originally developed by Ritchie and Spencer (1994) for analyses in applied social policy research. According to Gale et al. (2013, p.2), the defining feature of framework analysis is "the matrix output: rows (cases), columns (codes) and 'cells' of summarised data, providing a structure into which the researcher can systematically reduce the data, in order to analyse it by case and by code".

This method was chosen as framework analysis allows for comparisons to be made across the sample and also within individual interviews, meaning that whilst analyses of key themes arising across the entire dataset is possible, individual participants' views remain (Gale et al 2013). Additionally, a key aim of this qualitative component of the RCT was to increase our understanding of how each intervention operated and framework analysis allowed some specification of the dimensions of interest, whilst retaining the potential for emergent themes to revise or add to the framework. Using framework analysis also made it possible for each

of the researchers to code their own interviews and subsequently merge them together when applying the thematic framework, which was made easier by the highly structured way in which the data are synthesised when using framework analysis. Additionally, the summarising of data in framework analysis was helpful due to the relatively large number of interviews being analysed in this study (21 interviews).

Once the interviews were transcribed, an initial thematic framework, closely related to the topic guide, was developed. The framework was agreed on by the three researchers who conducted the interviews, a researcher responsible for merging coded interviews, and two researchers with experience in qualitative research. The three researchers who conducted the interviews then coded two interview transcripts each, with the researcher responsible for merging these coded interviews into the agreed framework attempting to merge them and the additional two researchers also reading through the transcripts and the initial coding. At this point, the framework was modified to encompass themes not present in the original framework by discussion and agreement amongst all the researchers involved. All the interview transcripts were then coded by the interviewing researchers and merged into the revised framework by the fourth researcher using NVivo 11 (QSR International, 2016). The final framework themes were agreed by all the involved researchers.

Ethics approval

Ethical approval was granted by the West of Scotland Research Ethics Committee 3 as part of a wider RCT (Jahoda et al, 2015). The International Standard Randomised Controlled Trial Number (ISRCTN) reference number is ISRCTN 09753005.

Results

The framework analysis was organised into six major categories: Before therapy; The therapy process; Relationships in therapy; After therapy; The impact of therapy; and Supporters' views on the therapy. Within these six major categories there were 17 sub-categories, with supporters mentioning a range of issues within each sub-category. Table 1 describes the number of supporters mentioning each specific issue, broken down by intervention type (Beat It – behavioural activation; or Step Up – guided self-help). A common overall framework of categories and sub-categories was generated for supporters across both the behavioural intervention and guided self-help interventions, with similarities and differences across the two interventions potentially emergent in the specific issues discussed by supporters. The same approach was taken to examining specific issues raised by supporters who were parents compared to supporters who were paid carers.Issues are only reported in Table 1 if more than one supporter across the whole sample mentioned the issue. Rather than repeating the numerical detail in Table 1, the results section will provide a narrative overview of supporters' experiences within the overall framework. It is also important to note that in addition to the quotes, some of the terms used in the results section (such as "low" or "down") have been chosen to reflect the language that supporters used.

Category 1: Before therapy

The first category related to supporters' perspectives before the therapy started, with Beat It and Step Up supporters reporting similar issues (see Table 1).

Supporters' views of participants before therapy. The first sub-category related to supporters' views of the people they were supporting before the therapy began. Supporters generally

reported that the person they were supporting was depressed or low before the therapy started; reasons cited for this included family bereavements/recent life events and weight issues.

> She'd put a lot of weight on and because of her weight she was getting a bit depressed and she didn't want to go out, she was getting down she was eating more and it was a little circle.
> (211 supporter interview, Step Up)

Supporters' expectations of the therapy. The second sub-category concerned supporters' expectations of the therapy, with supporters commonly mentioning a variant on being willing to 'give it a try' in the absence of other mental health support being available. While some supporters were unclear what to expect from either therapy, very few mentioned worries. Supporters commonly mentioned their hope that therapy would help the person they were supporting, most commonly in terms of building confidence, talking about their feelings, becoming happier and more positive in their thinking, and taking more control of their lives.

> I'd not really heard about anything else for people with learning disabilities who had got depression so yeah I thought it was a good idea and I'd give it a try.
> (218 & 219 supporter interview, Beat It)

Category 2: The therapy process

The second category related to supporters' experiences of the therapy process alongside the person they were supporting (see Table 1), with six sub-categories. Because the therapy

process was different for Beat It and Step Up (Jahoda et al., 2015), supporters' experiences of Beat It and Step Up will be described separately.

Beat It

The supporter's role. The role of the supporter was commonly described by supporters as providing 'moral support' and encouragement for the person they were supporting. Supporters also mentioned acting as an advocate for the person during the therapy, by explaining the therapists' words to the person and/or by encouraging the person to speak honestly to the therapist (or sometimes speaking for the person if the supporter interpreted the person as saying what they thought the therapist wanted to hear).

Materials. In terms of the materials used within Beat It sessions, supporters mentioned that completing and reviewing diaries was useful for the person and the therapist, although supporters not with the person at home mentioned it was difficult to routinely complete the diaries. The format of mood ratings was felt to be generally appropriate, although some supporters felt they were simplistic and they were sometimes adapted during therapy sessions. Supporters reported that both they and the person they supported particularly appreciated the formulation and plan for maintenance produced at the end of the intervention, as a truly person-centred record of the therapy and beyond.

Between sessions. A major component of behavioural activation involves people identifying potential activities to do between therapy sessions, and recording in the diaries how it went. Supporters commonly reported that the therapy stimulated the person, with support, to engage in a broader range of activities more frequently. However, it could be difficult to stimulate activities if the supporter was not part of the person's home life, and sometimes the person was not motivated to engage in the activities agreed in therapy sessions.

Learning about the person. Some supporters mentioned that the therapy had helped them to learn more about and better support the person, particularly in terms of really understanding the person and their difficulties.

Suitability of the therapy. Relatively few supporters discussed issues relating to the suitability of the therapy for the person they were supporting; those that did, reported that the therapy was appropriate and enjoyable for the person.

What worked well. Supporters reported a range of helpful factors that were not specific to Beat It, including the opportunity for the person to have honest and open conversations, the therapist being on the right wavelength, and using pictorial materials. Helpful factors specific to Beat It included the planning and doing of activities that were tailored to the person's interests and the sense of routine instilled by the therapy.

> It's changed my way of supporting [name] as well. It's understanding her more as well now because at one point we just sat and said 'behave' but we know now it's how she feels, how she feels deep down.
> (196 supporter interview, Beat It)

> Sometimes hard to actually do activities. Diaries difficult to always complete, he'd forget to do it some weeks. Sometimes do with (therapists) in sessions. Made me happy when he remembered to do it, got a routine which he'd been missing.
> (notes from 199 supporter interview, Beat It)

> The therapist is on the right wavelength for the nature of the client group we've got here. She explains things very well; she's a very natural person anyway, she's easy to get on with and I know that [name] got on with her really well because I can tell that the way [name] interacted with her, she was the right person to be doing this sort of

therapy. It was definitely person-centred and related to what came out of the activities. No problem with the actual activities.

(186 supporter interview, Beat It)

Step Up

The supporters' role. As with Beat It supporters, Step Up supporters mentioned their role as being to provide moral support/encouragement and to act as an advocate for the person in therapy sessions. Some Step Up supporters mentioned part of their role being to learn about depression and its management, not mentioned by any Beat It supporters.

Materials. In terms of the materials used in Step Up, supporters commonly mentioned the booklets being useful in both content and format, particularly booklets that were relevant to the person they were supporting. Some supporters reported that the way booklets were used sequentially in Step Up could be a little repetitive and inflexible, and would prefer the time spent on each booklet to be more tailored to the person's circumstances.

Between sessions. In accordance with the general Step Up approach, very few Step Up supporters mentioned activities between the therapy sessions.

Learning about the person. Supporters commonly mentioned that the therapy had helped them to learn more about, feel closer to and better support the person, with Step Up supporters putting a greater emphasis on knowing more about depression compared to Beat It supporters.

Suitability of the therapy. More Step Up than Beat It supporters discussed issues relating to the suitability of the therapy, commonly mentioning that the therapy was at an appropriate level and enjoyable for the person, particularly in terms of engaging with the booklets.

What worked well. Step Up supporters reported similar non-specific factors to Beat It supporters that helped the therapy go well, including the opportunity for the person to have honest and open conversations, the therapist being on the right wavelength, and pictorial materials. Helpful factors specific to Step Up mentioned by supporters included the booklets and the task-oriented problem-solving emphasis.

> I learnt loads and I now feel I'm in a better position to support [name] more effectively. Getting to understand where the anxiety comes from that leads to the depression; getting to know a lot more about [name's] past; obviously working together in a day service you don't always make that one to one time. It's made us closer.
> (203 supporter interview, Step Up)

> I do think she could have done with a little bit longer because personally the first couple of booklets weren't really too relevant, it just wasn't amazingly relevant but the last couple, you know where you tackle the problems head on, they were better I think and we could have done with a bit longer on them because with them coming at the end there was only a couple of weeks to really tackle the problems.
> (209 supporter interview, Step Up)

> The problem solving book is really good I've actually found it beneficial for myself. Definitely the sleeping one was good, it's good to recognise depression as well in the initial booklet because I think people don't realise, so I think all of the booklets were informative in different ways, but particularly I think it is important to recognise that you have a problem and that other people recognise that you have a problem as well.
> (289 supporter interview, Step Up)

Category 3: Relationships in therapy

The third major category (with two sub-categories) related to supporters' views of working with the person they were supporting and the therapist during the therapy, with many issues common to Beat It and Step Up supporters (see Table 1).

Relationship with the person in therapy. Supporters made relatively few comments about their relationships with the person they were supporting during the therapy, possibly because these relationships were generally long-standing. Some supporters mentioned different strategies in terms of letting the person speak for themselves vs. more actively encouraging/reminding/discussing the person with the therapist present, depending on their view of what would best support the therapy.

> I really liked the fact that as the weeks went by I could withdraw a little bit because the first session everything was coming through me and [name] was quite shy and would address things to me for me to pass back to the therapist but as the weeks went by she was quite confident to talk to the therapist.
> (204 supporter interview, Step Up)

Relationship with the therapist. Almost all supporters mentioned that they got on well with the therapist, who made them (and the person they were supporting) feel at ease and comfortable.

> I got on with therapist like a house on fire.
> (279 supporter interview, Beat It)

Both Beat It and Step Up supporters reported some common aspects of working together with therapists. Supporters reported having the person, therapist and supporter all together being helpful, because the supporter initially knew the person better than the therapist and they

could help each other generate ideas and plan. Some supporters mentioned that being in the sessions helped them know what was happening, and mentioned that although they offered to step out of therapy sessions so the person and the therapist could talk alone, the person and therapist wanted them to stay.

> I think it was easier with three because obviously for the person that knows me, that relationship and then the third person who is not as well known, I think it works better. (218 and 219 supporter interview, Beat It)

Category 4: After therapy

The fourth major category (with three sub-categories) concerned supporters' experiences of continuing to use elements of the interventions beyond the end of therapy.

Maintaining change. Supporters involved in both therapies generally reported similar issues relating to the maintenance of change after therapy (see Table 1).

While some supporters reported the person continuing to use materials and booklets from the therapy, usually with some prompts and adaptations to materials done with the supporter, other supporters reported that they or the person had not looked at any of the therapy materials/booklets since the end of the therapy. Some supporters reported that the person had made changes to their lives that had been planned in the therapy sessions, including engaging in new activities.

Barriers. Barriers to the maintenance of changes after therapy were reported by relatively few supporters, and included planned changes/activities not being encouraged in the person's home or not being available, having to prompt the person to use therapy materials, life events and physical illnesses.

Helpful factors. Specific helpful factors for maintaining change beyond the end of therapy were also mentioned by relatively few supporters, including the use of material that had been individually adapted by the person and the supporter, supporters routinely encouraging/prompting the person to do more activities and supporters being more receptive to the person asking for help and giving reassurance.

> We were actually reading through her book last week again, so we always bring it to light. Mood wise we've got some pictures that was printed off and mood has been good, so we've maybe looked at them once, just as a reminder that they're here, and you know if we feel that mood's going low again then we'll maybe pick up on trying to determine how you're feeling with them. But the booklet, we were looking through it last week again and it was in relation to the sleep, 'cos the sleep was just, she was feeling she wasn't getting her sleep. We look at the books about once a fortnight, and then just on a needs basis.
>
> (80 supporter interview, Beat It)

> We adapted the problem-solving worksheet, we talked about it together, it was very soon after it finished so we adapted it and made it a little bit simpler with less ideas and I think we had some more prompting type questions in there to explain so that it wasn't just like 'what's the problem; how do you solve it; what's the idea to solve it?
> It's really given me the confidence to try something different and move it on so we are still taking bits from it.
>
> (203 supporter interview, Step Up)

Category 5: Impact of the therapy

Supporters of Beat It and Step Up therapies generally reported similar issues concerning the impact of the therapy on the people they were supporting, and on any wider impacts of the therapy (see Table 1).

Impact on the person. Supporters mentioned a range of positive impacts of the therapy on the people they were supporting, including being involved in more activities and/or changing aspects of their routines such as sleeping routines, being more confident, communicating more about their feelings and what they wanted, being happier, and showing improved social skills. Fewer supporters mentioned positive impacts on the person's relationships with parents, supporters themselves, and the person gaining friends and/or more intimate relationships. Step Up supporters were more likely to report the person they were supporting being more empowered and problem-solving.

> It has done both (participant and his father) good as they are doing things together now like going to the pub for an orange juice.
>
> He's totally different. He improved last year working … [anonymised location] but his confidence has really improved now. It makes me happy and I can relax now knowing that he's got friends. He never had friends before.
>
> He's gone from doing nothing to working every day. Before he only went out on a Saturday or with us if we were out. He's a busy lad, it's so unusual for him to be working
>
> He's coping much better with crowds now, like going out for a meal with work.
>
> He's been texting his friends more in the past month and a half.
>
> (286 supporter interview, Step Up)

> A really big difference with her, more brighter, happier, she sings away (she never used to sing away before) she loves her singing, wanting to help everybody now.

She got more social skills, going out more, which she'll never say no. She'll always go out.

She's more happier anyway, she's more brighter. she's just a pleasure to have now. Everyone says she's a ray of sunshine when she comes in here.

She gained a lot of confidence, she can express herself more now, she's more happier (196 supporter interview, Beat It)

Broader impacts. Relatively few supporters mentioned broader impacts of the therapy beyond the person they had been supporting. Some supporters in paid roles mentioned they were now generally more proactive about mental health issues, and said they felt they could use the therapeutic approach and/or materials with other people they were supporting.

I've gone through and just gone in team meetings, 'these are really good. They've helped [name], have a read and when you're with [name] go through it as well.' It's helped.

There was a couple of them I thought 'oh doing the same one as [name] did could benefit them as well' especially because I think some of the other people that I support some of the other booklets would have been a bit more relevant as well, (possibly the sleep one) so just from seeing it you can think it could be relevant to quite a few. (209 supporter interview, Step Up)

Category 6: Supporters' views on the therapy

This category related to supporters' reflections on the therapies as a whole, and included two sub-categories.

Would recommend to others. Both Beat It and Step Up supporters were generally positive about the therapy they had supported (see Table 1), and would recommend whichever therapy they had supported to others.

Fewer supporters made specific recommendations for how the therapy could be improved.. Suggestions included more flexibility in tailoring the therapy to the person, having shorter and simpler sessions, having an extra review session some weeks/months after the end of the therapy, involving the person's family more (when appropriate), and (for Step Up) having additional booklets on topics such as diet, relationships and assertiveness.

> I do think it was helpful. Yeah I think they would recommend it yeah, they were helpful. I don't think it was too intense which was good, it was on a level that [name] could understand which was good, it sometimes can be different.
> (302 supporter interview, Beat It)

> It should be supported I think it should be supported and offered to people a lot more people. Because it does really, really help. I just can't believe that there is nothing out there for people with depression bar from going to the doctors and they say have some tablets. It proves that it can work without tablets. So there should be funding for it. So let's hope they do something about it.
> (295 supporter interview, Step Up)

> I think in [name's] case we could have started a little bit further along the process, we didn't need to start right at the very beginning with [name] because [name] can tell us what things he likes doing and things he would like to do.
> (186 supporter interview, Beat It)

It could go into things a little bit deeper perhaps, look at it a bit clearer perhaps more assistance.

(252 supporter interview, Step Up)

Discussion

This paper adds to the very sparse research literature on the experience and roles of supporters in psychological interventions for people with intellectual disabilities who are psychologically distressed. This is a commonly recommended adaptation to psychological interventions for people with intellectual disabilities (e.g., Beail & Jahoda, 2012; Lindsay et al., 2012a) but has very rarely been examined in research (Rose et al., 2005). This discussion will consider the findings as they relate to: 1) accessing therapy; 2) the role of supporters in the therapy process; 3) impacts beyond the end of therapy; 4) the feasibility of involving supporters in therapy.

In terms of accessing therapy, a common argument of clinicians has been that supporters may be useful in encouraging people with intellectual disabilities to attend therapy sessions and to maintain their participation in therapy (Beail & Jahoda, 2012; Lindsay et al., 2012a). With the general population, psychological interventions are often based on the assumption that people actively seek therapy and have the sense of agency and the power to make the necessary changes to their lives outside therapy sessions (Beail & Jahoda, 2012). These assumptions are less likely to apply to people with intellectual disabilities, where people are more likely to be referred by others for psychological therapy and are less likely to feel they have the power and control to make changes in their lives (Willner et al. 2005; Willner, 2006).

The RCT, of which this qualitative study was a component, reported high levels of uptake and retention of participants in both therapy arms, with 91% of randomised participants

completing therapy (Jahoda et al., 2017) and participants on average attending 86% of therapy sessions (Jahoda et al., 2017). In this study, supporters reported generally positive expectations of either therapy, particularly in the absence of existing support in their localities for people with intellectual disabilities and mental health problems, and also generally reported that the people they were supporting were motivated to take part in either therapy.

However, this high level of engagement must be considered in the context of a proactive RCT recruitment strategy offering two potentially credible therapies. Supporters were clear that the people with intellectual disabilities they were supporting were showing clear signs of depression, but that health services did not seem to recognise these signs of depression in terms of triggering action (beyond the prescription of antidepressants). In advance of therapy, supporters (whether family or staff) felt they had few resources to help them understand the person's depression and work with them to improve it. After the interventions, supporters reported themselves to be more confident and proactive in addressing the mental health needs of both the person they had supported through therapy and other people.

Throughout the therapy process, supporters generally discussed taking on the types of facilitative role envisaged by clinicians (Beail & Jahoda, 2012; Lindsay et al., 2012a). First, they reported that they acted as a bridge between the participant and the therapist, at times working as advocate, interpreter and motivator. The amount and nature of the 'scaffolding' provided by supporters varied according to the person they were supporting, and some supporters were highly attuned to the nuances of their supporter role. Some supporters also mentioned that the extent and nature of the support they provided changed over the course of the therapy as the person became more confident.

The role of the supporter was also important between therapy sessions, in terms of motivating and working with the person between sessions, and helping the person to share relevant

information about the therapy to other important people around them. The precise nature of the role taken on by supporters between sessions depended on the circumstances of the person and on the particular intervention, but supporters in both interventions were motivated to facilitate therapy-relevant activities between sessions on the part of the participant.

Supporters generally saw both interventions as useful in addressing the person's depression, with some differences in emphasis consistent with the intervention they were involved in. Both specific and non-specific therapist factors seemed to be important according to supporters. Step Up supporters more often talked about the intervention helping them to learn more about depression and its effect on the person they were supporting; Beat It supporters often talked about the intervention helping them to know and understand the person better.

The general demeanour of the therapist, and the opportunity to talk openly and honestly in a focused and structured intervention, were felt to be useful by supporters in both interventions. Given that most of the therapists were experienced in working with people with intellectual disabilities but inexperienced in delivering psychological interventions, this is highly encouraging when considering the extent to which these psychological interventions can be delivered effectively and at scale.

Supporters generally reported the person being happier, more confident and more socially active after therapy. The impact of the interventions on participants' lives seemed broadly non-specific. Again, consistent with suggestions from clinicians, supporters in this study reported an impact of the psychological therapy on their relationship with the person they were supporting; supporters reported having a closer and more understanding relationship with the person.

There was variation in the extent to which supporters reported that therapeutic materials and approaches were maintained beyond the end of therapy, and it should be noted that the

interviews took place a relatively short time after the end of therapy. Some of this variation seemed to depend on the contexts within which people were living. If supporters were not in relatively frequent contact with the person after the end of therapy, then facilitating the continued use of materials and approaches became more complex and indirect, through others in the person's life. Consistent with the accounts of participants, some supporters reported that continued use of the materials had not yet been needed post-therapy, but that they knew where the materials were and would use them if necessary. Supporters also modified the therapy materials to make them more individualised and relevant for the person they were supporting, and some were considering using the materials with other people they were supporting or, in one case, using the materials for themselves.

A final broader issue concerns the feasibility of routinely including supporters in psychological interventions for people with intellectual disabilities who are psychologically distressed, particularly within service contexts of limited support for people in their everyday lives. In the RCT as a whole, researchers had to liaise with referrers to identify supporters for 9% of participants. While 60% of participants had one supporter consistently throughout their therapy, 24% had two different supporters and 16% had three or more supporters (Jahoda et al., 2017). While the supporters being interviewed for this study were likely to have had a more positive experience, consistency of support, involvement in the person's life, and having time to spend with the person outside therapy sessions, were all mentioned as potential factors influencing the effectiveness of both the support and the therapy.

Finally, it is important to mention some methodological considerations relevant to this study. This paper exclusively reports on the accounts of supporters. While the views of supporters are largely consistent with both the quantitative data (Jahoda et al., 2017) and the qualitative data from participants with intellectual disabilities and therapists, there are a small number of instructive differences. For example, a small minority of participants and therapists

mentioned that the presence of supporters was not always constructive, which was not mentioned by any of the presumably more motivated supporters who agreed to take part in the interviews reported here. This also meant that other potentially negative aspects of including supporters, such as potential conflicts of interest and confidentiality, were less likely to arise in this study. The economic costs of supporter time (except where this was included as part of a person's service support) was also not included in the study (Jahoda et al., 2017), and because all participants had a supporter it was not possible to evaluate the impact of supporter involvement on outcomes for participants.

The timing of the interviews was designed to ensure that supporters still had vivid memories of their experience, but it meant that supporters' views on the longer-term impact (or not) of the therapy was not possible. Finally, while framework analysis was an appropriate choice of analysis method given the research questions and the volume of interview material, alternative analysis approaches would yield different insights into the experiences of supporters.

In summary, supporters in psychological interventions for people with intellectual disabilities and depression report taking on the facilitative roles envisaged by clinicians as being one component of effectively adapting psychological interventions for this population, with seemingly positive results.

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Table 1: Number of supporters mentioning categories and sub-categories by intervention type

Category/Sub-category	Beat It (n=11)	Step Up (n=10)
Category 1: Before therapy		
Sub-category: Participants		
Depressed/down	4	4
Life events/family bereavement	2	2
Weight issues	2	2
Lack of energy/mobility, withdrawal	2	1
Sub-category: Supporters' expectations		
Worth giving it a try	4	7
Hoping for positive impact on the person	5	5
Unclear what to expect	2	4
Nothing else available	1	2
Category 2: The therapy process		
Sub-category: The supporter's role		
Providing moral support/encouragement	6	5
Advocacy	6	4
Liaison between therapy and home	2	0
To learn	0	3
Sub-category: Materials		
Diaries useful (although support needed)	6	
Diaries difficult to complete in daily routine	4	
Mood ratings useful	5	0
Mood ratings too simplistic	2	1
Care plan person-centred and useful	4	
Booklets useful (when relevant)		8
Format of booklets useful (e.g. ticking boxes)		3
Using booklets could be repetitive/inflexible		3
Sub-category: Between sessions		
Therapy stimulating activities between sessions	7	2
Diaries/activities difficult to conduct	3	
Sub-category: Learning about the person		
Learned more about the person	4	5
Helped the supporter to better support the person	3	4
Made the supporter and the person closer	0	2
Sub-category: Suitability of therapy		
Therapy at right level for the person	4	5
Person enjoyed participating	1	7
Sub-category: What worked well		
Honest, open conversations	4	3
Therapist on the 'right wavelength'	2	4
Materials/mood ratings in pictures	3	3
Therapy in person's home	2	1
Planning/doing activities tailored to the person	4	
Helping to instil a routine	3	
Booklets		6
Task-oriented problem-solving		4
Category 3: Relationships in therapy		
Sub-category: Relationship with the person in		

therapy		
Intervening versus staying quiet	4	1
Sub-category: Relationship with the therapist in therapy		
Felt at ease/nice/relaxed	10	7
Having person, therapist and supporter helpful	3	4
Therapist and supporter helped each other	2	3
Good for supporter to know what's happening	1	4
Supporter offering to give person & therapist time	0	3
Tried to schedule for all three to be present	2	1
Category 4: After therapy		
Sub-category: Maintaining change		
Still using (adapted materials), with prompting	2	4
Not used materials since the end of therapy	3	1
With encouragement, still doing more activities	2	0
Continuing to make planned changes	2	2
Sub-category: Barriers		
Activities/changes not encouraged at home	2	2
Life events/physical illness	1	3
Need for person to be prompted/reminded	0	4
Support/services for planned activity not available	2	0
Sub-category: Helpful factors		
Using (adapted) materials	1	5
Supporter receptive to the person asking for help	1	2
Encouraging the person to do more	2	0
Category 5: The impact of therapy		
Sub-category: Impact on the person		
Talking/communicating more	5	2
More confident	5	3
Engaging in more activities	6	3
Happier	4	2
More empowered/problem-solving	1	4
Improved social skills	1	2
Better relationship with family	2	1
Better relationship with supporter	2	0
More friends/intimate relationship	1	2
Sub-category: Broader impacts		
Could use same approach with other people	1	5
Proactive mental health practice	2	2
Category 6: Supporters' views on the therapy		
Sub-category: Would recommend to others	6	5
Sub-category: Ideas for improving the therapy		
Tailor therapy to the person (materials/focus)	1	3
Shorter and simpler sessions	1	1
Extra review session sometime after end of therapy	1	1
Involve the person's family more	1	1
More depth	0	2
More booklets (e.g. diet, relationships, assertiveness)		2