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Mixed Experiences of a Mindfulness-Informed Intervention: Voices from People with Intellectual Disabilities, Their Supporters, and Therapists

Gemma M. Griffith¹ · Richard P. Hastings² · Jonathan Williams³ · Robert S. P. Jones⁴ · Judith Roberts⁴ · Rebecca S. Crane¹ · Hazel Snowden¹ · Lucy Bryning⁵ · Zoe Hoare⁶ · Rhiannon Tudor Edwards⁵

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Abstract

Objectives Mindfulness-based programs have been delivered to people with intellectual disabilities (ID) and aggressive behaviour with some success. The current study is part of a wider feasibility study, which aimed to test the adaptation of the Soles of the Feet (SoF) meditation practice to a six-session, one-to-one intervention delivered within the UK National Health Service. It was designed for adults with ID to help reduce their aggressive behaviour.

Methods Eighteen stakeholders were interviewed from three groups: (1) people with ID who took part in the intervention, (2) their supporters, and (3) therapists who delivered the intervention. Thematic analysis was used to analyse the data.

Results The intervention had high acceptability among participants, although they reported mixed outcomes, these outcomes aligned closely with reports on effectiveness from supporters and therapists. Some people with ID and their supporters reported positive changes, such as reduced aggression, increased sociability, and higher quality of life. Some participants reported no change.

Conclusions Four participants and their supporters reported clear benefits from the SoF intervention. For the three that did not report benefits, this appeared to be related to whether the person with ID understood the intervention and/or were motivated to reduce their aggressive behaviour. There was also evidence of supporters needing more direct instruction on how to facilitate the SoF intervention with the person they care for. Suggestions for future research are made, and clinical implications explored.

Keywords Intellectual disabilities · Mindfulness-based programs · Qualitative · Aggressive behaviour · Carers · Therapists · Thematic analysis · Soles of the Feet

The study of mindfulness-based programs (MBPs) has grown exponentially since the early 2000s and is an area of interest for both clinicians and researchers. MBPs are based on mindfulness-based stress reduction (MBSR) courses which were developed in the late 1970s (Kabat-Zinn 2013). Since then, MBPs have been

adapted for a large variety of clinical populations (Dimidjian and Segal 2015), including for people with ID (Chapman et al. 2013; Hwang and Kearney 2013).

It is estimated that 10–20% of people with ID engage in challenging behaviour (Allen et al. 2007; Cooper et al. 2009). Challenging behaviour is defined as being ‘of such an

✉ Gemma M. Griffith
g.m.griffith@bangor.ac.uk

¹ Centre for Mindfulness Research and Practice, School of Psychology, Bangor University, Brigantia Building, Penrhalt Road, Bangor LL57 2AS, UK

² Centre for Educational Development, Appraisal and Research: (CEDAR) Warwick University, Coventry, UK

³ Forensic Adolescent Consultation and Treatment Service, North Wales, UK

⁴ School of Psychology, Bangor University, Brigantia Building, Penrhalt Road, Bangor LL57 2AS, UK

⁵ Centre for Health Economics and Medicines Evaluation (CHEME), Bangor University, Bangor, UK

⁶ North Wales Organisation for Randomised Trials in Health (NWORTH), Bangor University, Bangor, UK

intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that that are restrictive, aversive or result in exclusion.’ (Royal College of Psychiatrists 2007, p.8). Challenging behaviours commonly include verbally or physically aggressive behaviours, self-injurious behaviour, and property damage. Challenging behaviours have a negative impact on quality of life, on carer well-being, and can result in admission to intensive and specialist residential, hospital or forensic services (Emerson 2000; Royal College of Psychiatrists 2007).

MBPs have potential to address a number of psychological processes that underpin the risk of anger and resultant aggressive challenging behaviour in people with intellectual disabilities (ID) (Wright et al. 2009). Aggressive outbursts may become automatic anger reactions, with little awareness of anger being present before the outburst. A meta-synthesis found that adults with ID are keen to learn how to self-manage anger (Griffith et al. 2013). MBPs can explicitly train awareness of the bodily, emotional and cognitive signs of anger, allowing for the individual to observe anger-related sensations in the body without attempting to avoid or act on them (Wright et al. 2009). The ability to self-monitor one’s own mood states is regarded as being central to anger regulation. MBPs may be useful for adults with ID as it is nonintrusive, can be personally empowering, not based on medication and promotes overall resilience and well-being (Gu et al. 2015).

In the USA, Soles of the Feet (SoF) meditation has been developed as a way of making MBPs accessible to people with ID (Singh et al. 2011) It has been successfully used in ID populations to self-manage anger and at long-term follow up has resulted in reported reductions or total elimination of aggressive behaviours (Adkins et al. 2010; Singh et al. 2003, 2007, 2008, 2011). A systematic review found the most frequent objective of MBPs for people with ID was the reduction of aggressive behaviour (explored in 7/12 studies), and of these, all reported a reduction after participating in an MBP (Hwang and Kearney 2013).

A recent meta-ethnography (Evans and Randle-Phillips 2018) analysed 16 studies in which people with ID were interviewed about their experiences of receiving psychological therapy. They identified helpful aspects of therapy such as feeling listened to and valued, opportunities to talk and therapies having a positive impact on their life. Difficulties included finding it hard to talk about challenging aspects and difficulty accessing the therapy and applying it in everyday life. There are even fewer studies in which participants with ID are asked about their experiences of an MBP. We found just three research papers on this topic, all of

which interviewed participants with ID who had taken part in a group-based MBP. One reported on the experiences of six participants who attended a weekly ‘relaxation and mindfulness’ group held in an inpatient unit. Participants spoke of feeling calmer and more relaxed, as well as what they found difficult e.g., ‘Hard to breathe from nose and mouth’ (Yildiran and Holt 2015, p. 53). Another reported a study on five teenagers with ID (aged between 13 and 15 years) who attended a 6-week MBP that drew on a variety of sources, for an hour a week. The teenagers reported the group as helpful and their parents reported a slight reduction in the impact that anxiety had in daily life (Thornton et al. 2017). Finally, Dillon, Wilson and Jackman, (Dillon et al. 2018) reported that 15 people with ID who attended a mindfulness group felt they gained benefits from the mindfulness practices such as feeling relaxed. The studies examining MBPs for people with ID are vastly heterogenous in terms of the interventions used, yet all studies show putative positive benefits, with no evidence of harm. Much more research is needed before we know for sure what the impact of MBPs is for people with ID, what interventions work best and for whom.

The participants in the current study were interviewed as part of a larger feasibility study in which a one-to-one manualised mindfulness-informed intervention, based upon the SoF (Singh et al. 2008), was delivered within NHS settings, named ‘Using Mindfulness for Anger and Aggressive behaviour with people with Learning Disabilities—Soles of the Feet intervention’ (henceforth referred to as UMAA-LD SoF). In the NHS, people with ID are often referred to as having an LD (sometimes interchangeably); as this was an intervention delivered via the NHS, the term LD was used when naming the intervention, although the term LD still refers specifically to people with an IQ of around 70 or below. This qualitative study aimed to explore how UMAA-LD SoF was experienced by people with ID, their supporters, and therapists. This included exploration of how intervention itself was experienced, the effect of the intervention, and what supported engagement with the intervention. This was explored with three stakeholder groups: (1) people with ID who participated in the study, (2) familial or paid supporters (hereafter referred to as supporters) and (3) therapists who delivered the UMAA-LD SoF.

Method

Participants

Eighteen participants were interviewed from the following three groups: (1) people with ID, (2) their supporters, and

Table 1 Demographic information about the three groups

Person with ID						Supporter	Therapists ^b	
ID no	Gender	Age	WASI score	ABAS General Adaptive Composite (GAC)	Does the data support benefits from UMAA-LD SoF? ^a	Relationship to person with ID	Gender	
1	M	44	58	59	Yes	Family member	F	Not interviewed
2	M	32	62	74	Yes	Other professional	M	Not interviewed
3	F	30	48	68	No	Paid support worker	F	Interviewed
4	F	28	71	78	Yes	Not interviewed	–	Not interviewed
5	F	22	47	59	Yes	Family member	F	Not interviewed
6	F	25	53	63	No	Paid support worker	F	Not interviewed
7	M	51	58	64	No	Paid support worker	M	Interviewed

^a A ‘Yes’ refers to when the person with ID and supporter both reported tangible benefits (e.g. feeling calmer, being less wound up etc.) arising from the intervention, with the exception of participant 4 who did not have a participating supporter but who spoke of the benefits herself. A ‘No’ refers to no tangible benefits arising from the intervention being reported by either participant or supporter, beyond a general enjoyment and participation in the UMAA-SoF sessions

^b There were three other therapists interviewed who delivered the intervention, but not to these participants

(3) therapists who delivered UMAA-LD SoF. See Table 1 for further demographic details.

People with ID Who Completed UMAA-LD SoF Seven participants were interviewed (50% of participants who completed the 6-month follow up in the wider feasibility study). Inclusion criteria were (1) over the age of 18 years, (2) with an ID (established through the administration of the Wechsler Abbreviated Scale of Intelligence 2nd Edition (WASI-II; Wechsler 2011) and Adaptive Behavior Assessment System© (ABAS; 2nd Edition [Harrison and Oakland 2003]), (3) had clinically significant difficulty with anger control as assessed by their clinician, (4) able to give informed consent and (5) had a family member or paid carer who had supported them for a minimum of 6 months, was available to participate in the treatment sessions and who provided a minimum of two hours support per week. All participants had a mild to moderate level of ID and completed the full intervention apart from participant 6, who completed four weeks of the intervention—her supporter decided to remove her from the intervention- but did not detail the reasons.

Supporters In the wider study, eight supporters remained in the study at 6-month follow up; of these, six supporters who had attended the UMAA-LD SoF sessions were interviewed (75%). Of those interviewed, two were family members, and four were paid carers. The supporters’ role was to actively engage with their family member/client in the UMAA-LD SoF sessions, providing support during the formal training sessions and at home.

Therapists Five out of 10 therapists who delivered UMAA-LD SoF were interviewed (50%). Two were the therapists of P3

and P7; the remaining three had taught the intervention to clients not interviewed in this study. Of these three, one therapist (Therapist C) had taught four UMAA-LD SoF courses, and the other two had taught a single course each.

Procedure

Ethical approval was gained both from the NHS research ethics committee and from Bangor University. This qualitative study was part of a larger feasibility study which recruited 19 people with ID who engaged with UMAA-LD SoF and retained 14 participants at the 6-month follow up. The protocol of the feasibility study is detailed in Griffith et al. (2016). Broadly, recruitment was via clinician referral in NHS ID services in Wales, and UMAA-LD SoF was delivered within NHS services. Informed consent was given by all participants for the study. The feasibility study had a recruitment rate of 90.5% and a retention rate of 73.7% (Roberts et al. 2019).

The data for this qualitative study was gathered in the final face-to-face researcher visit to the participant and their supporter at the participant’s home, which took place 6 months post-baseline. Interviews were conducted at the end of the researcher visit, after the participant had completed the quantitative outcome measures. These visits sometimes lasted over two hours, during which the trained researcher supported the person with ID to complete questionnaires. Due to participant fatigue, interviews were not possible for seven participants. There were five main areas participants were asked about: ‘What was learning about being mindful like?’ ‘What did you like/not like about mindfulness?’ ‘How difficult/easy was it to learn mindfulness?’ ‘Do you use SoF now?’ and, ‘Will you use mindfulness in the future?’ All questions were asked to all participants, with the researcher supporting the

participant by adapting and/or repeating questions if necessary. Interviews with participants with ID were fairly short and ranged from just over 5 min to around 13 min in length.

The therapist data was gathered within a 3-month period of delivering UMAA-LD SoF; although all 10 therapists were contacted for interview, their availability meant that only five were interviewed. All interviews were audio-recorded, semi-structured, face-to-face interviews.

UMAA-LD SoF The intervention is regarded as mindfulness-informed, not mindfulness-based. MBPs have the practice of mindfulness as a central methodology, whereas mindfulness-informed interventions draw upon the practice and philosophy of mindfulness, but also integrate other methodologies into the program. The intervention was delivered over six sessions, with sessions approximately 1 week apart, and is further described in Griffith et al. (2016). In brief, core SoF meditations by Singh et al. (2008) were used as a basis, during which participants were taught to recall situations that made them angry, then guided through the steps of the SoF meditation. These include acknowledging and noticing angry thoughts or emotions, and then shifting attention to the soles of their feet (a neutral part of the body). Participants were then encouraged to use the SoF meditation whenever they notice they are getting angry, with the intention that this can allow angry feelings to dissipate or reduce, so the participant is less likely to engage in aggressive behaviour.

There were some adaptations to the original SoF manual (Singh et al. 2008); the main adaptations were (1) UMAA-LD SoF designed for use in UK NHS settings. The UMAA-LD SoF manual provided specific outlines for each of the six sessions. Each session took up to 90 min, with the therapist pacing the session to meet participants' needs. See Table 2 for a typical session format. (2) A pack of educational materials suitable for people with ID that gave information about anger, aggression and mindfulness was provided. These were used in sessions and were also taken home by the participant to read. (3) UMAA-LD SoF sessions encouraged the participant to engage in short, daily home meditation practices each week.

Table 2 Typical format for a UMAA-LD SoF session

Content of session	Approximate time frame
Introducing the session	5–10 min
Review homework log	5–10 min
Psycho-educational component i.e. what is anger? How do I know that I am angry?	20–30 min
Comfort Break	5–10 min
Soles of the Feet meditation practice	20–30 min
Review of the session and home practice setting for next week	5–10 min

The home practices followed the progression of the six sessions. A CD with three tracks of SoF meditations (each 4–6 min long) were given to participants.

Data Analyses

The main research question explored was the impact of the SoF intervention on the lives of people with ID, with a secondary question about what supported their engagement with the intervention. All data that was not relevant to these questions was not analysed (for example, data about therapists' experiences of training to deliver UMAA-LD SoF). When it was not clear if the text was relevant to the research aim, it was included in the analysis in order to capture all potentially applicable data.

Thematic analysis was used to interpret data (Braun and Clarke 2006). The first author conducted separate thematic analyses for each participant group, in order to be consistent with the core principle of thematically analysing homogenous groups as far as possible. All the interview data collected from the participants with ID were used, whereas from the supporters and therapists, only the data relevant to the research question was analysed. Therefore, some data collected during these interviews is not included in this paper. For example, data on the impact of the intervention on the supporter or the therapist themselves, and practical implementation questions such as the SoF training and delivery.

First, the recorded interviews were transcribed, and all transcripts were read line by line by the first author, noting points of significance and emerging themes. The themes and supporting quotes were compiled in a separate document for each transcript, and then the interview documents were grouped together according to participant group, so there were three 'master' theme tables, one each for participants with ID, their supporters, and the therapists. The themes were then identified and developed during the write-up of the Results section, following the six-stage protocol for thematic analysis as described by Braun and Clarke (2006).

Thematic analysis is an inductive approach where the researcher develops themes from the data with—as far as possible—no pre-existing theories about what they 'should' find (Braun and Clarke 2006). To enhance reliability of the data analyses, the data from the supporter interviews were triangulated with the seventh author's initial analysis of the data as part of her MSc thesis, and there was full alignment on the thematic analysis between the two authors, with no disagreements about the themes generated. Additionally, the first author kept a reflexive diary throughout the analysis process to help ensure that the analysis was as unbiased as possible (Berger 2015). She is a researcher and mindfulness teacher and trainer and was aware of potential bias towards reporting positive effects of the intervention and ignoring or downplaying data which did not. Great care has been taken

to commit to the inductive nature of qualitative research, so as far as possible, the results presented represent the full range of the data.

Results

The data from the three groups is presented separately below, first, the data from the participants with ID, then the supporters and finally the therapists.

Participants with ID

Three superordinate themes were developed: (1.1) the journey: a mixed bag; (1.2) after-effects of UMAA-LD SoF and (1.3) mindfulness in everyday life—now and in the future.

The Journey: A Mixed Bag

Participants were largely positive about UMAA-LD SoF; a few were neutral and noncommittal in their response, and one person reported they did not like the intervention itself but enjoyed spending time with the therapist. A typical positive response was as follows:

P7: Yeah, put your feet on ground and enjoy.

I: Yeah.

P7: Yeah.

I: You remember doing that?

P7: Yes.

I: And what was that like for you?

P7: Good, good, yeah.

Three participants recalled that UMAA-LD SoF was hard to learn about at first, and one participant described UMAA-LD SoF as ‘Very very weird—trying to figure out how to do stuff’ (P4). Three of the participants who said it was difficult to learn also stated during the interviews that they had a goal in mind and wanted to reduce their aggression. These participants thus worked hard to understand UMAA-LD SoF and engage in the home practice. As the sessions progressed, three participants (P1, P2 and P4) reported that their understanding increased.

It was hard at the beginning (..) but I thought it was easy when I got used to it it was alright. (P1)

I think it was, it was hard at first, then talking to the nurse, got better at it. (P2)

Once you practice...it was getting easier. (P4)

Participants reported a range of different things that they liked about UMAA-LD SoF and felt generally positive about their experience, but throughout the interviews, they were not able to communicate precisely what it was about UMAA-LD SoF

that was helpful. For example, some spoke of the calming effect of meditation practice.

Very soothing. Very soothing, and relaxing. (P1)

It gave me a chilling out experience so I've got too much chat up there. (P4)

Um, just enjoying relaxing and putting my feet on the ground. (P7)

A core practice in the SoF intervention is when the therapist invites the participant to evoke a happy event in one session before being guided to shift their attention to the soles of the feet. This practice is then repeated using an anger-inducing event for the remaining sessions. Some participants were very clear that they enjoyed doing specific exercises such as the SoF meditation, although they found it difficult to articulate the concepts behind what they were doing, perhaps demonstrating that they did not understand the intention of the exercises fully.

P2: Um... I think it's probable... I like the most, eh... imagining the brain.

I: Right, OK.

P2: That was good, I liked doing that yeah.

I: Yeah. So, what were you picturing up there then?

P2: Like when they do say good things, stuff like that, plus lots of bad things imagine bad things as well, stuff like that there was as well. (...) Think back, you know. You feel like you're there.

Some were not able to go as far as to articulate what they liked best about the SoF intervention but seemed to have a largely positive experience.

I: And, what bit did you like best about it?

P5: Everything.

Some participants were neutral or noncommittal in their responses ‘It's ok’ (P3) and ‘Alright’ (P6), but either did not want to or could not elaborate further. In addition, P6 frequently spoke about how much she enjoyed talking to the therapist, although said she disliked the mindfulness practices and did not really engage with UMAA-LD SoF itself.

I: Yeah, did you like it [the meditation practice]? Or didn't like it?

P6: Didn't like it.

I: You didn't like it.

P6: No.

I: What didn't you like about it?

P6: Eh... don't want to talk about it.

I: Don't want to talk about it?

P6: Well, I like, I like talk to [therapist name]

All participants reported liking their therapist and getting on with them well. Overall, the UMAA-LD SoF sessions were a pleasant experience for participants and acceptable to them. It was notable that participants had different levels of engagement with the intervention, and this seemed to be reflected in the precision of their responses when asked about the learning process. Two participants expressed an aversion to an element of the interventions which asks participants to recall a situation that made them angry. ‘It was hard at the beginning (...) I get angry, tensed up in my body, kept up to three times, well it took three times to relax me, so well done.’ (P1) A core message of UMAA-LD SoF is to encourage participants to turn towards and experience their anger—along with the message that being angry is a natural emotion. This turning towards difficult emotions is what P4 found most difficult about UMAA-LD SoF.

I: Yeah, so which bits were hard?

P4: Focusing on what was angry and upsetting you.

There was a variation of engagement with UMAA-LD SoF between participants, but the majority were overall positive about the experience. Some found it difficult at first and reported that turning towards unpleasant feelings was challenging. What was difficult to uncover from the accounts was precisely what was good or difficult about the intervention beyond fairly broad statements of liking or disliking, which may be related to participants’ cognitive challenges.

After-Effects of UMAA-LD SoF

SoF meditation is a specific strategy participants are taught to apply when becoming aware of anger arising. However, the impact of UMAA-LD SoF was much broader than applying the use of this single technique. Several participants spoke of being generally calmer and able to self-regulate, which, for one participant, resulted in being able to participate in everyday activities, and for others, managing social relationships more skilfully. Many—but not all—participants noticed a positive change in themselves and attributed this to UMAA-LD SoF. Three participants spoke of a general sense of being less reactive to stress since the course. For example, P2 stated ‘I’ve gone a lot calmer since I’ve done the course’ and P4 reported that ‘I just can’t stay angry at things.’ P4 also spoke of how mindfulness was useful at particularly difficult times ‘It just helped me when a whole pile of stress going on.’

The SoF had a significant positive impact on P1 in terms of reduction in anger, he said; ‘My anger stopped, my anger stopped, stopped being angry. Stop being angry, stopped being so...wound.’ Rather than speaking about his reaction to particular situations, P1 seemed to be referencing a persistent state of being wound up and tense which meant he spent most

of his time alone in his bedroom ‘cooped up’, and did not participate in everyday activities before the SoF intervention.

P1: Before...I couldn’t do anything, but now I can do things.

I: Yeah.

P1: I can relax, watch TV.

Although not part of UMAA-LD SoF—which focuses on the emotional reactivity to anger—an effect of the intervention for three participants (P1, P2, and P5) was that they had developed and applied strategies for working with difficult interpersonal relationships so they were less likely to become reactively entwined in conflict.

Like and since when my dad’s trying to argue, I just erm, try not to ring him, I just say he text me, which is better innit? (P2)

Two participants said they did not notice any changes in themselves after the intervention; for example, P6 described herself as ‘All the same’ and was vague when asked to elaborate, perhaps indicative of a lack of understanding of the intervention. The following response was typical:

I: So, what do you think the biggest change is?

P3: I’m...Not to be.. Not to be happy or sad.

There was more evidence of participants not understanding some core concepts of UMAA-LD SoF. For example, a central message is that it is normal to feel angry sometimes; although P5 reported positive benefits of the intervention, she did not feel her anger was an acceptable emotion, which is evidence of a vague—or even inaccurate—understanding of core mindfulness concepts.

I: So, has learning the soles of the feet changed how you feel about being angry?

P5: Yes, always.

I: Do you feel it ok now to be angry?

P5: No.

Two participants gave conflicting answers during the interview, sometimes saying the intervention helped and sometimes saying the opposite. It was unclear if they understood the question or were complying with the interviewer.

I: Yeah...ok, do you think it [SoF] helped you at all?

P6: Yes, did help at all, yeah.

I: How did it help you?

P6: um...[pause]

I: If it didn’t help you, you can say: “it didn’t help”

P6: It didn’t help.

The participants who said the intervention had no effect on them were either unable or unwilling to elaborate on this point. It is therefore difficult to know how these participants experienced the intervention, or what aspects of UMAA-LD SoF were unhelpful, or, alternatively, whether this is indicative of them finding the intervention difficult to engage with. In contrast, when participants spoke of positive impacts, they were able to elaborate on what those positive changes had been and pointed to fundamental shifts in their behaviour or general sense of well-being.

Mindfulness in Everyday Life—Now and in the Future

Some participants had independently meditated at home successfully and spoke of engaging in meditation practice because it was relaxing and a generally pleasant thing to do. Many spoke of how they helpfully used mindfulness in their daily lives at the time of the interview; what was less clear from the interviews is whether, and how, they planned to continue using mindfulness in the future. Some engaged in independent meditation practices (i.e. without using the CD) at times where they felt it would be supportive.

It helps me to put my feet on the ground, and enjoying myself, relaxing...really good. (P7)

P5: I'm in bed last night I'm doing...my breathing exercise in bed.

I: Well done, so you're still doing it?

P5: Yeah, still doing it.

I: And do the people have to remind you or you just do it yourself?

P5: Do it myself.

Although the main intended outcome of UMAA-LD SoF is to enable participants to use the SoF mediation practice whenever they feel anger arising, only one participant explicitly stated that they used the SoF in this way: 'Soles of the feet, so if I get angry I think "Oh I'll take a deep breath and think of the soles of the feet."' (P1). Participant 5 showed some understanding of the concept of SoF, but it was unclear whether she used this in response to anger outside of the sessions 'You push it down to your feet instead of they going upwards to your head.'

As part of the UMAA-LD SoF intervention, each participant received a CD with three short guided meditations and was encouraged to use it in-between the six sessions. All participants said that they had used the CD at home, and this varied from using it several times per week at the time of the interview to 'a few times' (P7) in the past.

P2: Yeah. Still using it now sometimes [the CD].

I: Yeah. How often do you do it now?

P2: Erm...I do about four days, four days a week still. Three or four days, yeah.

The participants who reported benefits from UMAA-LD SoF also used the CD regularly, whereas those who did not were less likely to continue using the CD. It was difficult to interpret from the interviews in what way participants intended to use the SoF practice in the future; some said they would use it but were vague about how or when they would use it.

I: And will you carry on using what you've learned?

P2: Yeah, think I'll carry on.

I: You're gonna carry on?

P2: For good (laughs).

Some participants choose some parts of the intervention that they liked and would use in the future; again, it was unclear whether there was an intention to continue to practice mindfulness.

I: Ok, and, will you carry on with the soles of the feet, do you listen to the CD now?

P3: No, at the moment, no.

I: No, Ok. You don't do that. Do you ever use your breathing to calm yourself?

P3: Yes

The main aim of UMAA-LD SoF is to give participants a meditation practice they can use in any situation where they feel anger arising. Just one participant reported using SoF in this way, with the majority using a simple breath practice as and when needed to enhance their well-being. Some participants, although they listened to the CD regularly, did not appear to engage in the practices after the intervention had finished. It was difficult to discern, even among participants who said they currently benefited from their independent mindfulness practice, how they intended to use mindfulness in the future.

Supporters

The results from the six interviews with supporters are described below, five themes are described; (2.1) motivation is key, (2.2) understanding is key, (2.3) changes in aggressive behaviour, (2.4) everyday impact of SoF and (2.5) supporter understanding of SoF.

Motivation Is Key

The motivation of the person with ID played a significant role in the supporters' opinion of the suitability of UMAA-SoF. Two family supporters and one professional regarded high motivation as instrumental to successful engagement. In contrast, three professional supporters described their clients as having a lack of motivation which led to their clients deriving little benefit

from the course, beyond a superficial enjoyment of the social aspects of a trip out, or interaction with the therapist. Motivation to engage and levels of compliance with the recommended SoF activities varied between participants and largely split in half—three described the person they cared for as having actively engaged with the course. The other three supporters reported that their client did not understand the intervention and was not motivated to change, and did not—or could not—engage with UMAA-LD SoF intervention content.

Three supporters reported that their client/family member wanted to reduce their aggressive behaviour and were therefore self-motivated, some with a specific goal in mind:

She'd seen what she'd done and she realised it had taken her so many years to go on holiday after the last disaster and she didn't want to do it again. (Supporter 5)

The same three supporters reported that the person they cared for tried hard to engage with the SoF – which meant they were able to persevere even when initial difficulties were experienced.

He was determined he was going to do it, and he was there with the CD ... but he didn't need prompting to do it. (Supporter 1)

(He) made good use of the course and really give it his all, really tried hard, focussed and did everything that was asked of him outside. (Supporter 2)

In contrast, the other three supporters spoke of how the clients were not motivated by a desire for change and were largely indifferent to the content of the sessions, as they simply liked the break in their routine, or did the intervention due to expectations of others around them.

It's not something she'd say "I got to do it because it's going to help me". No, it's a case of "[therapist] is coming we are going to do it" it's done and it's put away. (Supporter 3)

However, all supporters spoke of a positive relationship with the therapist who the person with ID liked spending time with—independently of whether they perceived the course was suitable for their client or not.

Understanding Is Key

Half the supporters regarded the SoF as appropriately pitched to the understanding of the person with ID; the rest felt it was difficult to understand. Typical comments of those who felt the SoF was at an appropriate level:

Quite simple and easily accessed which is important. (Supporter 2)

Another supporter described how some initial difficulty was overcome by a willingness to persevere:

It was hard to start off with until she got into how things worked, understanding it, it's the understanding, perhaps to do with the disability you see, so you have to repeat and repeat until it's sunk in. Then once it was there it was fine. (Supporter 5)

The three professional supporters, however, felt their client did not have an understanding of the SoF intervention:

[Client] tended to repeat quite a bit of it, as opposed to answer what [therapist] was trying to ask her. (Supporter 6)

I just think on the whole she finds it hard to relax and she doesn't understand what you mean when you say relax. (Supporter 3)

A supporter felt his client struggled with the more cognitively demanding elements of the intervention, who was not able to recall a situation that made him angry to work with in the SoF meditation:

What is anger to him? And it- is it self anger or is it someone else's anger? You know, he still remembers other peoples as well and gets them mixed up. (Supporter 7)

However, all supporters reported that the person with ID was able to engage in the simple, more practical mindfulness practices (such as sitting still and focusing on the breath) during the sessions.

She'd do it in the sessions... and she could sit and close her eyes and she would breathe and she held the bean bag and things and she could do the physical sort of things. (Supporter 6)

All supporters reported that the person they cared for seemed to enjoy the sessions and were able to engage with some of the simpler meditations (focusing on the breath or the body). Some said the person they cared for struggled with recalling an anger-inducing situation and working with this in the sessions and did not appear to understand what was asked of them. It is unclear what differentiated this, although the qualitative data presented here points to motivation and lack of understanding being a crucial factor; those who wanted to reduce their aggressive behaviour (perhaps itself a sign of greater personal insight and understanding) also had a greater understanding of UMAA-LD SoF and were able to apply this learning to their everyday lives.

Changes in Aggressive Behaviour

The aim of SoF was to reduce instances of aggressive behaviour, and three supporters observed significant positive changes in the person they cared for. Three supporters who perceived benefits from the SoF course discussed positive changes in attitude and behaviour. However, two paid supporters reported no changes, and one (P7) was mixed, stating at first that there was no impact but then later said ‘It does take a lot less to calm him down (...) that has calmed down a bit and working much better in that way.’

Of those that reported a clear positive change in the person they cared for, one supporter spoke of how her family member’s aggressive response had reduced.

He’ll come in and say something’s happened ...and I said, “What did you do?” And he said “Oh, I let her get on with it.” ... he wouldn’t have done that before he would have been round banging on the window probably. (Supporter 1)

Similarly, the other two supporters gave examples of positive behaviour change in response to a situation that previously would have likely prompted an angry reaction:

A couple of weeks ago there was somebody who said something ... something along the lines of “What are you looking at?” and [client] just ... kept on about his business (..) Didn’t get involved. (Supporter 2)

Supporter 5 spoke of how she had noticed a general reduction in aggressive behaviour, although this did not arise from her family member actively implementing the SoF practice when she noticed anger arising but seemingly from more cognitive awareness about her behaviour in general;

She seems to think that little bit more before she kicks off (...) you can see she’s sort of backing off and then she... then she ju-... and then walks off (...) It’s made her understand things more that she can’t kick off whenever it suits her. She’s got to think about the consequences.

In contrast, the two supporters who reported no benefits in mood or behaviour, e.g., ‘I can’t say she has benefitted if I’m honest.’ (Supporter 3), attributed this to their clients not understanding the SoF sessions and were thus unable to actively engage in the intervention ‘If you don’t understand something, you’re not interested in it.’ (Supporter 6).

Everyday Impact of UMAA-LD SoF

The effects of UMAA-LD SoF were not limited to a reduction in aggressive behaviour; there were also reports of a broad

change such as a reduction in anxiety and increased confidence ‘Definitely more confident and more settled’ (Supporter 2) and better moods ‘That’s helped with [her] bad moods’ (Supporter 5). Although changes in moods are not an explicit target of UMAA-LD SoF, this was reported as changing for the better and had a positive impact on quality of life.

When he goes out he’s not so stressed and he’s not worrying so much (...) it’s brought his confidence back ... I think because he has the confidence to go out knowing that he doesn’t have to get involved in an argument. (Supporter 1)

All three supporters who considered that SoF was suitable for the person they cared for identified positive life changes, explaining how they had engaged more inclusively with everyday activities.

He’s been able to go out and it’s changed his life really, turned it right round. (Supporter 1)

This supporter perceived a radical change in outlook for the client, which also impacted on his being able to resume leisure activities:

There has been a self-realisation, that he is, umm, an adult in his own right, can make his choices and can keep out (of) situations if he chooses (...) [He’s] managed to return to situations, trips away at weekends and things that had to stop for a while. (Supporter 2)

Positive changes in relationships were also noted for the same three people. One supporter reported that their family member was more sociable within the family, and also started to form new relationships outside the family unit since the intervention:

He’s talking about other people that he’s met, you know he’s made friends at these places (...) he is joining in... he does get on with people they are all saying that he gets on. (Supporter 1)

Positive change was also evidenced by an absence of problems:

[She] hasn’t fallen out with anybody lately. (Supporter 5)

It is important to note that no changes in quality of life were reported for those who were not motivated to change and/or did not understand the intervention; supporters reporting on this did not go into any details beyond saying that little had changed in their client’s lives since the intervention—typical

responses were ‘I think he used it as a trip than it did something to help him’ (Supporter 7). One supporter wondered why the person they cared for had the intervention at all, ‘She doesn’t very often get angry’ (Supporter 3), and did not report a change in behaviour.

Supporter Understanding of UMAA-LD SoF

There was some evidence that two supporters did not understand the core principles of UMAA-LD SoF. This was only found among paid supporters: one said, ‘Some of it is really difficult to understand (...) even for me (...) I am a professional’ (Supporter 6). Another supporter recalled an incident where, immediately after a highly charged aggressive episode, he played the SoF CD in order to ‘try and calm him down’, and was ‘baffled’ that it did not help his client (Supporter 7). This action demonstrates that some supporters may not have understood the SoF intervention, and so were unable to be supportive of learning—which has to take place when the person is fairly stable and able to engage with angry feelings without getting caught up in them. The intervention does not attempt to ‘fix’ anger but rather offers an alternative way of relating to it. Of note is that the clients of these two supporters were among the participants with ID who did not appear to benefit from UMAA-LD SoF (See Table 1).

Therapists

The analysis of the five therapist interviews is described below; between them, they taught eight clients UMAA-LD SoF. The data presented is about their experience of teaching clients and working with supporters, in order to explore the secondary aim of the study about what supported the person with ID. The therapists who did not teach the participants in this study have been assigned letters (e.g. therapist A) to easily distinguish them from those that did. Two themes are described: (3.1) did clients with ID understand UMAA-LD SoF? and (3.2) supporters in sessions.

Did Clients with ID Understand UMAA-LD SoF?

The understanding (or lack thereof) of clients dominated the therapists’ accounts of their delivery of the SoF sessions. Three therapists had clients who they felt did not understand the SoF intervention; one felt their client did understand it, and another had some clients that did and others that did not understand. One therapist did feel that their client was fully engaged in the process:

She gave me such a wonderful level of depth in her responses that I was in no doubt that she’d understood what I was asking her. (Therapist A)

Those that reported a lack of understanding also felt the client enjoyed the sessions despite not being able to engage fully with the content; here is a typical comment:

It just wasn’t clicking for him. I showed him the snow globe and explained how it represented his thoughts. He asked if it was real snow. He just seemed to be missing the point. Another example is that when we did the sitting and breathing practice, whatever I said he would repeat. For example, if I said sit comfortably, he would reply “Yes I’m comfortable”. He just kept talking throughout, which is part of him. He was happy to do it but it wasn’t making any impact. He didn’t get the essence of it. (Therapist B)

During the interviews, therapists were keen to stress that further screening before UMAA-LD SoF would have been beneficial, to assess whether clients were cognitively able to participate in the intervention, and additionally to check their motivation and willingness to commit to a mindfulness practice.

In relation to eligibility and I think certainly the level of cognitive ability is one consideration (...) So I think with a robust eligibility screening tool then absolutely it will be really valuable. I think perhaps I should also consider motivation and commitment to engage in that process, alongside cognitive ability. (Therapist A)

Supporters in Sessions

The intention of UMAA-LD SoF was that supporters would come to all sessions and thus gain an understanding of mindfulness themselves, and then be able to support the client to engage in practicing mindfulness at home. In this sample, just one therapist reported that having a supporter present was beneficial to one of their clients. The rest either reported no impact or an actively negative impact on the sessions.

I think the support teams were a bit more on the ball and they were trying to incorporate the practice into activity schedules and things like that (...) with family members they just, the ones I was working with, they were just sitting there because they had to, or they fell asleep, it was my voice sending them off so they weren’t as engaged as the support team. (Therapist C)

For the therapists, supporters who sat in on the sessions but did not join in caused difficulties, and having a supporter at the sessions was another ‘task’ that the therapist had to monitor during the sessions.

I think dealing with the [paid] carer and getting her to be motivated as well with the approach, that was definitely a challenge. (Therapist C)

Another therapist reported on the lack of consistency of supporters, so the person with ID had no consistent support to help them apply the SoF practices at home.

I think I had six different support workers within the eight weeks so it didn't help and then because it's a haphazard rota (...) And it didn't help her because then [paid supporters] weren't relaying the stuff even though I'd spent time with them. I couldn't spend time every week with a different support worker, there wasn't the time for that. (Therapist 3)

Therapists spoke about how wider organisational issues prevented supporter engagement, and also on an individual level, how supporters needed support to enable them to (a) understand UMAA-LD SoF and (b) help to adequately support their client at home.

It would be nice to have just a little bit of a training pack for the supporters that are gonna support them, so they have a better understanding of why we're coming in and what we're doing. (Therapist 3)

It seems that some supporters struggled to help the person with ID due to lack of engagement and high staff turnover. Therapists felt that supporters needed extra training beyond simply coming to the sessions with the person they care for.

Discussion

The interview data points to the feasibility of UMAA-LD SoF, which was found to have high acceptability among people with ID, therapists, and some supporters. There was mixed evidence of how helpful UMAA-LD SoF was for participants with ID; some people with ID and their supporters reported fundamental positive shifts in their quality of life, such as better able to handle anger so it did not turn into aggression, increased general mood and increased sociability. Others reported enjoying interacting with the therapist but did not seem to experience any shifts in anger, aggression or quality of life. For a full picture of the impact of UMAA-LD SoF, the qualitative data presented here should be compared to the pre-post intervention outcome results (Roberts et al. 2019).

Rollnick (1998) defined 'readiness to engage' with therapy as a combination of 'willingness' and 'ability', and Willner (2006) proposed that this should be considered for cognitive behavioural interventions for people with ID. The current research supports that this may also apply to UMAA-LD SoF, as

readiness to engage with UMAA-LD SoF co-occurred with reported benefits. Implicit in client accounts, but explicit in supporter and therapists accounts, was that readiness to engage with therapy was linked to positive outcomes. As this is a feasibility study, no research has yet been conducted to explore for whom UMAA-LD SoF may be most suitable, but this points to a need to examine readiness to engage in future research. This also has parallels with broader research about underpinning mechanisms of MBPs. For example, according to the intention, attention and attitude (IAA) model, intention is an essential contributing mechanism leading to positive changes from mindfulness practice (Shapiro et al. 2006). Intention refers to how people who practice mindfulness need to know *why* they are practicing mindfulness in order to see any changes. In this sample, there was some evidence that some participants with ID did not appear to have an internalised sense of *why* they were doing this intervention (some saw it as a trip out or simply enjoyed talking to the therapist), which was associated with few changes. The clinical implications of this are potentially important and point towards the need for careful assessment and orientation with a specific focus on examining cognitive ability and readiness to engage with therapy, and the intention of the participant. This could be decided during an orientation and introductory mindfulness session with a therapist who could determine, in collaboration with the participant, whether UMAA-LD SoF is suitable for the client at that time.

Cognitive ability to engage with the intervention seemed to also have played an important role here, one that therapists and supporters in particular emphasised. It is interesting to note from Table 1 that the WASI scores of those who reported a wide range of benefits from the intervention ranged between 47 and 71 (P1, P2, P4, P5), and those for whom no tangible benefits was reported had WASI scores of between 48 and 58 (P3, P6, P7). Although comparing qualitative findings with demographic variables is not an aim of qualitative research, this putative link between reported understanding of the intervention (and therefore linked to outcome) with IQ levels has important clinical and research implications. The data here suggest that UMAA-LD SoF may be most suitable for people with mild levels of ID, although it should be noted that both the person with the lowest WASI score in the group (P5) and her supporter did report tangible benefits from UMAA-LD SoF. Previous work has also reported successful engagement with the SoF intervention for three individuals with moderate ID, although the intervention was much more intense than UMAA-LD SoF. Singh et al. (2007) delivered the SoF intervention several times a day during initial training, and then training continued formally for 35 weeks. Participant IQ scores were not reported by Singh et al. (2007) making direct comparisons difficult, but this evidence together does suggest that

some people with moderate ID may require support beyond six sessions to understand and engage with mindfulness-informed interventions.

Participants with ID found it particularly difficult to recall an angry situation and use this in the SoF sessions. This happened in two ways: (a) participants did not understand the purpose of recalling an angry situation, and so could not apply this to learning about recognising their own anger arousal signals in the body, thus missing a key part of the SoF intervention and (b) when participants understood the connection between evoking an angry situation and how to learn from this, they experienced aversion in turning towards this difficult experience, as being angry is often an inherently unpleasant experience. This finding has much in common with the findings from a meta-ethnography of interviews with people with ID who had received a range of psychotherapies (Evans and Randle-Phillips 2018). They also found that some participants had difficulty understanding the therapeutic intervention and found talking about difficult situations challenging. Hence, these issues are not unique to UMAA-LD SoF but represent a challenge for many psychotherapies adapted for people with ID.

Another key finding concerned the role of the supporters. It was anticipated that supporters would come along to the sessions, take part in and learn about the UMAA-LD SoF intervention, and thus could encourage clients to engage in the practice at home. However, there were reports of some supporters not engaging in the sessions, or there were different supporters coming to the sessions, making consistent support at home difficult. People with ID did not comment that this was an issue, although therapists felt this potential source of support for the client was not utilised fully. Supporters did not report being disengaged themselves, but there was evidence of them not fully understanding the SoF intervention or how best to support their client. There may be multiple factors which contribute to this, such as the majority of supporters having no formal training in working with people with ID (Smith et al. 1996), nor in the SoF model they were asked to support in the present study. Therapists felt that an information pack for supporters would have helped them to support their clients. Lack of supporter engagement also points to a wider issue—other researchers have seen mindfulness-informed interventions as systemic interventions that train and involve the people who support the person with ID, because it is important that the person with ID is surrounded by a supportive context in order to make positive changes. For example, Singh and Jackman (2016) developed a mindful engagement support (MES) for caregivers, an in-depth training process involving regular contact over several months, which encourages caregivers to develop a personal mindfulness practice alongside training on how to support the person they care for. There is a potential double benefit of this; if more focus is given to supporters to build mindfulness skills, this may lead to supporters'

enhanced personal well-being, as well as better supporters (Noone and Hastings 2010). It may be that elements of the MES could be adapted for use in NHS settings, and future research could focus on this question. Of note is that findings about supporters are in contrast to other research; for example, there have been reports that people with ID who attended anger management groups with their supporter had better outcomes than those that attended alone (Wilner, Willner 2006). More recently, supporters felt they actively contributed to intervention effectiveness with people with ID and depression (Scott et al. 2018), which may point towards the role of supporters being key, with possible cost-effectiveness benefits (Edwards et al. 2015).

The term 'teaching' has been used throughout to describe the UMAA-LD SoF intervention, which is in keeping with the developer of MBSR, Kabat-Zinn (2013) having grounded MBSR within a culture of education rather than therapy—for example, the facilitators are 'teachers' and the weekly sessions termed 'classes'. In SoF however, the facilitators are described as 'therapists' (Singh and Jackman 2016). Likewise, in UK NHS settings, psychosocial interventions delivered to people with ID are usually called 'therapy' and delivered in a therapeutic context. Whether UMAA-LD SoF is best described as an educational intervention or a therapeutic one is therefore unclear and is an issue worthy of future exploration.

Limitations and Future Research

The greatest limitation was sample size, and the data not being taken from everyone who was in the study at 6-month follow up. The data here represent 50% of people with ID, 50% of therapists and 75% of supporters; we therefore do not know the experiences of those not interviewed. However, the interview data given was rich and represented a range of experience, and important clinical implications arose from the data. Participants who dropped out of the intervention were not interviewed, perhaps biasing the interviews towards those that found the intervention most helpful. In the future, qualitative research efforts should be made to capture and interview those who drop out of an intervention. That said, 18 people were interviewed for this study, and their accounts closely align, which points to a consistent account of the potential impact of the UMMA SoF intervention for people with ID who wish to reduce their aggressive behaviour.

The qualitative data suggests that for some individuals, the SoF had a large positive impact; for some, it seemed to have very little to no impact. The data here tentatively point to 'readiness to change' and cognitive ability as the dividing factor between those who benefited from the intervention to those that did not. To whom this intervention works for and why is worthy of further investigation. If this feasibility study is to be further developed, it may be worth capturing 'readiness to change' at the start of the

intervention to see if this is associated with outcome variables. As the putative evidence points towards the intervention having an impact on those who were able to understand and implement it, the inclusion criteria of the current study may need to be adjusted in light of these findings to only include people with mild ID. Furthermore, it would be worth examining the role that supporters' play in supporting interventions for their family member or client with ID, perhaps via qualitative interviews to find out how researchers and clinicians could best support supporter engagement.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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