**The impact of a Mindfulness-Based Stress Reduction course on the psychological wellbeing of individuals with an intellectual disability**

**Authors**

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**Abstract**

Research Aim: to evaluate the impact of a 12-week Mindfulness-Based Stress Reduction (MBSR) course which was adapted for people with an intellectual disability (ID)

Methods: Ten participants with ID (male = 5, aged 17-74; mean = 37.6, SD = 16.8) completed measures of wellbeing and understanding of the concepts of mindfulness before and after the course, provided information about any additional practice and gave feedback on their perceived benefits of the course.

Results: No significant difference was found between mean wellbeing or understanding scores before and after the course. A significant relationship was found between additional practice and post course wellbeing scores. Perceived benefits of mindfulness included reduced stress, increased self-control and confidence.

Conclusion: MBSR may be effective for people with ID but the benefits may not always be reflected in changes in questionnaire scores. The amount of practice of mindfulness exercises may be an important component in increasing wellbeing.

Keywords**:** Intellectual disability; mindfulness; mental health; wellbeing; interventions

Introduction

There has been an increasing interest in mindfulness-based approaches, such as Mindfulness-Based Stress Reduction (MBSR: Kabat-Zinn 1990) and Mindfulness-Based Cognitive Therapy (MBCT) (e.g. Fjorback et al 2011) as effective interventions for psychological distress. For example, research indicates that MBSR is related to reduced stress, depression, and anxiety (Goldin & Gross 2010, Segal et al 2013), while MBCT was found to decrease relapse in those with depression (Kuyken et al 2016). The approaches have the common elements of attending, in an accepting way, to current experiences (Kabat-Zinn, 2013), which is thought to result in a change in perspective, increased flexibility in thinking and behaviour, and improved self-awareness and regulation (e.g. Shapiro et al 2006, Tang et al 2015).

People with an intellectual disability (ID) are at particular risk for mental health difficulties, due to factors such as social exclusion, stigma, limited support networks, discrimination (Idusohan‐Moizer et al 2015, Stacey & Edwards 2013), deprivation, poverty and other adverse life events (Emerson & Hatton 2007). Estimated prevalence rates of mental health difficulties for this group range from 30-50%, which are greater than for their typically developing peers (Cooper et al 2007, Smiley 2005). Despite evidence that approaches other than medication can be helpful in addressing the mental health difficulties of people with ID (e.g. Taylor et al 2008), there is only a limited range of non-pharmacological approaches that are used with this group (Chinn et al 2014, Kroese et al 2013).

The limited research that exists suggests that mindfulness-based approaches can be of benefit to people with developmental disabilities, but that they are rarely offered (Alborz et al 2005). Early work by Singh et al (2007) found an improvement in aggression of three people with ID, which was sustained at two year follow up. In two systematic reviews, mindfulness approaches were indicated as having long term beneficial impacts on the psychological wellbeing and behaviour of people with developmental disabilities, including aggression (Chapman et al 2013, Hwang & Kearney 2013). A later study by Idusohan‐Moizer and colleagues (2015) found reductions in depression and anxiety and increases in compassion for self and others in a group including individuals with ID, following a MBCT intervention. Despite this growing evidence base, the number of research studies and participant numbers continue to be small and the underlying mechanisms for this group of people are still unclear.

 This study aimed to add to the small, existing evidence base by investigating the benefits of mindfulness in a cohort of participants with ID, completing a 12-week mindfulness course, based on the standard format of the MBSR treatment protocol developed by Kabat-Zinn (1990). The research questions were whether this mindfulness approach improved mindful awareness and overall psychological wellbeing and which aspects of the course were identified as beneficial by the participants.

Method

Design

Ethical approval for the study was obtained from the first author’s university ethics committee. The study design was an opportunistic sample of a cohort of individuals who were participants in a free to attend ‘Mindfulness for Life!’ course for people with ID, delivered by an Advocacy Group based in the North East of England.

Participants

Recruitment was via the organisation delivering the course. The course was advertised to individuals accessing services through the Advocacy Group. Participation was voluntary and was initiated by the individuals with ID. Those who expressed an interest in the course were offered an interview with a representative from the Advocacy Group and the Clinical Psychologist delivering the programme, to ensure they fully understood what would be involved. A total of 30 participants initially registered for the course. Those who had signed up for the course were provided with information about the study and an opportunity to discuss it. Those who wanted to take part completed a consent form. Of the 30 people who registered for the programme, 17 made the decision to attend and also signed the consent form. Of these 17, 7 dropped out of the programme, leaving 10 attendees who had agreed to participate in the research project. Participation in the research study element was voluntary. The research participants were aged 17 to 74 (mean = 37.6, SD = 16.8) and five were male and five were female. No formal information was available about level of ID, but all participants had verbal communication.

Measures

Participants were asked to complete the measures below.

1. The Short Warwick-Edinburgh Mental Wellbeing scale (SWEMWBS) is a seven-item version of the Warwick-Edinburgh Mental Wellbeing scale (WEMWBS), which has been found to correlate well with the WEMWBS (Taggart et al 2015). Participants are asked to tick the box that best describes their experience of each statement over the past two weeks using a 5-point Likert scale (none of the time, rarely, some of the time, often, all of the time). All items are scored positively and scores for each item range between 1 to 5, giving a maximum score of 35. The overall score is the total for each item, and there is no weighting. A higher score indicates a higher level of psychological wellbeing (Taggart et al 2015, Tennant et al 2007).
2. Mindful Awareness for Individuals with Intellectual Disability Scale (MAIDS: Griffith et al 2016). The MAIDS is a 10-item self-report measure which aims to measure mindfulness processes in relation to problem areas, such as anger. Participants circle the response that best describes their experience of each statement using a 3-point Likert scale (yes, don’t know, no) scoring 0 to 2. Five of the ten items are reverse scored, giving a maximum score of 20. The overall score is the total for each item, and there is no weighting. A higher score indicates a higher level of mindful awareness. The items can be subdivided into the following categories; observing, describing, awareness, non-judgement of inner experience, and non-reactive to inner experience.

Participants were asked to complete these measures pre and post attending the mindfulness course. These were completed on an individual basis and participants’ responses were assigned a code rather than names to ensure anonymity.

In addition, participants reported the extent of their daily practice and the number of additional informal practice sessions they attended. At the end of the final session, participants were asked to give their views about their understanding about, and perceived benefits of, the course. This group course evaluation discussion was led by two members of the Advocacy Group team who had not been involved with the programme delivery or attended any of the sessions. This enabled objective collection of comments and feedback from the participants. While the feedback was provided on a group basis, individual comments were recorded and displayed on a flipchart, rather than being assigned to a particular individual. These comments were subsequently collated and summarised by the first author for the purposes of the paper.

The Intervention

The intervention comprised twelve weekly 2-hour sessions. The mindfulness programme was an adaptation of the MBSR treatment protocol developed by Kabat-Zinn (1990). It was delivered by an experienced mindfulness practitioner who was an NHS Consultant Clinical Psychologist with extensive experience of working with individuals with ID. He had also completed training to ensure compliance with recommended standards for mindfulness teachers (UK Network for Mindfulness-Based Teachers 2015). He was assisted by a co-facilitator who identified as having ID and who had attended a practice group for over a year, after attendance at an initial course. The co-facilitator contributed in a number of ways. This included: leading a short breathing or body-scan based meditation at the beginning of each session; assisting the mindfulness practitioner during practical demonstrations by providing examples of how the various meditation techniques were performed; helping to support weekly, participant led informal practice sessions that were offered in addition to the ‘formal’ programme; and contributing to spontaneous role plays to illustrate key ideas (for example, taking the role of the facilitator’s negative thoughts during a challenging situation). This helped to create a concrete visual story to illustrate how mindfulness can help individuals to step back and observe thoughts rather than becoming embroiled in them.

The mindfulness programme was delivered in a large open plan room, with natural daylight, based on the standard format of the treatment protocol developed by Kabat-Zinn (1990). Participants sat in comfortable upright chairs, or were invited to move around the room, lie on a foam mat, or utilise a blanket depending upon the mindfulness activity underway. All choices were voluntary and those with mobility issues were invited to remain seated.

Modifications to the standard format of the MBSR included increased levels of repetition of the materials and a longer programme duration. This allowed for a slower pace to ensure the concept being explained could be adequately demonstrated. With the exception of ‘choice-less awareness’ exercises, the programme included key MBSR learning goals and practices (Zabat-Kim 1990). Participants were encouraged to provide their own thoughts and experiences. Each session was ‘recorded’ on a large sheet of paper to create a story board, helping to illustrate the practices and learning of the session. At the beginning of each session, the story boards were used to recap what had been covered and to reinforce the concept of mindfulness.

A variety of metaphors were used to help explain the process of bringing mindfulness into everyday life e.g. choosing not to get onto the ‘thought train.’ Practical elements were introduced to increase participant involvement. For example, participants were invited to make a ‘snow globe’ containing a photograph of themselves. The snow globe represented the whirlwind of thoughts we sometimes experience, but with time the ‘snow’ (our thoughts) settle and the globe (or mind) becomes clear. In a later session, participants decorated a ‘sweet spot’ jar which was then filled with a note of good or positive events which were due to occur the following week. These thoughts were then used for discussion in the subsequent sessions to emphasise the theme that mindfulness is not about switching off or calming down, but about learning to wake up and be more aware of the positive things that happen in our lives. A number of exercises were introduced and practiced throughout the weekly sessions including breathing, body scan meditation and stretching exercises.

Results

Table 1 illustrates the pre and post-course SWEMWBS and MAIDS scores. Six participants had increased SWEMWBS scores after the course, three had reduced scores and one had not changed. In respect of MAIDS scores, four participants increased their score following the course, one was unchanged and six reduced their score, indicating lower mindful awareness. No significant differences were found between mean scores on SWEMWBS before and after delivery of the mindfulness course [t(9) = -0.832, p = 0.427] or between mean MAIDS scores [t(9) = 0.213, p = 0.836]. No significant relationship was found between post course SWEMWBS and MAIDS scores (r=.261, p=.466).

<Insert table 1 about here>

Additional Practice

The number of days per week on which participants practiced the exercises out with the course ranged from 0-4 (M = 1.5, SD = 1.3). The number of additional sessions attended by participants ranged from 0-4 (M = 1.9, SD = 1.7). No significant relationship was found between MAIDS scores after the course and the extent of daily practice (r = -.077, p = .832) or number of additional sessions attended (r = -.14, p = .699). A significant relationship was, however, found between SWEMWBS score following the course and amount of daily practice (r = .565, p = .045) and number of additional sessions attended (r =.663, p = .018).

*Participants’ views of the mindfulness course*

Table 2 illustrates the participants’ reports of their understanding about, and perceived benefits of, the mindfulness course

<Insert table 2 about here>

Discussion

 The present study aimed to explore the benefits of a mindfulness course for individuals with ID. The results were somewhat mixed. Whilst psychological wellbeing, as indicated by SWEMWBS, change scores before and after the course increased for six of the ten participants, there was no significant change in scores overall. Similarly, there was no significant increase in mindfulness awareness following the course. The lack of significant change may have been due to the small sample size, may indicate that the course was not universally helpful to participants in increasing wellbeing or that the measures were not appropriate.

In respect of the latter, the SWEMWBS has good psychometric properties (Tennant et al 2007) but it has not been specifically validated for use with people with ID. The MAIDS, whilst developed for use with people with ID, has limited research pertaining to its psychometric properties. Further research on the performance of both is needed to determine their appropriateness as outcome measures for people with ID.

The results indicated that having more opportunities to practice mindfulness (i.e. practicing exercises at home and attending informal additional practice sessions) was significantly associated with increased psychological wellbeing. Kabat-Zinn (1990) specifies one of the ground rules of MBSR as completing 45-minutes of mindful practice, six-days per week. This volume of practice was not undertaken by any of the participants. The additional practice sessions may have mitigated the lack of daily practice, however attendance at these sessions was also varied. This may indicate that a 12-week course is not long enough to consolidate the benefits of mindfulness approaches for all participants and that a longer course or more opportunities for practice may maximise the benefits. Hwang & Kearney (2013) highlight the importance of prolonged intervention and practice periods in their review of 12 mindfulness studies, with eight studies having practice periods of between six months and two years.

Opportunities to practice were not, however, associated with increased mindfulness awareness, nor was a significant relationship found between mindfulness awareness and psychological wellbeing. This suggests that an understanding of mindfulness practices may not be as important as repetition of the mindfulness exercises to psychological wellbeing (e.g. Siegal 2007).

Both the MAIDS scores and the qualitative results indicated that participants varied to some extent in their understanding of the mechanisms and exercises underpinning the mindfulness course, although many could articulate both aspects clearly. Brown and Ryan (2003) highlight that mindful capacity differs from person to person and, whilst having ID does not appear to be a barrier to participating in and benefiting from mindfulness-based approaches (Chapman et al 2013, Hwang & Kearney 2013, Robertson 2011), research has indicated that some participants can initially find mindfulness procedures difficult to understand because they could not easily remember or visualise past events (Singh et al 2007). This understanding may, however, be increased by using straightforward language, clear instructions and repetition (Chapman & Mitchell 2013), focusing on experiential practices and methods of reflection and ensuring that the group size is not too large (Morrissey & Ingamells 2011).

The fact that the course had a co-facilitator with ID may also have been helpful in making the concepts and exercises accessible to the participants. Singh and colleagues (2011) also report on a person with ID who taught her peers ‘Meditation on the Soles of the Feet’ in order to help them control their anger and aggressive behaviour. Further research into peer facilitation in mindfulness-based practices is, however, needed to clarify what the associated benefits might be.

 There is a balance to be struck between adhering to the core elements of MBSR (Santorelli et al 2017) and delivering the course in a structured but flexible manner to meet the needs of participants (Dobkin et al 2014). In the present study, the course was delivered by an experienced practitioner who also had extensive expertise of working with people with ID. Differences between the curriculum guide (Santorelli et al 2017) and the course which was evaluated in the study were the omission of the full day ‘mindfulness retreat’, and the formal yoga practice sessions. These differences may have influenced the outcome of the course for some participants.

 The feedback gathered during the final session demonstrated the benefits of mindfulness as highlighted by the participants. Although no significant differences in wellbeing or understanding of mindfulness concepts were demonstrated on the quantitative measures, the qualitative feedback illustrated a range of important ways in which the participants felt that attending the course had been of benefit to them, including reduced stress and increased self-control and confidence. This is consistent with previous research that mindfulness, and in particular MBSR, can be adapted and delivered to participants with ID with positive outcomes (e.g. Chapman et al 2013, Chapman & Mitchell 2013, Dobkin et al 2014, Robertson 2011).

Limitations

The study reflected an evaluation of a ‘real world’ mindfulness group, however this had associated limitations. The sample size was relatively small, there was no control group or extended follow up period. The participants also varied in terms of their level of ID, but no information about their cognitive abilities were available. An important aspect of MBSR is “inquiry” about perceptions, mental and behavioural habits, and patterns of behaviour which may affect learning and growth (Dobkin et al 2014). The qualitative feedback indicates that a number of participants were able to reflect on the potential mechanisms of mindfulness, the purpose of the exercises and the benefits for themselves and others. The extent to which level of ID influences the ability to enquire and self-reflect is, however, unknown and is an important area for future research.

Implications for Practice

 The results of the study, while based on a small sample size, have a number of implications for nurses wishing to offer mindfulness-based interventions to people with ID. The finding that psychological wellbeing was related to additional practice highlights the importance of building in opportunities to practice the exercises through, for example, longer duration of the programme, shorter but more frequent sessions and/or regular opportunities to meet and practice as a group. Participants can also be supported to practice at home, for example by identifying clear and concrete goals, and a designated time and place to carry out the exercises (Jahoda et al 2017).

The concepts that are fundamental to approaches such as MBSR need to be communicated to people with ID in an accessible and concrete way (Jahoda et al 2017), although the results of our own study suggest that promoting understanding of these concepts may be less important than creating opportunities for participants to directly experience the concepts through practical activities and consolidate their skills through rehearsal and repetition. Future research will be useful in identifying the optimal balance between exercises that facilitate understanding and those that are experiential in adapted MBSR programmes for people with ID, in order to maximise mental health and wellbeing.

The project also demonstrates the opportunities for closer partnership between health services and the third sector. The results offer some proof of concept of the potential success of this approach, with the next step being to make such partnership provision available to those who might benefit most. This may include relapse prevention of depression (Segal et al 2013) and early intervention for stress related mental health problems (Idusohan-Moizer et al 2015, Miodrag et al 2013).

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| **Implications for Practice** |
| * Ensure opportunities to practice mindfulness exercises are built in to the intervention
* Fundamental concepts need to be communicated in a clear and accessible way
* Provide opportunities to directly experience the concepts through practical activities
* Allow key skills to be consolidated by facilitating rehearsal and repetition
* Consider ways in which interventions might be offered in partnership with third sector organisations
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**Table 1: Pre and post-course SWEMWBS and MAIDS scores**

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|  | **Pre**  | **Post**  |
| **Scores** | **Mean (SD)** | **Mean (SD)** |
| SWEMWBS  | 24.86 (7.53) | 26.24 (5.03) |
| MAIDS  | 10.90 (1.60) | 10.70 (2.83) |

**Table 2: Participants’ reported understanding about and benefits of the mindfulness course**

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| **Topic Areas** | **Examples** |
| **Benefits of mindfulness** |
| *Stress reduction* | “It helped me to notice where stress was” |
|  | “Mindfulness has actually helped with my stress…didn’t think about thoughts at school…better last week, thinking more about my body, not thoughts” |
|  | “Really good, help me when stressed” |
| *Increased self-control* | “It’s helped me to slow down” |
|  | “Mindfulness lets me separate my anger from my body. If I am angry I can go outside and do my mindfulness. I take a minute to do my mindfulness to calm down. If I’m cross I get hot…doing mindfulness cools me down” |
| *Ease of use* | “You can do mindfulness anywhere” |
|  | “…can do it anywhere and nobody knows you’re doing it” |
| *Increased self-confidence* | “this is the first time I came [to the course] without support. Mindfulness gave me the confidence to do it”. |
| *General impact* | “It helps me in everyday life, helps me focus on my breathing” |
|  | “It needs to keep going so everyone can have a sense of happiness” |
|  | “It’s helping us” |
| **Understanding of mindfulness** |
| *Mechanisms* | “…it’s about being awake, noticing your body, slowing down. It’s like having a torch and shining it on a part of your body…being more aware of your body”  |
|  | “…not worrying about past or future” |
|  | “We all share the same secret, that we all get stressed” |
|  | “Your mind just does what it does, it’s like a puppy” |
| *Exercises* | “The snow pretty much represents your thoughts…around you all of the time and then settle with mindfulness” |
|  | “When it [the snow] settles it’s like when you’re calm” |
|  | “…[the snow globe] it’s your mind” |