



A pilot evaluation of an 8-week mindfulness-based stress reduction program for people with pre-symptomatic Huntington's disease

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Abstract

People with Huntington's disease (HD) face difficult emotional and practical challenges throughout their illness, including in the pre-symptomatic stage. There are, however, extremely limited psychosocial interventions adapted to or researched for HD. We adapted and piloted an 8-week mindfulness-based stress reduction (MBSR) program in people with pre-symptomatic HD to determine if the program (i) was feasible and acceptable to participants, (ii) resulted in increased mindfulness understanding and skills, and (iii) led to improved psychological adjustment. Quantitative measures of mindfulness, emotion regulation, mood, and quality of life were administered pre and post the MBSR program and at 3-month follow-up. Measures of mindfulness practice and session clarity were administered weekly. Qualitative participant feedback was collected with a post-program interview conducted by independent clinicians. Seven participants completed the 8-week course. The program's feasibility and acceptability was supported by excellent retention and participation rates and acceptable rates of home practice completion. In addition, qualitative feedback indicated participant satisfaction with the program structure and content. Two core mindfulness skills (observing and non-judgment) showed significant improvement from pre- to post-assessment. Participant qualitative feedback indicated increased confidence and capacity to use mindfulness techniques, particularly in emotionally challenging situations. Participant questionnaire data showed good psychological adjustment at baseline, which did not change after treatment. Psychological benefits of the program identified in qualitative data included fewer ruminations about HD, reduced isolation and stigma, and being seen by others as calmer. These findings justify expansion of the program to determine its efficacy in a larger, controlled study.

Keywords Mindfulness · Depression · Quality of life · Pre-symptomatic · Huntington's disease · Psychological interventions

Introduction

Huntington's disease (HD) is an autosomal dominant neurodegenerative disease, meaning that offspring of an affected parent have a 50% chance of inheriting the mutation and eventually developing HD (Reiner et al. 2011). HD presents complex psychosocial challenges across the lifespan. In childhood, the experience of a parent with manifest HD can lead to challenges related to compromised parenting, family

stress, and taking a "young caregiver" role (Kavanaugh et al. 2015; Mand et al. 2015; Vamos et al. 2011; van der Meer et al. 2012). With early adulthood comes the decision of whether to access predictive genetic testing (Crozier et al. 2015; Meissen et al. 1991), the outcome of which may affect many significant life decisions (Gong et al. 2016), particularly reproductive choices (Quaid et al. 2008). The knowledge that one carries the genetic expansion is accompanied by uncertainty of the timing and nature of disease onset and fears of disclosure due to the risk of discrimination (Codori and Brandt 1994; Raluca et al. 2015). In addition, the increasingly challenging care of an HD-affected parent also impacts many adults with pre-symptomatic HD. Despite these challenges, HD often remains an unspoken secret within families (Schwartz 2010). In other words, while the actual disease may not have manifested, adults with pre-symptomatic HD will usually have experienced cumulative psychosocial impacts, with early life aversive events, social

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stigma, carer burden, “symptom hunting,” and significant future worries (Gluyas et al. 2023; Ho and Hocaoglu 2011; Theed et al. 2018; Timman et al. 2004).

Psychiatric difficulties have been shown to be prominent amongst those with pre-symptomatic HD (Achenbach and Saft 2021; Epping et al. 2015). These are potentially a function of the above-identified psychosocial challenges. For example, a positive gene test has been linked to increased anxiety, depression, and suicidal ideation (Crozier et al. 2015; Decruyenaere et al. 2003; Honrath et al. 2018; Timman et al. 2004), and these negative emotional states can persist (Gargiulo et al. 2009; Timman et al. 2004). Neurodegeneration is also likely to be a contributing factor, and brain atrophy has been found to occur more than a decade before predicted motor onset (Tabrizi et al. 2012). The 10- to 15-year preceding manifest motor symptoms are often affected by subtle cognitive and psychiatric changes, such as changes in processing speed and executive function (Paulsen et al. 2014) and increased apathy, depression, irritability, perseveration, and obsessions (Epping et al. 2015). There is also initial evidence of difficulties with aspects of emotional regulation such as emotional awareness (Zarotti et al. 2018).

Those with pre-symptomatic Huntington’s disease usually have limited contact with specialist HD services, typically annually or on request (Frich et al. 2016), potentially leaving important areas of psychosocial need unaddressed. In a systematic review of interventions in HD, Zarotti et al. (2020) highlighted the need for effective interventions for the multi-dimensional psychosocial and psychiatric problems associated with pre-symptomatic HD. Psychological interventions which optimize current life experience and build skills that may be psychologically protective have been particularly recommended as an important adjunct to existing approaches (Theed et al. 2018; Wild and Tabrizi 2014).

Few previous studies have addressed this concern. Specifically, A’Campo et al. 2012 conducted an 8-session cognitive behavior therapy group and found an increase in seeking social support, but no significant post-group differences in depression, anxiety, quality of life, or coping strategies. Stopford et al. (2020) examined feedback from a small ($n = 6$) single-session narrative therapy group, with participants reporting reduced isolation and normalizing of their experience. Eccles et al. (2020, 2021) investigated the feasibility of conducting a randomized controlled trial of mindfulness-based cognitive therapy for Huntington’s disease, an intervention which incorporates mindfulness and elements of cognitive therapy. The authors initially aimed to include participants at different stages of HD but were able to recruit only those with pre-symptomatic HD. The feasibility of a randomized controlled trial was viewed as low, given recruitment difficulties and the rareness of HD. For the 12 individuals who took part, however, the program was shown to be acceptable and to support the development of mindfulness skills and the reduction of stress (but not

anxiety and depression, which were low at baseline) (Eccles et al. 2020; Eccles et al. 2021).

A growing body of research shows the benefit of mindfulness treatments for people with neurodegenerative conditions, such as common dementia syndromes (Quintana-Hernández et al. 2016; Wong et al. 2017), multiple sclerosis (Simpson et al. 2014), Parkinson’s disease (McLean et al. 2017), and motor neurone disease (Pagnini et al. 2017). A systematic review identified several randomized controlled trials which showed improvements in psychological functioning as a result of learning mindfulness for those with long-term and progressive neurological disorders (Robinson et al. 2019) and highlighted the potential benefit of mindfulness for the complex physical, emotional, and social difficulties associated with these disorders.

Our research encompassed an examination of mindfulness for pre-symptomatic HD, as we believed this intervention would be suitable for improving psychological adjustment and mitigating some of the negative psychosocial experiences of people with pre-symptomatic HD. It was conducted during a similar time period as the Eccles et al. (2020, 2021) study and investigated an alternative mindfulness program, namely, the mindfulness-based stress reduction program. Mindfulness-based stress reduction (MBSR) (Kabat-Zinn 1982) is a well-established 8-session group-based intervention. MBSR has demonstrated reliable positive effects on depressive symptoms, anxiety, stress, and quality of life for people with a variety of mental and physical disorders, as well as within non-clinical populations (Gotink et al. 2015). People with pre-symptomatic HD vary in the extent and type of symptomatology they experience. Some have no clinically significant symptoms, others have emerging subtle neuro-cognitive changes, and/or current mood or other psychiatric difficulties (Epping et al. 2015). Given the broad evidence-base of efficacy for MBSR in both clinical and non-clinical populations, and its focus on “wellness” rather than the disease itself (as per Kabat-Zinn 1996, cited in the MBSR Standards of Practice, Santorelli 2014), MBSR is a program that is well-suited to this range of experience.

Kabat-Zinn, who developed the MBSR program, has defined mindfulness as “the awareness that arises from paying attention, on purpose, in the present moment and non-judgmentally” (Kabat-Zinn 2013, p. 24). People with pre-symptomatic HD often experience worries about what a future with HD may bring, as well as hypervigilance to HD symptoms. Mindfulness approaches may assist with identifying unhelpful reactions to stressful thoughts and experiences and may support the development of more helpful responses, through fostering skills in observing, acceptance, and non-judgment. Learning mindfulness may also support those with pre-symptomatic HD to embrace moments in the present felt as positive and valuable, particularly important given the anticipation of a compromised future with HD symptoms and a shortened lifespan. Furthermore, mindfulness skills could potentially protect against subtle

neurobehavioral changes associated with early HD, by supporting emotional regulation capacities. Finally, the group-based nature of the MBSR program may provide opportunities for increased social connection and formation of a positive social identity that integrates the lived experience of pre-symptomatic HD (e.g., Haslam et al. 2016; Wakefield et al. 2013).

This pilot study aimed to determine whether an 8-week mindfulness-based stress reduction (MBSR) program, adapted for people in the pre-symptomatic period of HD, was (i) feasible and acceptable to participants, (ii) enabled an understanding of mindfulness and the development of mindfulness skills, and (iii) had the potential to reduce distress and enhance psychological adjustment.

Methods

The group MBSR program involved attending eight sessions conducted by clinical psychologists and neuropsychologists with expertise in working with people who have HD, which were run in 2017. Facilitator and participant manuals were developed based on standard MBSR protocols (Kabat-Zinn 2013; Santorelli 2014). The adaptation of the MBSR manual for use in people in the pre-symptomatic stage of HD involved giving participants the opportunity to reflect upon their unique experiences of HD. In addition, a number of alterations to the program were made with the goal of either accommodating or mitigating the impacts of incipient cognitive and behavioral changes, such as mild apathy or reduced attentional control, on engagement with the intervention. Examples of the alterations included the following: (i) a 1½-h session rather than the recommended 2½ to 3½ h and no 1-day retreat, (ii) daily formal practice of 30 rather than 45 min, (iii) a slower pace of delivery with extra repetition of experiential exercises, and (iv) a strong focus on building motivation to engage in regular practice. Motivation-building included problem-solving of barriers to home practice, weekly encouragement of participants to identify and use practice-maintenance strategies, daily practice-reminder text messages, and highlighting how self-compassion can foster motivation (cf. Breines and Chen 2012). There was also regular reinforcement of the benefits of mindfulness and their identified “personal visions” and discussion of research on the effects of mindfulness on emotions and cognition. As per the MBSR program, participants were asked to complete between-session mindfulness practice, including formal (body scan, mindful yoga, mindful breathing) and informal (utilizing mindfulness while engaging in routine daily tasks) methods.

We identified potential participants for the study from the patient database at Calvary Health Care Bethlehem (CHCB) Statewide Progressive Neurological Diseases Service (SPNDS), Victoria, Australia. To be included, participants

were required to be in the pre-symptomatic stage of HD, meaning that they were confirmed to have the CAG expansion for HD but had not yet manifested clinically significant motor symptoms. With the exception of one participant who had reduced their number of work hours due to non-motor symptoms of HD and had a total functional capacity scale (TFC) score of 12, all participants had a TFC score of 13 (Huntington’s Study Group, 1996). Eligible participants were informed that program requirements involved attendance at eight, weekly, 2-h sessions, after business hours, at CHCB. Exclusion criteria included significant psychiatric or cognitive disability, limited English proficiency, and a history of irregular attendance at routine clinic appointments. Based on these criteria, a subsample of 20 participants were invited to participate. Ten agreed and provided written informed consent. All had completed at least 12 years of education. Most worked full-time and lived with a partner/spouse, had a previous psychiatric history, and had been taking a psychotropic medication for months to years, predominantly a selective serotonin reuptake inhibitor (antidepressant).

The study design was a single group study, with measurements at baseline (pre-intervention, T1), post-intervention (T2), and after a 3-month follow-up (T3). Participant outcomes after MBSR training were compared to the baseline assessment, and no control group was studied for comparison.

To determine whether the MBSR program may be effective in building mindfulness skills, we administered the Five Facet Mindfulness Questionnaire (FFMQ; Baer et al. 2006; Baer et al. 2008) and the Difficulties in Emotional Regulation Scale (DERS; Victor and Klonsky 2016). The FFMQ is a 39-item self-report measure developed to quantify five component skills of the broader construct of mindfulness: (1) observing one’s inner experience, (2) describing one’s inner experience with words, (3) acting with awareness, (4) being non-judgmental towards one’s inner experience, and (5) being non-reactive towards one’s inner experience. The DERS is an 18-item scale assessing aspects of emotional dysregulation. It was included as a measure of mindfulness due to the scale content relating directly to the mindfulness skills of responding, rather than reacting, to emotions.

To examine the effects of the MBSR program on distress and psychological adjustment, we utilized the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith 1983) and the Personal Wellbeing Index-Adult (PWI; International Wellbeing Group 2013). The HADS is a 14-item self-report tool developed to screen for symptoms of anxiety and depression. It is widely used in medical populations due to its focus on non-physical aspects of anxiety and depression, such that it is not artificially inflated by symptoms associated with physical ill-health. Large-scale studies of people with pre-symptomatic Huntington’s disease have also

employed the HADS (e.g., ENROLL-HD; Achenbach and Saft 2021). The PWI was developed to measure the subjective dimension of quality of life. It comprises both a general single-item scale PWI-A (“How satisfied are you with your life as a whole?”), as well as the seven-item PWI-B, which asks respondents to rate satisfaction with quality-of-life sub-domains, i.e. standard of living, health, achieving in life, relationships, safety, community-connectedness, and future security.

Two additional measures were administered weekly, namely the Mindfulness Adherence Questionnaire (MAQ; Wong et al. 2017; Wong et al. 2016) and session clarity ratings (out of 10). The MAQ is a 12-item self-report measure developed to assess participants’ adherence to formal and informal mindfulness practices, including details of the number and average length of practice sessions in the previous week. It was specifically developed to assess mindfulness adherence within an MBSR program for people with mild cognitive impairment (Wong et al. 2016). Participants rated the clarity of sessions out of 10, allowing us to screen for any problems related to difficulty understanding the program content.

To obtain qualitative feedback regarding the MBSR program, specialist HD nurses from our clinical service, who were not associated with the research project, conducted semi-structured phone interviews within 2 weeks of program completion.

To address our first aim, which was to investigate the feasibility and acceptability of the MBSR program, we examined retention and attendance rates, responses to the MAQ, and session clarity ratings. For the second aim, to determine participant understanding and acquisition of mindfulness skills, we used a series of paired *t*-tests to compare T1 responses on the FFMQ and the DERS with T2 and T3 responses. Similarly, to assess our third aim of examining the program’s impact on psychological adjustment, we used *t*-tests to compare T1 scores on the HADS and PWI with T2 and T3 scores. We used paired *t*-tests because they have been shown to be robust to extremely small sample sizes (de Winter 2013). As this was a pilot evaluation, no adjustments were made to statistical significance tests to account for the number of comparisons (Rubin 2017). In relation to the post-course qualitative interview data, two of the authors (CG and SV) categorized the interview statements according to each of the three study aims. These responses were then further coded into sub-themes. Where there were discrepancies between the raters in the categorization of themes, these were discussed until agreement was reached.

Ethical approval for the study was granted by the Research Ethics and Ethics Committee at Calvary Health Care Bethlehem and the Monash University Human Ethics Research Committee.

Results

Regarding our first aim, which was to determine feasibility and acceptability, we first examined attendance at sessions and withdrawal. Seven out of ten participants who initially commenced the program (5 female; age: $M = 49$, range = 36–60) completed the entire 8-week course and follow-up session (retention rate = 0.7). Two participants withdrew after the first session citing discomfort with the attendance and homework expectations, and one reluctantly left due to a family member’s acute healthcare requirements. For the seven participants who completed the program, the attendance rate was 92%. This included some “make-up” sessions which were pre-arranged when a participant was unavailable and which involved a phone consultation with one of the facilitators. Homework adherence (MAQ) showed that participants engaged in an average of 6.9 ($SD = 2.4$) formal mindfulness practices per week, with an average length of 16.6 min ($SD = 6.6$). At 3-month follow-up, participants reported engaging in 1.9 ($SD = 1.6$) practices per week for an average 17.8 ($SD = 17.3$) min. Qualitative feedback pertaining to the program feasibility and acceptability is presented in Table 1, Section 1, and demonstrated participants’ generally positive experiences of the group structure and content, with some reservations about practice expectations.

In terms of our aim of obtaining preliminary evidence regarding whether the members of the group were able to develop mindfulness skills and understanding, we found statistically significant improvements on the FFMQ dimensions of observing and the non-judging of inner experiences (Table 2). Despite the absence of other statistically significant results, examination of effect sizes suggested clinically significant change with large and medium effects on several scales (observing, acting with awareness, non-judging of inner experiences, non-reacting to inner experiences, and the FFMQ total), and the overall pattern of change in mean scores across the FFMQ subscales and the DERS-18 was in the expected direction (Table 2). Qualitative feedback relating to the development of mindfulness skills indicated increased ease with mindfulness practice, engagement with immediate sensory experience, awareness of thoughts and emotions, and awareness of options for responding rather than reacting (Table 1, Section 2).

Psychological adjustment and mood, as indicated by HADS depression and anxiety scores, were in the “normal” range across all three time-points: pre-intervention, post-intervention, and follow-up (see Table 2). Given this observation, tests of statistical significance were not performed. Similarly, quality of life as measured by the PWI showed no significant changes across time. In qualitative feedback relating to psychological adjustment, participants commented on reductions in preoccupation with future HD worry, that the group instilled a positive

Table 1 Qualitative themes relevant to the three study aims based on post-intervention participant feedback

Summary of themes	Participant quotes
Section 1: feasibility and acceptability of the program	
Format: participants expressed satisfaction with the group location, session length, course length, and time of day (post-work and pre-dinner)	<p>“Very clear...written book [participant manual] was good to refer to”</p> <p>“Right [session] length...any longer and it’s hard to stay focussed”</p> <p>“Ten sessions [would be] better...seemed to run out of time at the end of each session...didn’t want to stop conversations that spontaneously happened”</p> <p>“Ideal for working people”</p>
Content: this was endorsed as clear, detailed, and interesting. Focus seen as motivating and positive. Appreciation expressed for the range of practice options taught	<p>“[The facilitators] knew their stuff... [I liked] doing it with them, [they] shared experiences...communicated it well...rephrased when necessary”</p> <p>“Pitched well. Covered everything I hoped”</p> <p>“I liked learning the different techniques”</p> <p>“Good variety of meditations”</p>
Home practice: expectations viewed as challenging by some	<p>“Found... the informal (homework) more difficult to do”</p> <p>“[Homework was] more work than I expected”</p> <p>“A lot doing it twice a day... couldn’t fit it all in”</p>
Section 2: development of mindfulness skills and understanding	
Skill development: experience of mindfulness practice becoming more natural and accessible	<p>“I can do formal practices without listening to the recording now”.</p> <p>“[Practice is] easier...getting easier and more natural...I was fighting it quite a lot [at the start]”</p> <p>“[Practice is] feeling more natural...was worrying I wasn’t doing it the right way.... I don’t have to do that anymore”</p>
Present moment focus: intensified awareness of a range of sensory activities and experiences	<p>“[Completing tasks mindfully] was an intensely sensory experience, even with mundane tasks”</p> <p>“I found myself finding pleasure in listening to a cricket”</p> <p>“I could even do it [be mindful] while washing the dishes.”</p> <p>“It intensified my experience of being at the beach”</p> <p>“Taking each day as it is, making the most of each day”</p> <p>“Bringing yourself into the now...makes you feel tranquil and calm”</p>
Mindfulness of thoughts: increased awareness of thoughts and response options	<p>“[I’m] not catastrophizing anymore... I used to do this a lot”</p> <p>“I don’t sweat the little things now...”</p>
Mindfulness of emotions: more aware of emotions and stress levels, with increased capacity to respond rather than react to challenging emotions	<p>“I didn’t realise how stressed I was until after I’d done the [STOP] practice and noticed the change”</p> <p>“I’m better at noting change or rising feelings and can decide whether or not to go down that path.... Even though I’m aware I sometimes still do it!”</p> <p>“If I feel agitation starting, I start breathing...and using present moment focus...maintain perspective”</p> <p>“[I’m] better at noting change or rising feelings and can decide whether or not to go down that path [of reactivity] ...Even though I’m aware, I sometimes still do it!”</p> <p>[Relating to emotional reactivity]: “Doing this has changed my behaviour when riding my bike and a car comes too close. I used to chase them down and hammer on the bonnet. Now I just let it go”</p> <p>“I used STOP to calm myself and breathe when I was stressed about missing a meeting [at work] ...didn’t change the event, but didn’t feel as bad”</p>
Section 3: psychological adjustment	
Other’s observations: of improved emotional states	<p>“[My] boss has noticed that I’m less grumpy and critical”</p> <p>“Others tell me I’ve changed, even though I don’t notice it myself”</p> <p>“[My] partner says I’m easier to live with”</p>
HD-related thoughts: increased ability to focus on the present rather than future fears	<p>“[Mindfulness] enables me to live for now because I can’t control when it [HD] will hit me.”</p> <p>“My mind doesn’t race off to HD anymore... [I] see my daughter, who is gene positive, as my daughter...not focusing on the HD”</p> <p>“I used to worry a lot about getting HD, but that mindset is exhausting. Now I figure that I just get on with things whilst I am healthy and if I do get HD, I can ...worry to my heart’s content, because then I will genuinely have something to worry about. In the meantime I enjoy the moment and that I am healthy.”</p>

Table 1 (continued)

Summary of themes	Participant quotes
Benefit of group program: there was strong expression of the benefit of the program in reducing isolation and stigma, and allowing a positive connection in relation to HD	<p>“Meeting other people with HD is a huge thing...they know exactly how you’re feeling”</p> <p>“Nine or ten pre-HD [people] in the same room blew me away...Didn’t need to explain why things were an issue...they got it...the human connection was amazing”</p> <p>“This group forces you to confront HD in a positive way...not hide it”</p> <p>“Different to telling friends; here everyone knows what it really means”</p> <p>“Listening to what other people with HD experience and feeling relieved that you aren’t the only person having these thoughts”</p> <p>“[The course] de-isolated us”</p> <p>“In this group, HD is not my dirty little secret”</p> <p>“Would have been great to have the opportunity to talk more because in my family, it wasn’t talked about...it’s nothing to be ashamed of.”</p>
Instilling hope: taking action with the hope that practicing mindfulness will be protective as HD symptoms emerge	<p>“really hope ... strategies [are] so well embedded [and I] continue to practise them when I become symptomatic ...assuming I don’t lose insight”</p> <p>“[To be able to] recognise reactive emotions as HD kicks in, [to] manage it better”.</p> <p>“Too early to see if it is useful or not in the long term; better than doing nothing!”</p>

sense of connection and understanding with similar others as well as a sense of hope for the future (Table 1, Section 3).

Discussion

The first aim of this pilot study was to examine the feasibility and acceptability of the MBSR program for those with pre-symptomatic HD. The program feasibility was

strongly supported by the excellent attendance rate (92%) and relatively low drop-out rate (30%). A review of non-clinical MBSR studies has shown similar drop-out rates, ranging from 3 to 51% and averaging 17% (Khoury et al. 2015). Participants described experiencing the practical aspects of the program as manageable, which also supported program feasibility and likely contributed to consistent attendance. Specifically, in their qualitative feedback, participants expressed satisfaction with the group location (a

Table 2 Descriptive statistics, effect sizes, and paired *t*-test comparisons for questionnaire measures of mindfulness skills and psychological adjustment

Scale	Pre-intervention M (SD)	Post-intervention M (SD)	Pre- to post- intervention Cohen’s <i>d</i>	Follow-up M (SD)	Pre-inter- vention to follow-up Cohen’s <i>d</i>
HADS-A	6.1 (3.0)	5.3 (2.9)	0.27	5.8 (3.0)	0.35
HADS-D	5.1 (3.2)	6.1 (4.9)	0.16	6.8 (5.1)	0.38
PWI-A	7.9 (1.1)	7.1 (2.6)	0.21	6.7 (2.3)	0.37
PWI-B	55.1 (11.9)	56.4 (15.8)	0.06	56.9 (14.4)	0.09
DEERS-18	45.6 (16.5)	40.3 (9.4)	0.30	42.7 (12.8)	0.20
FFMQ—sub-scales					
Observing	26.1 (5.2)	29.4 (4.9)*	0.81	30.6 (4.6)**	1.38
Describing	22.4 (4.4)	24.0 (4.3)	0.31	25.1 (5.2)	0.38
Acting with awareness	22.9 (4.9)	24.9 (4.9)	0.47	24.7 (4.8)	0.43
Non-judging of inner experiences	26.1 (9.5)	31.7 (6.2)**	1.44	30.7 (5.6)*	0.83
Non-reacting to inner experiences	20.6 (5.5)	22.1 (5.6)	0.21	23.4 (2.9)	0.50
FFMQ total	118.1 (15.7)	132.1(15.3)*	0.74	132.0(13.7)*	0.84

* $p < 0.1$ (trend), ** $p < 0.05$

Paired *t*-tests compare post-intervention and 3-month follow-up scores with pre-intervention scores. Effect sizes are commonly interpreted as small ($d = 0.2$), medium ($d = 0.5$), and large ($d = 0.8$) (Cohen 1988)

“non-clinical” meeting space in the hospital), course length (8 weeks), time of session (post-work and pre-dinner), and session length (1.5 h). The reduction in the session length, made to accommodate possible early cognitive changes, may have assisted with concentration in and engagement with the sessions. Qualitative feedback supported strong engagement with the session content and practices, with participants viewing the program as clear, interesting, motivating, and positive. Participants expressed appreciation for the diversity of mindfulness practices taught, which enabled their practice to be personalized to those practices they found to be most accessible and helpful. The approach of developing an individualized practice is a standard aspect of MBSR and may be particularly important for addressing the potentially heterogeneous psychosocial and cognitive needs of those with pre-symptomatic HD.

Participants broadly adhered to the between-session mindfulness practice requirements, supporting the program acceptability. Practice averaged once per day for about a quarter of an hour, which is comparable to the percentage completion of homework in studies with similarly reduced homework requirements (Parsons et al. 2017). We had reduced the practice requirements from 45 to 30 min in order to seek a compromise between the potential for early HD-related reductions in concentration and our awareness of the “dose-response” mindfulness practice effect, i.e. that increased practice leads to improved psychological outcomes (Carmody and Baer 2008; Parsons et al. 2017). Despite the reduction in home practice requirements, home practice expectations underpinned two dropouts after the first session, and the qualitative data showed that participants viewed home practice expectations as quite demanding. At 3-month follow up, home practice had decreased to an average of one to two times per week, and participants indicated a high level of variability in terms of length of practice. Systematic examination of the continuation of mindfulness practice following MBSR programs has been neglected in previous studies, precluding comparison of our result with prior research (Parsons et al. 2017). In their qualitative data, however, Eccles et al. (2021) also identified a reduction in home practice over time in their pre-symptomatic HD participants, although participants described continuing to use mindfulness informally in daily life.

The second study aim was for participants to develop a theoretical understanding of mindfulness and practical mindfulness skills. Supporting the achievement of this aim, we found statistically significant pre to post increases in participants’ practice of two core principles of mindfulness (large effect sizes), including taking an observing stance towards experiences and a non-judgmental approach towards thoughts and feelings. We did not find significant changes on the other FFMQ dimensions (describing, acting with awareness, non-reacting to inner experiences, FFMQ

total); however, scores trended in a positive direction, with effect sizes ranging from small to large. The results provide overall support to the findings of Eccles et al. (2020), which showed effect sizes in a positive direction on FFMQ scales and particularly strong findings on individual scales which, similar to our findings, included the non-judgment scale. We also found positive but non-significant changes on the DERS-18, with small effect sizes. A larger study with sufficient power would be needed to enable a more comprehensive understanding of which skills may be developed through mindfulness training. Qualitative findings also supported the development of mindfulness skills, with participants describing increased familiarity and confidence with implementing mindfulness skills and progressively reduced reliance on the recordings to assist daily practice.

The positive effects on the FFMQ observing and non-judgment scales were consistent with previous research examining the efficacy of MBSR for psychiatric and medical patients (Hjeltnes et al. 2017; Naliboff et al. 2020). The observing scale of the FFMQ incorporates items which refer to awareness of different sensory experiences (e.g., aromas, feelings in the body, emotions). Qualitative feedback further indicated the development of this skill, and participants provided many examples of the ways in which informal practice enhanced their sensory experience and present-moment awareness, allowing them to take pleasure in enjoyable and even mundane activities, such as doing the dishes.

The non-judgmental items of the FFMQ refer predominantly to responding to internal emotions and thoughts with acceptance rather than criticism. This approach towards thoughts and emotions, rather than “controlling” or “criticizing” emotions, has been identified as an important component of emotional regulation (Gratz and Gunderson 2006; Velotti et al. 2015). While changes on the measure of emotional regulation (DERS-18) did not reach statistical significance, the qualitative data suggested the development of important skills in emotional regulation. For example, many participants reported changed responses to stress and to difficult thoughts and emotions, including increased capacity to recognize signs of stress, to “distance” themselves, and then to respond more thoughtfully and calmly. Acceptance of emotions and thoughts without judgment may be an important capacity underpinning these skills. Supporting this notion, previous studies have linked non-judgment to positive psychological functioning, including reduced worry, repetitive thinking, and rejection sensitivity (Cash and Whittingham 2010; Naliboff et al. 2020; Sedighimornani et al. 2019; Velotti et al. 2015), with one study finding that increased capacity for non-judgment developed through an MBSR intervention was associated with greater pre- to post-reductions in anxiety (Naliboff et al. 2020).

The third aim was to explore whether the MBSR program had the potential to reduce distress and enhance

psychological adjustment. Due to the baseline mood and quality-of-life measures showing minimal evidence of psychological difficulty prior to the start of the program, we had insufficient dynamic range in these measures to be able to observe change. This same challenge was observed by Eccles et al. (2020). Qualitative data, however, provided a rich source of information about positive psychosocial changes which touched a range of domains relevant to the experience of pre-symptomatic HD. Participants described receiving positive feedback about their emotional health from those at home and in the workplace. They indicated they had fewer intrusive HD ruminations and less preoccupation with future fears, with increased focus on present life experience (as per results above supporting the development of “observing” skills). This description was consistent with the experiences of participants in Eccles et al. (2021) study; the ability to focus on positive activities and disengage from HD thoughts may be an important element of coping with the experience of living with pre-symptomatic HD (Hubers et al. 2016).

Participants were effusive about the benefit of meeting others who were gene positive for HD, feeling that there were others who automatically understood their unique experience. This was consistent with the beneficial sense of shared identity and community reported by participants in the Eccles et al. (2021) mindfulness program. In our program, meeting similar others appeared to enable a sense of connection in positively facing HD, reducing isolation and shame associated with “the dirty secret” of HD. A reduction in stigma and isolation can only be psychologically protective for those in dealing with an illness that has for so long been left hidden and silenced (Schwartz 2010). With HD symptom onset viewed as outside of one’s control, participants saw engagement in the program as an avenue for taking positive action for one’s general health and wellbeing. Qualitative feedback showed that participants found it meaningful to learn a skill which was helpful not only in their present lives, but which had the possibility of future benefit. Some participants were positive about the potential of mindfulness to delay or mitigate HD symptom onset.

Supporting the representativeness of our sample, the majority of participants had a prior psychiatric history and were treated with antidepressants, similar to other large pre-symptomatic HD studies (e.g., from the ENROLL-HD database; see Achenbach and Saft 2021; Andriessen et al. 2022). Participants showed low baseline levels of depression and anxiety, consistent with our decision to exclude those with a current psychiatric episode from participation because of the potential for this to impact on engagement with the MBSR program. We did note that one participant demonstrated worsening responses on a range of the outcome measures, and it emerged that this participant had been informed that they had transitioned to the early symptomatic phase of HD

midway through the course and had also ceased taking an antidepressant during the recruitment phase. Emotional stability may be important for engagement in psychological interventions such as mindfulness (Mohr et al. 2010), which require reasonable levels of concentration and motivation to participate, and the suitability of MBSR for those with HD with active psychiatric symptoms needs further exploration.

This pilot project was limited in scope and generalizability by the small sample size, the lack of a control group, and the self-selection of participants into the program, which may have biased the results towards identifying benefits in learning mindfulness. While there are promising signs that MBSR is a valuable psychological intervention for pre-symptomatic HD, evidence for its utility requires more formal investigation with larger sample sizes and a randomized controlled trial design. An active control group would ideally involve the de-isolating benefits of the group experience, along with the opportunities to share coping strategies, but without the mindfulness skills training. While Eccles et al. (2020) have questioned the feasibility of such a randomized controlled trial due to challenges with recruitment, strategies for overcoming these (e.g., online forum, potentially a briefer program, scheduled after business hours) should be considered in order to progress our understanding of the potential of mindfulness interventions, given the identified need for psychological approaches for pre-symptomatic HD (Zarotti et al. 2020).

The utility of questionnaires assessing psychological adjustment was limited in the current study due to the presence of floor effects, a problem also identified by Eccles et al. (2020) in their study of mindfulness in pre-symptomatic HD. A significant challenge of future studies remains the selection of outcome measures that are targeted and sensitive to the variables that are significant to the experience of pre-symptomatic HD. There may be a need to develop further HD-specific measures with consideration of the qualitative responses of participants, as these may provide clues to the types of benefits of psychological interventions valued by people with HD (e.g., rumination about HD, social connectedness). It may also be useful to incorporate more extensive assessments of adaptive aspects of psychological functioning, such as capacity to manage negative thoughts and strong emotions, and for self-compassion. Another improvement to the current study measures could be the use of “real-time” rather than weekly retrospective measurement of formal and informal practice, as accurate estimates of practice adherence and quality of practice have been identified as necessary to identify the mechanism of action within mindfulness-based interventions (Alsubaie et al. 2017). With the reality of home practice expectations proving excessive for some, these expectations need to be explicit and considered carefully by potential participants prior to commencing MBSR.

This pilot study included a brief follow-up period of 3 months. Longer follow-up periods, e.g., 1 to 2 years, would be needed to explore whether benefits of learning mindfulness amongst those with pre-symptomatic HD are sustained over time. Our participants expressed a hope that mindfulness would be protective in the face of future HD. The question of whether mindfulness skills could impact on HD symptom onset or expression would require even more enduring longitudinal research over many years, as per the clinical research recommendations that emerged from the PREDICT-HD study (Paulsen et al. 2014). MBSR focuses on increasing present-moment attention, non-judgmental awareness of inner experiences, reducing emotional reactivity and encouraging acceptance. These are all capacities that could be considered as potentially protective to subtle changes in aspects of emotional regulation which may emerge in pre-symptomatic HD (Zarotti et al. 2018). Such capacities may also have the potential to build cognitive reserve for the cognitive and psychiatric changes associated with symptomatic HD (Wild and Tabrizi 2014), such as reduced attentional capacity and self-awareness, impulsivity, and irritability (Epping et al. 2015; Paulsen et al. 2014). Despite the challenges associated with investigating this topic, this may be an important consideration given that information about disease-modifying lifestyle interventions is a priority for those with pre-symptomatic HD (Braisch et al. 2016) and in light of the need to incorporate consumer priorities in research programs (National Health and Medical Research Council 2016).

Further research is also needed to consider the use of mindfulness in later stages of HD, including identifying when mindfulness may be most relevant and what alterations might be required to the intervention and to outcome measures. Given evidence of anosognosia or reductions in awareness as manifest disease progresses (Sitek et al. 2014), the sustainability of some aspects of mindfulness may diminish, so its value may be greater in the pre-symptomatic, prodromal, or early symptomatic disease stages. Mindfulness training may also be useful for a spouse or significant companion, who could not only benefit themselves from the intervention, but could also reinforce practice with their partner, and support the skill use in the event of early neurocognitive or neurobehavioral changes. The assessment of psychological outcomes may need to be supported by companion report of outcome measures, particularly as participants develop motor or cognitive disease signs.

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Author contribution The study's conception and design involved Cathy Gluyas, Julie Stout, and Fiona Fisher. Sarah Velissaris wrote the initial version of the manual. This was adapted by Fiona Fisher, Cathy Gluyas, and Marie-Claire Davis during running of the program. Marie-Claire Davis supervised data collection and conducted the quantitative analysis with Sarah Velissaris. The qualitative analysis was completed by Sarah Velissaris and Cathy Gluyas. The draft of the manuscript was written by Sarah Velissaris and Cathy Gluyas, and all authors commented, refined, and approved the final manuscript.

Declarations

Ethics approval Ethical approval for the study was granted by the Research Ethics Committee at Calvary Health Care Bethlehem (ref: 16121501) and Monash University Human Research Ethics Committee. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5).

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

Conflict of interest The authors declare no competing interests.

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