Quality improvement project aimed at integrating an adapted mindfulness-based stress reduction programme into a paediatric psychology service

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ABSTRACT

In our paediatric service, referrals for young people with chronic health problems significantly increased in times of acute stress, for example, during exams, and offering support in a timely manner was often a challenge. In order to respond more efficiently to this increase, a group intervention was introduced.

Mindfulness-based stress reduction (MBSR) is an 8-week course well known for the management of stress and illness in adult populations. While mindfulness-based approaches are used with children and young people, this was not currently available within our service. Group interventions were introduced in a phased approach to investigate the feasibility and acceptability of offering MBSR groups to young people living with chronic illness. We began by offering MBSR taster sessions to adolescents aged between 15 years and 19 years (N=25). Uptake was good (72% of people referred attended the sessions) and qualitative feedback indicated that this was indeed an acceptable approach. An adapted MBSR programme for adolescents was then developed and run over a period of 4 weeks (N=17). Uptake and treatment adherence were 65% and 82%, respectively, and compared well against our a priori targets. Qualitative feedback indicated that these 4-week courses were too short, and therefore, we aimed to introduce a group programme of 8 weeks in duration, in line with the standard MBSR format, referred to as MBSR-AH. Uptake of the extended groups fell short of our targets (35 %), although treatment adherence remained high with the majority of participants completing at least 75% of the course.

In this paper, we describe a phased intervention to assess the feasibility (uptake) and acceptability (treatment adherence) of integrating a group-based mindfulness programme into our service. We also describe the adaptations to the standard MBSR

programme to one more suitable for young people.

THE PROBLEM

Rate of psychological difficulties in children with chronic illness may be up to four times higher than their healthy peers. This has implications for ongoing quality of life and medical management, and therefore, developing age-appropriate psychological interventions is essential.¹ The relatively small child and adolescent clinical psychology service currently receives over 300 referrals per year of young people aged 0–19 years with a range of physical health conditions, including diabetes, inflammatory bowel disease, rheumatological disorders, chronic pain and fatigue and offers over 3000 face-to-face contacts a year. The majority of these contacts are offered as systemic family therapy and individual psychology based on a variety of psychological models for young people and their families, which all aim to encourage condition management and adaptation to health problems. Previous audits have demonstrated that our current service is well received by young people and their families with high levels of satisfaction,² although they would prefer to be seen sooner than is sometimes possible. We are committed to bringing new and innovative ideas in order to be responsive to the needs of our patients. One of the challenges is when demand exceeds resources, and we are unable to offer assessment and treatment as quickly as families would like. This often occurs in the months prior to exams when there is a spike in referrals. This is perhaps not surprising as it is well known that chronic health problems can be exacerbated by stress: either through a direct effect of stress hormones such as cortisol on the immune system^{3 4} or that stress affects the ability to adhere to medical management.

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As a team, we found it unsatisfactory to place young people on a waiting list for therapy in the context of an acute stressor, potentially only offering an appointment when the stressor has passed. It was felt, therefore, that offering group-based interventions would be pragmatic approach to this issue as multiple individuals with the similar difficulties could be seen in one session, thus avoiding the need for an extended waiting list. Furthermore, such an approach could perhaps be more appropriate than individual therapy as it would serve to reduce the isolation that is often reported by young people with chronic health problems and provide the context where young people could support each other. We began therefore to consider ways in which we could introduce an evidenced-based group intervention that targets stress and stress management skills into our service.

The MBSR programme is a group intervention originally designed for adults with chronic health problems but which has been increasingly used with children and adolescents.⁵ This project used a phased process to pilot the introduction of MBSR groups to the clinical psychology service for young people aged between 15 years and 19 years. In order to consider whether such an approach might be feasible, acceptable and sustainable in the longer term, we measured uptake to groups (feasibility) and treatment adherence (acceptability).

BACKGROUND INFORMATION

There is a complex relationship between stress and physical illness, with increasing evidence that stress can trigger changes to the immune system.^{3 4} People with chronic health problems therefore can find themselves locked in a vicious cycle, with stress exacerbating physical symptoms and the health problems themselves causing stress.

MBSR is a well-known programme that directly targets the relationship between stress and illness.⁶ It consists of an 8-week group programme, with each session lasting 2.5 hours. In these sessions, there is a core curriculum of didactic teaching about stress and illness, the use of core mindfulness meditation practices in session and home-based practices of up to 1 hour per day. Mindfulness is defined as 'paying attention in a particular way: on purpose, in the present moment, and non-judgmentally'. The aim of the 8-week course is to draw attention to the habitual ways the mind and body respond to difficulties, in particular the way in which resistance brings additional suffering. A systematic review and meta-analysis of randomised control trials using MBSR or mindfulness-based cognitive therapy (MBCT; an adaptation of MBSR designed originally for people with chronic depression), concluded that the evidence supports the use of MBSR and MBCT to alleviate both mental and physical symptoms in adults with a range of chronic illnesses, as an adjunct to cancer treatment and in prevention of health difficulties.⁷ There is also emerging evidence that for some conditions, for example, Crohn's disease and ulcerative

colitis, MBSR may have a direct on disease progression and flare ups in people with high levels of stress.⁸

MBSR is increasingly being used with children and adolescents with a range of emotional and physical health problems with promising results.⁵ However, we felt it was important to recognise that MBSR in the standard format is an intensive treatment, involving over 60 hours of meditation and exercises related to stress management over a period of 8 weeks. Furthermore, our clinical experience working with young people with conditions such as chronic pain or fatigue, for example, is that there can be a reluctance to access psychological care. This reluctance is often because of sensitivity to the suggestion that these difficulties are psychosomatic, 'in the mind' and not 'real'. It could be the case that mindfulness-based interventions, with the emphasis on 'mind training', would be seen as epitomising a message that some conditions are psychosomatic in origin and therefore rejected. It seemed necessary to establish therefore whether such an approach would be of interest to the young people attending the hospital, before attempting to adopt this as part of routine practice.

MEASUREMENT

The primary outcome measures for this project were feasibility (the percentage of people who took up the offer of attending an MBSR course relative to those referred) and acceptability (defined as the percentage of people attending at least 75% of the sessions). In order for the service to consider rolling out MBSR as a routine part of the service, it was decided that uptake and treatment adherence should be at 50% or over.

STRATEGY

The team felt that integrating a rolling programme of MBSR groups represented a pragmatic and responsive way of managing referrals; however, it was recognised that there could be initial start-up costs that might prove unacceptable in a climate where most NHS trusts find themselves with a budget deficit. These costs included time and expense of training a member of staff in MBSR and materials such as the audio recordings of meditations for home practice yoga mats and CDs. These start-up costs were managed by offering study leave but not course fees for MBSR training, and the materials were donated to the service.

It was decided that a phased intervention, beginning with taster sessions, would be an appropriate first step. This iterative process is described in more detail below. It was decided to focus specifically on older adolescents (aged 15 years and above) as it was our view that more radical changes would be needed to the MBSR content and materials for younger age groups. Furthermore, the increase in referrals around exam time tends to be observed mostly in the older adolescent group.

DESIGN

The various phases of this intervention are described below:

Step 1: taster sessions

We began the project by running taster sessions, designed to include didactic information about mindfulness, provide the opportunity for participants to experience some short meditations and also experience being in a group situation. Each of these sessions lasted approximately 3 hours. Taster session and subsequent groups were run by author 1, a level 1 teacher in MBSR, who has also had training in the 'b' programme via the Mindfulness in Schools Programme, a mindfulness course designed for secondary school children aged 15 years and above.⁹

Step 2: 4-week MBSR groups

Following the success of the taster days in terms of both uptake and perceived usefulness of such an approach, it was decided to proceed to offering young people a 4-week MBSR group, conceptualised as an extended mindfulness 'taster' group. In consultation with a specialist-approved mindfulness supervisor and consulting the literature on appropriate adaptations for adolescents, a 4-week course was designed that mapped onto the first 4 weeks of the standard MBSR course. Each session was 1.5 hours in duration in comparison with the standard 2.5-hour format. Participants were taught one key meditational practice, the body scan, which in session lasted no longer than 15 min. Participants were also given a CD to practice this at home, 6 days out of 7 days, and brief written information was given to accompany each session.

Flyers were developed and sent to clinics and referring consultants who usually referred for individual psychology. The flyers were updated at each stage by adding quotes from young people that had participated in the previous group.

Step 3: the development of MBSR-AH

Given the uptake rates and adherence rates of the 4-week courses, it was decided to develop an MBSR course adapted for adolescents, subsequently referred to as MBSR-AH. This was modelled on the standard MBSR format but included shorter session times (1.5 vs 2.5 hours), shorter meditations, which began at 15 min in session, and were extended over the duration of the course to 25 min. All key meditation practices were incorporated including the body scan, mindful movement and sitting meditation. The mindful movement meditations were significantly adapted in comparison with the standard MBSR protocol. Activities of daily living such as standing and basic stretching were incorporated into the mindful movement practices rather than offering yoga or Qi Gong exercises, in recognition of the trainer's area of professional practice. All participants were given CDs to practice the body scan, mindful movement and sitting meditation at home, and a shorter more adolescent friendly version of the MBSR manual was provided.

In addition to the meditation practices, many of the other MBSR programme elements remained, including letter writing, group exercises to bring attention to the relationship between body and mind and poetry were incorporated. It was not possible to offer a day long silent retreat on these courses.

At this stage, we also added a change to the referral process. Prior to this point, referrers had been able to refer directly to the taster session or 4-week courses. However, given that this new course involved considerably more commitment and resources, author one contacted all potential participants prior to the group. This contact was to describe the intention of the intervention, discuss the commitment required and answer any outstanding questions. This was also an opportunity to consider whether participants were suitable for the group programme in line with the Good Practice Guidelines.¹⁰

RESULTS

The project began with MBSR taster sessions. Twenty-five people aged between 15 years and 19 years were offered the taster session (32% male) and 18 people attended (72% uptake, 33% male). At the end of the session, participants were given a brief questionnaire about areas where they felt the ideas could be useful to them, answering each item on a Likert scale of 0 to 10 (0=not useful at all and 10=extremely useful) and likelihood of attending a longer course. Young people suggested that mindfulness could be useful in approximately 50% of the domains of life listed (as assessed by rating of 7 and above), and the majority would welcome attending an MBSR course. These data are outlined in table 1.

Participants were also asked about the 'worst things' of the session. Some participants indicated that the taster session was not sufficiently focused on pain/illness and that the techniques were hard to learn. It was concluded

Table 1 Perceived usefulness of mindfulness in various life domains

Domain	N	Range	Mean
Exams	18	4–10	7.50
Sport	18	0–8	4.61
Anger	18	2–10	7.56
Sleep	18	3–10	7.56
Pain	18	4–10	6.83
Sadness	18	0–10	6.22
Eating	17	0–10	4.22
Stress	18	4–10	7.94
Relationships	18	0–9	6.00
Worry	18	3–10	7.17
Likelihood of attending an MBSR course	18	5–10	7.61

MBSR, mindfulness-based cognitive therapy.

that these were matters that would be addressed in a longer intervention

Step 2: 4-week courses

The high attendance rates and additional feedback provided sufficient justification to offer an MBSR group to young people with health difficulties attending the hospital. A total of 26 young people were offered the 4-week course. Twelve of the 18 young people who attended a taster session were offered the opportunity with the other (the remaining six people were had reached 19, the cut-off for our service or were engaged in another psychological therapy). Fourteen additional referrals were received for the 4-week MBSR course. Of the 26 people offered the course, 17 (65%) opted in and 14 (82%) attended at least three of the four sessions. These results therefore exceeded our a priori targets. However, a number of participants indicated that they felt that these courses were too short in duration. This is captured in the quotation below.

4 weeks is quite short. Only a week for learning a new technique, trying to understand it and why we do it, and practicing it, is too short. Spread out the same information into more sessions.

Step 3: MBSR-AH groups

The feedback gave us justification to begin planning to introduce an MBSR course of 8 weeks. Unfortunately, we encountered several practical obstacles in doing this because of therapist annual leave and school/college timetable. A compromise arrangement was made and a course of 7 weeks in duration was organised, which fitted in more easily with school/college term and exam timetable. The main focus of sessions 7 and 8 is around self-care and keeping mindfulness alive, respectively. These elements were incorporated into one extended session of 2 hours. These groups were also run in the early evening to avoid additional disruption to education.

In total, 29 referrals were received, and on this occasion, seven people were excluded due to issues of risk (frequent suicidal ideation or self-harm) or the person was currently engaged in another psychological therapy. Of the 22 people offered the course, only eight people

opted in to the intervention (36%). However, six of these attended 75% of the sessions or more. Patient demographics for the 4-week and 7-week courses can be seen in table 2 below.

In summary, uptake to these extended courses is reduced in comparison with 4-week courses (36% vs 65%), with potential participants either stating that they were not interested or that the course would interfere with school or social life plans. However, treatment adherence, however, remains high throughout.

Interviews with five course participants and two parents were conducted. Three themes emerged regarding the perceived utility of this approach for managing health and illness. A brief summary of these is given below.

Finding a community

... community, that's what you sort of lose, like I know I withdrew a lot from friends and schooling and everything and I was on my own, well that's how I felt anyway, and didn't really like talking to others, because then I would have to explain. But these were all people, we were all on the same line, and they knew everything, so that I found very helpful.

Understanding the link between body and mind

Learning to take my mind out of the equation and listen to my body more.

[P]acing myself, that's where I struggled, realising when I need to pace myself. I'd be like "no, no, no, do everything more, do whatever I can, and then crash and burn for about a week!

Being with what is here

It made me pay attention to my body, not focusing on the pain, but acknowledging that the pain is there.

A full qualitative analysis is currently in preparation.

Lessons and limitations

The data from this three-step phased intervention suggest that a mindfulness-based intervention is of both feasible and acceptable to young people with health problems. Uptake to the longer groups dropped from 65% to 36%. This is despite moving the group programme to the early

Table 2 Patient demographics and referring specialties

	Offered	Uptake	Referring specialty of attenders (N)
4-week group	N=26	N=17	Gastroenterology/pain (5)
Mean age (years):	17	17	Adolescent medicine (5)
Age range (years):	15–19	15–19	Rheumatology (2)
% male	31	30	Chronic fatigue syndrome (2)
			Haematology (1)
			Epilepsy (1)
			Urology (1)
7-week group	N=22	N=8	Gastroenterology/pain (5)
Mean age (years):	16	16	Chronic fatigue syndrome (2)
Age range (years):	14–18	15–17	Epilepsy (1)
% male	32	37.5	

evening to make it more possible for people to attend and not miss school/college lessons. The lower uptake for the longer group is consistent with studies of 6-week MBSR programmes in a similar age range.¹¹

Treatment adherence remained high in courses of both 4-week and 7-week duration, with the majority of people completing 75% or more of the course they were offered. This suggests that if we can do more to encourage people to attend, they are likely to find the content relevant and complete the intervention. The feedback from participants was rich and informative about the benefits of mindfulness; therefore, funding was successfully applied for to make a short video to be used for future recruitment to try and increase uptake for future groups. This video of four previous participants (one male, three female and a mother of one of the participants) is now available to young people considering attending groups. Information about the groups is available in clinics, and people can self-refer directly using an Eventbrite sign up system. On the basis of these data, we have now begun running groups that are 6 weeks in duration. It was decided that this was an appropriate response to the feedback that groups of 4 weeks are too short, while taking into account the lower uptake rate when longer groups are offered. This also comfortably allows for groups to be scheduled around term time and examination periods and to continue rolling out this programme within existing resources. One major limitation of this project, however, is that we have no longer term outcome data about the effectiveness of MBSR-AH.

CONCLUSIONS

MBSR interventions are feasible and acceptable to young people referred to a paediatric clinical psychology service. However, the standard MBSR format was heavily adapted to make it more accessible to young people, and despite positive feedback from participants, it cannot be assumed that the impact of MBSR-AH is the same as a standard MBSR programme. Changes in emotional well-being or health-related outcomes were not collected, and this matter does need to be addressed. The largest group of people attending MBSR-AH were gastroenterology patients. We are currently running a funded waiting list randomised control trial to evaluate MBSR-AH in adolescents and young adults with inflammatory bowel disease.

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Contributors JD and DC were responsible for implementing the different phases of this project. JD ran all of the taster sessions and groups and was responsible for designing MBSR-AH. MH was involved in the data collection and initial manuscript preparation. JD and DC prepared the final manuscript preparation, and JD was responsible for submitting the paper.

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