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Impact of Dance Movement Psychotherapy on the Wellbeing of Caregivers of Children with Autism Spectrum Disorder

Abstract

Objectives

Sustaining the wellbeing of caregivers of children with Autism Spectrum Disorder (ASD) can be highly demanding. This study explored the impact of DMP intervention on the wellbeing of caregivers in comparison with their standard care routine.

Study design

This pilot evaluation study used a quasi-experimental design.

Methods

Thirty-seven caregivers of children with ASD were recruited from two special educational needs settings and were allocated to the DMP intervention or the control group depending on their availability to attend the sessions. The participants in the intervention group received five DMP sessions lasting 90 minutes each. Adult Wellbeing Scale (AWS) and Parenting Stress Index- Short Form (PSI-SF) were the two outcome measures that were administered before and after DMP to measure the impact of DMP intervention on caregiver's wellbeing and parental stress.

Results

The retention rates were poor, with only 50% of participants in the DMP intervention arm attending at least 70% of the sessions until its end. The Minimal Clinically Important Difference (MCID) was achieved for a small effect size in both outcome measures in the DMP intervention group but not in the control group. Results from the ANCOVAs showed a significant difference in post-intervention scores between the DMP intervention and the control group for AWS ($F_{1,33} = 106.474, P < 0.001$) but not for PSI-SF. In addition, a significant association was found between pre-intervention scores and the number of sessions attended with the post-intervention scores of both AWS and PSI-SF.

Conclusions

The results of this pilot DMP study are promising. However, before running a larger randomised controlled trial, strategies to support caregivers to attend the intervention need to be considered carefully.

Keywords: Wellbeing, Parenting Stress, Dance Movement Psychotherapy, Caregivers, ASD, Teachers

Impact of Dance Movement Psychotherapy on the Wellbeing of Caregivers of Children with Autism Spectrum Disorder

Autism Spectrum Disorders (ASD) are a group of neurodevelopmental disorders, which begin early in childhood and persist for the rest of the person's life^{1,2}. Children with ASD present heterogenous strengths and challenges, which often require undivided support and attention from the caregivers (defined here as any individual who can support the child's development, including mother, father, grandparents, teachers and teaching assistants). Despite intense endeavour from the caregivers, only some children become independent, while a significant amount of children continue to need care³. Due to the demands placed on caregivers, and a lack of resources and support available to them, high levels of stress and burnout are not uncommon^{4,5}.

The impact of burnout on caregivers can be far reaching. As noted by Kristensen et al.⁶, physical and psychological exhaustion can affect the caregivers' relationship with their children and with other family members. It can also impact on their work. Especially when children are identified with neurodevelopmental disorders and special educational needs such as ASD, caregivers face unique challenges that may impact their wellbeing. Existing literature, for example, shows that the stress experienced by caregivers of children with ASD can be much higher than caregivers of other types of disabilities and those with typically developing children^{7,8}. Furthermore, both teachers and parents experiencing burnout are more likely to experience problems with their physical health, higher levels of anxiety, greater occurrence of depression and lower levels of overall wellbeing^{9,10}. This indicates that interventions just for children diagnosed with ASD may not be enough. Holistic and family-oriented approaches are necessary for the better management of children with ASD. The NICE guidelines¹¹ for ASD in England recognises the need for respite care, short breaks, advice on welfare benefits, as well as the carer's own assessment of their wellbeing. However, very few of the studies on interventions focus specifically on the social and emotional wellbeing of caregivers. Instead, a greater emphasis has been on skill development, psychoeducation and awareness of caregivers¹²⁻¹⁴. Hence, the current pilot study aimed to explore if Dance Movement Psychotherapy could be beneficial to enhance wellbeing of the caregivers of children with ASD.

Dance Movement Psychotherapy (DMP) as it is known in the UK, is one of the arts therapies, next to music, drama and art psychotherapy, that aims to support the integration of mind and body through the use of creative movement expression^{15,16}. Growing research in the

field of DMP has noted the benefits of DMP in stress reduction and alleviation of depression^{17,18}. Because of a dearth of studies specifically on DMP and caregivers, a mixed-methods study that was conducted in India laid the foundation for the current study^{19,20}. Earlier findings indicated that the DMP's therapeutic process enhanced the resilience of the mothers of children with ASD and helped them tackle parenting stress and depression. There was a statistically significant reduction in Parenting Stress Index-Short Form (PSI-SF)²¹ and Hamilton Depression Rating Scale (HAM-D)²² scores. However, the study sample was limited to a small number of Indian mothers with a specific socio-cultural, economic and political background. Thus, there was a need to explore this intervention further in a larger group of caregivers, from different socio-cultural backgrounds. Hence, the current study explored how DMP practice can support the wellbeing of caregivers of children with ASD in England, attempting to expand the pool of participants and broaden the cultural specificity of previous work.

Methods

The quasi-experimental pilot study design and findings reported in this article are part of a larger mixed-methods doctoral study. Prior to conducting the study, ethical approval was sought through the Faculty of Arts and Sciences at Edge Hill University.

Participants

For this study, caregivers were defined as persons in the child's circle to whom the child is close and familiar and who are in a position to support the child's development. They were recruited from two Special Educational Needs (SEN) schools in the North West of England that specialised in the education of children and young people with ASD. The inclusion criteria for the study were: they needed to be caregivers of (any) children below 16 years with a diagnosis of any level of severity of ASD, intellectual abilities and associated problems as per the Diagnostic and Statistical Manual, Fifth Edition (DSM-5)²; eligible caregivers also had to be willing and able to consent and participate in the study, have sufficient command of English to complete the research interviews, and actively participate in group interactions in English.

As shown in the CONSORT flow diagram (Figure 1), of the 18 schools approached, eight expressed interest. However, only four schools proved suitable based on the number of children available and responses from the parents. Two schools fully engaged with the study

and invited parents and teachers to take part in the study. Twenty-six parents and 21 teachers were allocated to either DMP intervention (experimental group) or standard care as usual (control group) depending on their availability to attend the sessions.

[Figure 1]

Intervention

A DMP intervention protocol was developed as per TIDieR guidelines²³. The complete design of the protocol and the findings of the fidelity assessment are described in the first author's doctoral thesis²⁴. Given that the optimal number of participants for group psychotherapy sessions is considered to be between five and eight participants²⁵, it was decided to limit the caregivers' groups to this number. Teachers and parents were grouped separately to protect their professional and personal life boundaries. Five sessions lasting for 90 minutes were delivered once a week for four groups in two locations by a qualified and registered dance movement psychotherapist. The protocol had an eclectic or integrative framework with eight principles derived from the findings of the preliminary work conducted in India,^{18,19} ongoing parallel projects on depression^{26,27} (called Dancing the Blues and Arts for the Blues) and a systematic review on depression by Karkou et al.¹⁸. The sessions were semi-structured and each session focused on different themes such as identifying personal strengths and challenges, enjoyable moments with children, setting new vision and exploring new ways of moving to address their challenges. The sessions began with an opening ritual, followed by a warm up and development of the theme and finally a closing ritual.

Outcome measures

The Adult Wellbeing Scale (AWS)²⁸ and Parenting Stress Index-Short Form (PSI-SF)²¹ were used to assess primary outcomes on wellbeing and parenting stress. All the participants (teachers and parents) answered AWS and only parents answered PSI-SF. AWS²⁸ is an eighteen item self-inventory with a four-point rating scale from (0=yes, definitely) to (3=no, not at all). Internal reliability, convergent validity and construct validity tested using factor analysis showed that the total score of this tool was psychometrically sound for evaluating the wellbeing of caregivers. The total score section was found to be reliable with a good internal consistency (Cronbach's $\alpha = 0.87$).

PSI-SF is a brief version of the Parenting Stress Index²¹. This is a thirty-six item self-inventory and uses a five-point rating scale from 1 (strongly disagree) to 5 (strongly agree). raw total scores above 90 indicate clinically elevated levels of stress. With high internal consistency for the total scale (Cronbach's $\alpha = 0.92$) and good external criterion validity (0.86), this is a good tool for assessing parenting stress.

Analysis

A total of 19 parents completed the PSI-SF²¹ at pre- and post-intervention time points. Of these, eleven parents were assigned to the DMP intervention and eight to the control condition. A total of 37 caregivers completed the AWS²⁸ at pre- and post-intervention time points; this figure includes both parents and teachers. Of this total, 20 caregivers were assigned to the DMP intervention and 17 to the control condition. One-way Analysis of Variance (ANOVAs) were performed to test for differences in pre-intervention PSI-SF and AWS scores between the DMP intervention and control conditions. Following this, two separate Analysis of Covariance (ANCOVAs) were performed to test for differences in post-intervention PSI-SF and AWS scores between the DMP intervention and control groups. In the first ANCOVA post intervention AWS scores were entered as the dependant variable and pre-intervention AWS scores as well as number of sessions attended were entered as covariates in the model. Group (i.e. DMP intervention and control conditions) was entered as a fixed factor in the model. This analysis was performed to determine whether post AWS scores differed between those receiving the DMP intervention and those in the control condition while controlling for pre-intervention AWS scores as well as number of sessions attended by the caregiver. This latter covariate was entered in the model to account for the variation in the number of sessions that the parents actually attended, used as a proxy measure of their engagement in the intervention. A similar ANCOVA was performed on PSI-SF scores. Here the post-intervention PSI-SF score was entered as the dependent variable, while pre-intervention PSI-SF score and number of sessions attended by the caregiver were entered as covariates in the model and group as a fixed factor with 2 levels (i.e. DMP intervention and control conditions). As this was a pilot study, minimal clinically important difference (MCID) was used to for determining whether the DMP intervention was influencing AWS and PSI-SF change scores to reach our predetermined minimal clinically important difference. To calculate the change score equivalent to the MCID, the standard deviation of the baseline scores was multiplied by 0.2 (small effect size)²⁹. In addition, eta squared was also calculated to determine effect size for all tests performed and

then converted to Cohen's d using free online software by Psychometrica³⁰. An alpha level of 0.05 was chosen to determine statistical significance.

Due to the high attrition rate in the parents' data set, as an exploratory step, a Per Protocol (PP) approach was also used. As per the PP criteria set for the parents' data set, only four participants were eligible from the experimental condition to be included in the analysis of PSI-SF data. Due to this small sample size, non-parametric tests, specifically Wilcoxon signed-rank test and Mann-Whitney U test, were preferred for within and between subject's analysis. The Wilcoxon signed-rank test was used to compare the paired data of pre and post DMP coming from the same group and indicated if there were differences within the groups attending DMP and within the group which received only standard care. The Mann-Whitney U test on the other hand compared the scores of the participants who attended DMP and the control group with standard care as usual.

Results

The total sample had 37 participants and their age ranged between 28-56 years (Mean=39.25 years). Also, there were more females than males (Table 1): only six men out of 37 participants in the full sample. All the participants were British and the majority were from a white ethnicity. Demographics on the marital status of the participants indicated that many of them were single parents. Many were also raising more than one child. One of the participants who was a single parent was raising four children and three of those children were attending SEN school.

[Table 1]

Means and standard deviation for AWS and PSI-SF scores pre-and post-intervention, separated by DMP intervention and control groups are shown in Table 2 and 3. Inspection of the mean scores in the tables show a decrease in AWS and PSI-SF scores between pre- and post-intervention time points for both those in the DMP intervention and those in the control condition. However, the change in scores for both the AWS and PSI-SF is notably greater for the DMP intervention group than the control group (Figure 1 and 2).

[Table 2]

[Figure 2]

[Table 3]

[Figure 3]

Results from the one-way Analysis of Variance (ANOVA) showed no significant differences in pre-intervention AWS or PSI-SF total scores between DMP intervention and control conditions. Results from the first ANCOVA showed that pre-intervention AWS score ($F_{1,33} = 106.474, P < 0.001, \eta^2 = 0.093$, Cohen's $d = 0.64$) and number of sessions attended ($F_{1,33} = 28.244, P < 0.001, \eta^2 = 0.025$, Cohen's $d = 0.32$) was significantly associated with post-intervention AWS score. A significant difference in the post-intervention AWS score was also found between DMP intervention and control groups ($F_{1,33} = 4.418, P = 0.04, \eta^2 = 0.004$, Cohen's $d = 0.13$), with those in the DMP intervention showing greater AWS scores post-intervention than those in the control condition (coefficient = 2.551, SE=1.214, 95% CI: 0.082, 5.020).

Results from the second ANCOVA showed that pre-intervention PSI-SF score ($F_{1,15} = 298.744, P < 0.001, \eta^2 = 0.053$, Cohen's $d = 0.47$) and number of sessions attended ($F_{1,15} = 14.415, P = 0.002, \eta^2 = 0.003$, Cohen's $d = 0.11$) was significantly associated with post-intervention PSI score. There was no significant difference in post-intervention PSI-SF score, however, between those in the DMP intervention and those in the control condition ($F_{1,15} = 0.136, P = 0.7, \eta^2 = 0.00002$, Cohen's $d = 0.01$). Due to the high attrition rate in the parents attending DMP (N=4), Wilcoxon signed-rank test was performed for total scores of PSI-SF before and after DMP within subjects, according to Per Protocol criteria. No significant difference was observed in the pre and post-intervention scores after DMP ($Z = -1.826, P > 0.05$). Likewise, for the comparison between DMP and control group, Mann-Whitney U test

was used. The results showed no significant difference for the post total scores of PSI-SF between DMP intervention group and control group ($U = 5.5$, $Z = -0.726$ $p = .46$).

Results showed that for AWS the mean difference between pre- and post-intervention score was greater than our predetermined minimal clinically important difference (1.234) for the DMP intervention group (i.e. $2.4 > 1.234$) but this was not the case for the control group (i.e. $0.12 < 1.234$). Similar results were found for PSI-SF scores with the mean difference between pre- and post-intervention PSI-SF score being greater than the MCID (5.172) for the DMP intervention (i.e. $9.36 > 5.172$) but not the control condition (i.e. $2.3 < 5.172$). These results suggest that whilst the difference in post-intervention score for PSI-SF between DMP intervention and control group was not statistically significant, the mean difference in pre- and post-intervention score for the DMP intervention group achieved the MCID for a small effect size. Further, MCID for a small effect size was achieved only in the intervention group but not in the control condition.

Discussion

This study was piloted to evaluate the impact of a DMP intervention protocol on overall psychological wellbeing of caregivers, including parents and teachers, as well as parental levels of stress after a course of DMP sessions. Only in the DMP intervention group the MCID was achieved for both outcome measures used in the study, i.e. Parenting Stress Index-Short Form (PSI-SF)²¹ and Adult Wellbeing Scale (AWS)²⁸ group. Differences in post-intervention measures for the AWS but not the PSI-SF were significantly higher for those in the DMP intervention compared to those in the control condition. These statistical outputs indicate that as a pilot study the designed DMP intervention was having a clinically significant effect on both PSI-SF and AWS outcome measures in caregivers and a statistically significant effect only on the AWS measure used in the study.

Positive associations between personal resources, mental health and the effects on wellbeing have been established³¹⁻³³. The post-intervention mean scores of AWS have shown decrement in participants who received DMP and who attended DMP sessions consistently. This suggests DMP's role in enhancing the caregivers' personal strengths, offering new ways of looking at and dealing with the challenges with mindful composure might have been critical in lowering the depression, anxiety and irritability captured in the AWS measure.

The mean scores in the PSI-SF have shown a downward trend (decrease of parenting stress) after DMP intervention in the experimental condition but not enough to show statistically significant difference, unlike the findings from the study conducted in India²⁰. This could be because of several differences such as child-related, family-related, socio-cultural, political and individual factors between the samples. The baseline scores of the participants in the two studies were fairly different as the severity of parenting stress was much higher in the Indian study compared to the present study. Due to lack of external resources and facilities available to the people in low and middle income countries such as India, epidemiological studies have documented significantly higher stress levels in parents of children with disabilities in developing countries, when compared to reports of parents from developed countries³⁴⁻³⁷. Hence, these demographic baseline variables might have emerged as key factors accounting for differences in PSI-SF after DMP in caregivers with higher levels of burnout. This leaves the discussion open to consider whether it would have been better to have set tighter inclusion criteria to involve only those participants who needed psychological support or encourage participation from any caregiver as prevention from burnout and promotion of wellbeing. Either way, there is a need for therapists to consider available services for this population that reduce stress and encourage wellbeing as a way of improving global applications of DMP with this client population.

This study presents several limitations in terms of lack of randomisation, no blinding and small heterogeneous sample which will need to be carefully considered in any future studies. In addition, the study's sample retention rates were poor, with only 50% of participants in the DMP intervention arm attending at least 70% of the sessions. Even though many caregivers were interested in attending the intervention, practicalities around scheduling the sessions were challenging. Data on the social conditions such as educational levels, housing and occupations of the participants could have provided greater inferences with regards to retention and adherence. This alarming low retention rate also leads to critical thoughts on acceptability of the intervention by the participants and raises further thoughts on how to mitigate for perceived and actual barriers in participation. In this study, our plans for one hour-long sessions for twelve weeks changed to manage attrition; sessions were condensed into five weeks for 90 minutes at a time to minimise commuting time. Longer duration of sessions instead of short frequent sessions could be a longer-term solution. Future studies could also investigate service delivery methods that minimize time and resource commitments of participants, such as technology facilitated interventions³⁸ or research designs with simple data

collection processes. Supporting parents in better planning and preparation by offering bus rides or offering temporary caretakers in place for their children to free them up to attend the sessions could also help with lowering attrition rates. Nevertheless, in line with the NHS Five Year Forward View for carers³⁹, further explorations on accessibility of therapeutic interventions are necessary as they could have wider implications on addressing health inequalities and community integration.

Overall, the findings of this study indicate promising effects for DMP on the wellbeing of caregivers who attended and engaged in DMP. The findings also indicate the need to explore the wider use of DMP for caregivers in general and not just limiting its use for the carers of children with ASD. Further, both the PSI-SF and AWS are outcome measures that can be included in future large-scale studies of this nature, and those more generally designed to address caregiver and parent wellbeing. However, a key point here is that the number of sessions attended by the caregivers was significantly related to the post-intervention measures for both the PSI-SF and AWS. This suggests future studies of this kind should focus on supporting the caregivers to attend the sessions as this is likely going to effect the impact of the designed intervention.

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Author Contributions

SA was responsible for organizing, collecting data, analysing and writing up the current paper. It was conducted as a part of her doctoral thesis.

JP was the member of the supervisory team, supported the statistical analysis and contributed to the revisions and edits of the paper.

VK guided and provided corrections for the article as the director of studies for the thesis.

SM and TK were the members of the supervisory team. They contributed to the development of study design, revisions and edits of the paper.

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