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The impact of the implementation of the Dutch combined Meeting Centres Support Programme for family caregivers of people with dementia in Italy, Poland and UK

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The impact of the implementation of the Dutch combined Meeting Centres Support programme for family caregivers of people with dementia in Italy, Poland and UK

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The impact of the implementation of the Dutch combined Meeting Centres Support programme for family caregivers of people with dementia in Italy, Poland and UK

Abstract

Objectives: The MEETINGDEM research project aimed to implement the combined Dutch Meeting Centre Support Programme (MCSP) for community-dwelling people with dementia and caregivers within Italy, Poland and UK and to assess whether comparable benefits were found in these countries as in the Netherlands.

Method: Nine pilot Meeting Centres (MCs) participated (Italy-5, Poland-2, UK-2). Effectiveness of MCSP was compared to usual care (UC) on caregiver outcomes measuring competence (SSCQ), mental health (GHQ-12), emotional distress (NPI-Q) and loneliness (UCLA) analysed by ANCOVAs in a 6-month pre-test/post-test controlled trial. Interviews using standardised measures were completed with caregivers.

Results: Pre/post data were collected for 93 caregivers receiving MCSP and 74 receiving UC. No statistically significant differences on the outcome measures were found overall. At a country level MC caregivers in Italy showed significant better general mental health ($p=0.04$, $d=0.55$) and less caregiver distress ($p=0.02$, $d=0.62$) at post-test than the UC group. Caregiver satisfaction was rated on a sample at 3 months ($n=81$) and 6 months ($n=84$). The majority of caregivers reported feeling less burdened and more supported by participating in MCSP.

Conclusion: The moderate positive effect on sense of competence and the greater mental health benefit for lonely caregivers using the MCSP compared to UC as found in the original Dutch studies were not replicated. However, subject to study limitations, caregivers in Italy using MCSP benefitted more regarding their mental health and emotional distress than caregivers using

UC. Further evaluation of the benefits of MCSP within these countries in larger study samples is recommended.

Word count: 250

Keywords

dementia, family caregivers, post-diagnostic support, Adaptation-Coping Model, Meeting Centres Support Programme, psychosocial interventions

Introduction

Dementia is one of the major causes of disability and dependency among older people worldwide. It is frequently overwhelming, not only for the people who have it, but also for their caregivers and families. The impact of dementia on caregivers, family and societies can be physical, psychological, social and economic (World Health Organisation, 2016). The prevalence of dementia in the EU in 2015 was 9.6 million and predicted to rise to 14.7 million by 2035 (Organisation for Economic Co-operation and Development/European Union, 2016). It is widely recognised that family members provide the majority of support for people with dementia who live at home (Luengo-Fernandez, Leal & Gray, 2010). This can place considerable demand on family caregivers not just in terms of tasks and supervision but also coping with the changes in the person they are caring for and the changes in their relationship.

Caregiving can be highly satisfying (Hellström, Nolan & Lundh, 2007). However, a large number of studies pay testament to the fact that family caregivers of people with dementia experience high levels of stress, symptoms of depression, poor health and well-being and social isolation (Schulz, O'Brien, Bookwala & Fleissner, 1995; Brodaty, Gresham & Luscombe, 1997) as well as financial hardship. Evidence suggests that levels of stress and distress increase over time due to the progression of dementia (Froelich et al., 2009; Kannan, Bolge, Del Valle, Alvir & Petrie, 2011). The increasing number of national dementia strategies recommends diagnosis at earlier stages (Brooker, La Fontaine, Evans & Saad, 2014). Receiving a timely diagnosis can help people and their families to prepare for the impacts of dementia and in planning appropriate lifestyle changes, thereby maximising opportunities for emotional, social and practical adjustment. This in turn can minimise dementia-related distress and increase the opportunities to

live at home for longer with a better quality of life, both for the person with dementia and their family. However, people are often unsure where to get help, and post-diagnostic support is rarely well coordinated.

Interventions for family caregivers have the potential to improve their quality of life and that of the people with dementia they care for (Selwood, Johnston, Katona, Lyketsos & Livingston, 2007; Thomas, Dalton, Harden, Eastwood & Parker, 2017). Family caregivers may benefit best from tailored interventions since factors such as the quality of the previous relationship, social support, personality factors and ethnic background can influence the care-giving experience (Marziali & Climans, 2009). According to Dickinson et al. (2017) well-designed and clearly structured multicomponent interventions can help maintain the psychological health of caregivers of people with dementia and delay institutionalisation of the latter. In order for them to be most effective, interventions should include both educational and therapeutic components, and delivery via a support group can enhance effectiveness.

Furthermore, research suggests that decreases in wellbeing of the person with dementia correspond with increases in stress and distress experienced by their family caregivers (Burgener & Twigg, 2002; Holst & Edberg, 2011). Thus interventions which involve improving the wellbeing of people living with dementia alongside their family caregivers are likely to be an important factor influencing outcomes for both the person with dementia and the family caregiver. While the evidence indicates that supporting both the person with dementia and their family caregiver tends to be most effective, in practice relatively few interventions exist that have taken this combined approach (Van't Leven, 2013).

The Meeting Centre Support Programme

The Meeting Centre Support Programme (MCSP) is a well-researched mode of delivering locally tailored post-diagnostic support for people living with dementia and their family caregivers in the Netherlands.

The MCSP typically serves a local community of around 5,000 older people. The Meeting Centre (MC) 'club' is usually offered 3 days per week, supporting 10-15 people plus families on any one day in easily accessible community locations. The small team of staff is led by a manager with relevant health and social care qualifications and experience and who has the skills to lead the team and engage with people with dementia, their families and the local community. People attend according to their need and preference three or less days a week. Evidence-based post-diagnostic psychosocial interventions relating to information and psychoeducation and emotional, social and physical well-being are provided in a friendly manner, tailored to the needs of the local members by a small team of staff and volunteers trained in the ethos of person-centred dementia care. The interventions are informed by the Adaptation-Coping Model (Brooker, Evans & Dröes, 2017; Dröes, Van Mierlo, Van der Roest & Meiland, 2010), which distincts several adaptive tasks/challenges in dealing with the consequences of dementia and maintaining an emotional balance, such as coping with disabilities, preserving a positive self-image, developing and maintaining social relationships, and developing an adequate care relationship with health care professionals. The model provides a way for people with dementia and family caregivers to conceptualise their adjustment to living with dementia post-diagnosis,

and presents the staff team with aims for cognitive, emotional and social support on an individual and group level.

Family caregivers (those most involved in the care which may be the partner, a son or daughter, but also a friend or acquaintance) have easy access to practical information, personal advice and emotional, social contact and peer support. Family caregivers are encouraged to engage in and contribute to the club activities by, for example, sharing skills and expertise. As well as this general attendance at the MC there are a number of MC activities that focus more specifically on family caregivers. Families will need different support at different times to help them adjust to their changing situation. This might be information and signposting in the initial stages after diagnosis and at a later stage practical and emotional support (Brooker et al, 2017). In order to map the situation of the person with dementia and the family caregiver and the aspects on which they need support, a 'psychosocial diagnosis' is prepared and a support plan formulated (Brooker et al, 2017).

MCs provide *informative/educational meetings* by expert guest speakers from care and welfare organisations, which are usually held in a series of ten monthly meetings covering a wide range of topics such as different types of dementia, responding to changes in behaviour and mood, legal aspects of dementia and the support needs of family caregivers. These meetings are open to the wider public as well as MC participants. In addition, monthly *discussion groups* are led by the MC Manager along with an external expert where appropriate. These meetings were intended only for family caregivers who were members of the MC. Initial discussion groups mainly covered similar topics to the *informative meetings* but as time progressed, family caregivers

bring in their own issues to discuss. Within the MC, there are larger *monthly centre meetings*, which are attended by people with dementia, family caregivers and staff to discuss how the MC is run. Family caregivers (alongside the person they are caring for) also have access to a ‘consultation hour’ with a member of MC staff. Here people can discuss any individual problems or questions they had. These could concern practical questions, but also emotional support or personal questions. The local focus enables collaboration between services counteracting the fragmentation of care.

A multi-centre effect study comparing people participating in the MCSP and those attending regular day care in the Netherlands found that after six months of participation family caregivers experienced more sense of competence, less burden and perceived they were better supported by professionals than caregivers who utilized only regular day care for the person with dementia as respite (Dröes, Breebaart, Meiland, van Tilburg & Mellenbergh, 2004; Dröes, Meiland & van Tilburg, 2006). They also found that family caregivers who reported higher levels of loneliness at baseline reported fewer psychological and psychosomatic complaints after being supported by the MC (Meiland, Dröes, de Lange, Vernooij-Dassen & van Tilburg, 2010). People with dementia who attended a Meeting Centre displayed fewer behavioural problems along with improved mood and self-esteem (Dröes et al, 2004; Dröes, Breebaart, van Tilburg & Mellenbergh, 2000). Also, there was a trend of delayed admission to a nursing home (Dröes et al., 2004). In a second study Dröes et al. (2006) were not able to confirm the moderate positive effect on family caregiver’s sense of competence shown in their first study. However, the MCSP proved more effective than traditional psychogeriatric day care in decreasing psychological and psychosomatic symptoms in lonely caregivers and a majority of MCSP family caregivers experienced less burden and more professional support.

Present Study

The authors of this paper were part of a European Joint Programme - Neurodegenerative Disease Research funded project MEETINGDEM (JPND_HC-559-018) that adaptively implemented the MCSP model in Italy, Poland and the UK, taking into account cultural and contextual requirements, through a 12-month period of collaborative community engagement (Mangiaracina et al., 2017). A project team in each country conducted an evaluation of the impact on people living with dementia and their family caregivers. The objective was to ascertain if the results were comparable with those found in the Netherlands.

In relation and of interest to the present study, attending the MCSP was associated with significantly higher Quality of Life scores (feelings of belonging, self-esteem, positive affect) for people with dementia who attended compared to a control group receiving usual care (Brooker et al, 2018). Higher attendance levels were associated with greater neuropsychiatric symptom reduction and increased feelings of support.

In this paper we focus on the impact of the programme on family caregivers attending the MCSP. More specifically, we investigated whether attending the MCSP in Italy, Poland and the UK resulted in comparable benefits to the results found in the Netherlands.

Methods

Design

In order to allow comparison of findings, the research adopted the methodology from the original effect study in the Netherlands. A pre-test post-test control group design was used comparing people with dementia and family caregivers attending the MC with a Usual Care (UC) control group on several outcome measures. Pre-test data were collected within one month of participants starting to attend the MC. This was to allow for participants and Meeting Centres' personnel to have some time to decide if MCSP matched the participants' needs and if they were interested to participate in MCSP and the ethical consideration that we wanted to prevent potential participants feeling that participation in the study was a pre-requisite of attending the MC. For UC pre-test data were collected on recruitment. Post-test measurement was performed 6 months after the baseline measurement. In addition, family caregivers completed a user satisfaction questionnaire after 3 and 6 months of participating in MCSP (Szcześniak et al., submitted). Reasons for drop out, and life events were also recorded. The research received ethical approval in the separate countries and all participants consented to be included in the project.

Meeting Centres Support Programme Intervention

Compliance with the ethos of the original MCSP model was maintained to a high degree in that the MCSP support programme, as set out in the MEETINGDEM study protocol (Droes et al, 2017) and the Meeting Centre Support Programme Guide Book and Toolkit, for family caregivers was followed by all three countries. Country specific requirements resulted in small variations in inclusion criteria, frequency of programme components and culture specific activities.

Meeting Centres Support Programme Participants

The target group of the study were people with mild to moderate dementia and their family caregivers attending MCs in Italy, Poland and the UK. There were no additional exclusion criteria for people with dementia or family caregivers, except that the person with dementia attended the MC for at least one day a week and that the caregiver was willing to somehow participate in the caregiver support programme. Overall nine MCs took part in the study: five in Italy, two in Poland and two in the UK. The recruitment target was 75 person-caregiver dyads across the three countries who attended the MCSP and 75 person-caregiver dyads who accessed UC, giving a total of 150 dyads (25 per arm in each of the three countries). This would enable the analysis to demonstrate moderate effects ($d=0.5$), with a power of 0.80 and alpha 0.05, allowing for a drop-out of 15% over the 7 months of the study.

Usual Care comparison

Within the original research in the Netherlands the UC group consisted of family caregivers of participants of Psychogeriatric Day Care units within nursing homes. The provision of day care varies greatly across Italy, Poland and the UK. Within the current study, the UC participants were recruited from a cohort group on a similar part of the dementia pathway attending day centres, dementia cafés and lunch clubs, within the same locality but outside the MC catchment area.

Measures

Background information

Background information on age, education level and gender was collected for all participants (people with dementia and family caregiver) alongside information on longitudinal change in individual factors of the person with dementia (comorbidities, physical disability, use of other types of support) between pre and posttest that may have influenced outcomes in the caregiver. In addition, life events of the person with dementia and their caregiver in the month before the posttest were registered during the interviews. The severity of dementia was quantified by the Global Deterioration Scale (GDS) (Reisberg, Ferris, de Leon & Crook, 1982).

Outcome measures

Standardised, reliable and validated outcome measures (Moniz-Cook et al, 2008) were used in respect of the following outcomes.

Sense of competence

The 7-item Short Sense of Competence Questionnaire (SSCQ) (Vernooij-Dassen et al., 1999) was used to assess the family caregiver's feeling of competence. The 7 items are rated on a 5-point Likert scale ranging from 1 (agree very strongly) to 5 (disagree very strongly). The items reflect the level of competence or feelings of being capable of caring for the person with dementia on three domains: satisfaction with the person with dementia as a care recipient (3 items), satisfaction with their performance as a caregiver (2 items), and the consequences of involvement in care for the personal life of the caregiver (2 items). The total score is based on items where the response is "disagree" or "disagree very strongly", with higher scores indicating a greater sense of competence (Dam et al, 2017).

General mental health

The General Health Questionnaire (GHQ-12) (Goldberg & Williams, 1998) was used to measure psychological and psychosomatic symptoms. Each of the 12 items on the scale has four responses, two of which are positive and two which are negative. The scores are based on the items where a negative response is given, with higher scores indicating poorer mental health.

Emotional distress caused by neuropsychiatric symptoms

The impact of neuropsychiatric symptoms in terms of 12 domains of behaviour and the emotional distress for family caregivers was measured using the Neuropsychiatric Inventory (NPI-Q) (Cummings et al., 1994). Each of the 12 NPI-Q domains asks the caregiver to reflect on three aspects of different behaviours or emotions with regards to the person with dementia: Firstly, the presence or absence of the behaviour; secondly, if present, the severity of the behaviour on a scale of 1 (low) to 3 (high); and thirdly, the distress caused to the caregiver on a scale of 1 (low) to 5 (high). For this paper, the relevant scores are based on the total of the distress scores, with higher scores indicating greater distress.

Loneliness

The 3-item UCLA Loneliness Scale (Russell, 1996) was used to assess feelings of loneliness. The scale uses three response categories: hardly ever; some of the time; often (Range: 1 to 3). The scores for each question are summed with a higher score indicating greater levels of loneliness. This scale displayed satisfactory reliability and both concurrent and discriminant validity in a non-dementia related study (Hughes, Waite, Hawley and Cacioppo, 2004)

Perception of burden and satisfaction with support

A large scale user satisfaction study was carried out as a separate part of the MEETINGDEM project (Szcześniak et al., submitted). As part of this, a user satisfaction questionnaire comprising of a number of dimensions requiring a Likert type response (Dröes, Meiland,

Schmitz & van Tilburg, 2011) was completed by the family caregivers participating in the MCSP group at 3 and 6-months. For the present study the replies on two questions relating specifically to caregiver perceptions of burden and support are reported on here.

Procedures

Standard procedures for participant recruitment, informed consent, and the administration of the measures were adopted across all three countries. Participation in the research was voluntary. All MC members were invited to participate in the research by the MC Manager within the first month of attendance. If they were willing to participate they underwent an informed consent procedure. They were provided with a Participant Information Sheet and the contact details of the research team to contact about participating in the study or for further information. All caregiver measures were administered by a researcher at baseline (within one month after starting to visit the MC) during an interview with the caregiver, either at the MC (for the MCSP group) or in their own home (for the UC group). Post-test data were collected using the same measures six months after the pre-test data collection point and after three and six months for the self-report satisfaction questionnaires. Participants who dropped out of the MC or UC before post-test data collection were not included in the effect evaluation.

Data Analysis

A similar method of analysis was adopted to that used in the Dutch study in order to maximize the comparability of findings (Dröes et al., 2006). Baseline characteristics of the family caregivers in the MC and UC groups were analysed descriptively with differences between the groups being tested (two-sided, $\alpha \leq 0.05$) using t-tests (for ordinal and interval data) and

Chi2- tests (for nominal data). The data collected on the outcome measures (SSCQ, GHQ-12, NPI-emotional distress, UCLA) were subject to covariance analyses (ANCOVA's) on the post-test measurements including the baseline measurements as covariates in the analyses, both overall and at a country level. Cohen's d effect sizes (Cohen, 1998) were calculated for each ANCOVA. As in the original Dutch study these analyses were carried out for completers only. We checked if there was selective dropout in our study by testing for differences between characteristics of completers and non-completers at baseline within groups (MCSP/UC) and also tested for differences in background characteristics at baseline between the completers of the MCSP and UC group. We did this by using t-tests (for ordinal and interval data) and Chi2- tests (for nominal data). To check if changes in outcomes within the MCSP group were related to attendance, spearman rank correlation tests were calculated for attendance at the MC against change between baseline and follow-up outcome scores (two-tailed at 95% significance). In respect of the results of the two questions included from the user satisfaction questionnaire percentage changes were calculated for the data after three and six months and then the differences were tested with Wilcoxon matched pairs signed rank tests. A Spearman rank correlation coefficient was calculated to determine the relation between experienced emotional support and satisfaction of caregivers with the different elements of the MCSP caregiver programme.

The data overall (all countries) were combined to assess differences between the MCSP and UC groups. Although the study was not sufficiently powered to fully test differences per country and between countries we explored the differences between MCSP and UC groups at a country level (within the countries).

Results

Numbers recruited to the study

Initially 130 family caregivers were recruited for the study in the MCSP group and 93 family caregivers in the Usual care group by means of an informed consent procedure. 9 and 6 family caregivers respectively however dropped out before the data collection started (see Figure 1). Baseline data were collected from 121 caregivers attending the MCSP and 87 accessing Usual Care (see Figure 1). There was attrition of 23% in the MCSP group and 15% in the UC group between baseline and follow-up data collection. Those who quit the study for whatever reason could choose to continue to attend the MC. Data analysis was therefore based on the completed measures at pre-test and post-test from 93 family caregivers attending the MC across Italy, Poland and the UK, and 74 receiving UC. Recruitment to the MC study was through the MCs in the respective countries. Recruitment to the UC group was through health or welfare organisations (UK 3/41; Italy 15/25; Poland 15/21) or through GP's (UK 0/41; Italy 0/25; Poland 4/21) or through non-governmental/charitable support services (UK 31/41; Italy 10/25; Poland 0/21). A small number were recruited through other contacts, namely referrals from other participants (UK 7/41; Italy 0/25; Poland 2/21).

A small number were recruited through other contacts, namely referrals from other participants (UK 7/41; Italy 0/25; Poland 2/24). For the user satisfaction questionnaire 81 family caregivers participating in MCSP responded after 3 months and 84 caregivers after 6 months.

-----**Insert FIGURE 1 here**-----

Levels of participation in the evaluation varied between countries. For example, in the UK, 52% of those who attended the Meeting Centres completed the evaluation, while the corresponding figure in Italy was 42%. No data were collected that allows comparison of those attendees who did and did not participate.

Participant characteristics

Background information was collected for all family caregivers who completed the study including gender, age, civil status, education level, employment and relationship to the person with dementia, as shown in Table 1. MCs aim to meet the needs of people with mild to moderate dementia. Differences in severity of dementia of the person with dementia between the MCSP and UC groups were tested using an independent samples t-test which was not significant ($p=0.25$, $d=-0.21$), suggesting that family caregivers in both groups were coping with a similar range of disabilities. There were no significant differences between the general characteristics of the family caregivers attending the MC and UC (Table 1). In both groups there were more females than males; the average age of both groups was approximately 64 years; the majority were living with a partner or were married with over half caring for a spouse or partner, with a smaller percentage caring for a parent. The remainder of the family caregivers ('completers') in the MCSP group were caring for a grandparent or sibling other family member, friend, or someone else. In the UC group, the remaining caregivers ('completers') were caring for another family member, friend or someone else. A majority of caregivers lived with the person for whom they cared.

Comparison of completers and non-completers

As we did a completers analysis only and dropout rates were higher in the MCSP group than in the UC group, we checked for selective dropout by testing for differences between characteristics of completers and non-completers at baseline within groups (MCSP/UC).

Overall, there was not found to be any significant difference between caregivers completing the study and those not completing the study in either the MCSP or UC group.

-----**---Insert TABLE 1 here**-----

Although there were no statistically significant differences between countries, there were some interesting trends. Family caregivers in the UK were slightly less likely to be male than in Italy and Poland. Family caregivers in Poland tended to be younger than those in either Italy or the UK, while the UC family caregivers in the UK were older than those in the other countries.

Patterns of attendance at the MC by caregivers

Table 2 shows average number of attendances at the MCs in each country and overall. Levels of use, given the different types of support offered and the amount of time the MC was open, varied according to individual needs with some people utilising the MC every day it was open whereas others were infrequent users. Overall attendance by family caregivers was considerably higher in the UK (mean=26.9) than in Italy (9.4) and Poland (8), this was also the case for attendance to the different type of activities (informative meetings, discussion groups, general MC meetings, and joining in with MC activities).

-----Insert TABLE 2 here-----

Outcomes

The outcome measures that were completed by family caregivers at pre-test and post-test, are summarised in Table 3. The ANCOVA did not show a statistically significant difference between the country outcomes.

-----Insert TABLE 3 here-----

General mental health

Overall the ANCOVA did not show a statistically significant difference between the MCSP and UC groups on the GHQ. Analyses on a country level showed a significant difference for Italy: caregivers participating in MCSP appeared to have a better general mental health at post-test than caregivers receiving usual care ($p=0.04$; $d=0.55$).

Sense of competence

No significant differences were seen for the SSCQ measure in the ANCOVA, not overall for the three countries or at a country level. Overall, the mean scores for both the MCSP and UC caregiver groups improved by follow-up, although the UC group had a higher sense of competence than the MCSP group at both baseline and follow-up.

Loneliness

The ANCOVA did not show any significant difference between the MCSP and UC groups on the UCLA scale as a whole or at the country level. While the MCSP scores improved slightly from baseline to follow up and the UC scores remained the same, family caregivers in the MCSP group felt more lonely than those in the UC group at both baseline and follow up. Feelings of loneliness decreased most in caregivers from the MCSP group in Poland. The results from the

ANCOVA analysis of the GHQ using loneliness (UCLA) as classification factor (additional covariate) showed no significant benefit on mental health of MSCP over UC in family caregivers who felt more lonely at baseline (in contrast with the finding in the Dutch study).

Emotional Distress caused by Neuropsychiatric symptoms

Overall the ANCOVA did not show a statistically significant difference between the scores for the MCSP and UC groups for the part of the NPI measure looking at emotional distress caused to the caregiver. However, analyses at a country level revealed that the MCSP group in Italy experienced less distress from neuropsychiatric symptoms of the person with dementia ($p=0.02$; $d=0,62$) than the UC group at post-test.

A check on longitudinal changes in possible influencing factors of the person with dementia (illness, physical disability, psychotropic drugs, use of other types of support) between pre and post-test within and between groups, and life events of the person with dementia and family caregiver within one month before the post test, did not reveal differences between groups that may explain the effects found.

Perception of caregiver burden and support

Responses on the two questions from the user satisfaction survey showed that the large majority of family caregivers (83.5%) felt less burdened after three months of participation in MCSP (48.1% much less; 35.4% a little less); after six months this number increased significantly to 91% ($p<0.04$, 57.7% much less; 33.3% little less). In Italy, 77.5% of caregivers felt less burdened after three months, rising to 85.0% after six months. In Poland the figures were 83.3% and

94.4% respectively, while in the UK 100% of family caregivers felt less burdened at both time points.

The majority of user satisfaction respondents reported feeling emotionally supported by other family caregivers (68.2%, a lot; 25.0% sufficiently) In addition they reported high levels of support from MC staff (69.2% a lot; 25.0% sufficient). There was a positive correlation between satisfaction with the family caregiver MCSP programme elements and experienced support: Higher levels of satisfaction with MC meetings was correlated with higher levels of perceived support from other MC family members ($\rho=0.34$, $p=0.05$ and $\rho=0.43$, $p=0.003$ respectively). As the user satisfaction survey related to satisfaction with and impact of the MSCP, it was not completed by the UC participants meaning that comparable results were not available from this group.

Relation between attendance at the MC and changes in outcome measures

Spearman rank correlation tests for attendance at the MC against change between baseline and follow-up outcome scores (two-tailed at 95% significance) showed no significant correlation for any of the family caregiver outcome measures.

Moves to institutional care

8 (6.6%) people with dementia from the MCSP group (6 from Italy; 0 from Poland; 2 from the UK) and 2 (2.3%) from the UC group (both from Italy) transferred to a care home between baseline and 6 months' follow-up.

Discussion

This study was primarily focused on the adaptive implementation and validation of the MCSP model in three very different European countries and to see whether the effects in the original Dutch studies could be replicated. Although many of the benefits for people with dementia were replicated (Brooker et al, 2018) we were not able to replicate the moderate positive effect on family caregiver sense of competence that was shown in the first Dutch study (Dröes et al., 2004) but not confirmed in the second Dutch study (Dröes et al., 2006). Also the greater mental health benefit for lonely family caregivers using MCSP compared to lonely family caregivers using UC (Meiland et al., 2010) was not replicated. However, on a country level, findings suggest that family caregivers in Italy benefitted more from MC regarding their mental health and emotional distress than caregivers who received usual care. Comparison of baseline characteristics of completers and non-completers within groups (MCSP/UC) showed that there is no evidence to suggest that dropout had an impact on the findings.

Feedback about family caregiver satisfaction was at a high level similar to the Dutch evaluation with the majority of family caregivers feeling less burdened after 3 months and even more after 6 months of participation in MCSP. Feeling emotionally supported appeared positively related to satisfaction with the MCSP caregiver programme elements.

So, what are the reasons for this lack of replication? It may be that the MC intervention was not effective for family caregivers in this study, although the high levels of satisfaction and the partial benefits in the Italian sample would argue against this. People living with dementia are an enormously heterogeneous group and some of the differences found between the current study and the Dutch study may be due to differences in characteristics of participants in the two

studies. For example, in the current study MC participants had more severe levels of dementia generally than the UC sample reported by Dröes et al. (2004).

It could be argued that family caregivers are an even more heterogeneous group than people living with dementia and so translating a service intervention for them from the context of one country to another may be more problematic. The pre-post data was collected during a six-month period during the first year of MCSP implementation. This means that the new service was still in the process of being fully established which may have reduced its impact. The MCs were established over a relatively short period of time and it may have taken a greater amount of time for the model to bed into the new countries. All these issues may have diluted the effect. The study was not sufficiently powered to test this by within country analysis. Although the MC model focusses both on the person with dementia and the family caregiver, there may have been a tendency at the start of the service to concentrate more on the quality of the offer for the people with dementia at the expense of the quality of the intervention for families. This may have been exacerbated by the fact that the sample had more severe levels of dementia than the Dutch sample on the whole. Again this may have diverted some of the focus more towards the needs of those with dementia, at least in the set-up stages. A follow-up evaluation after one year in a sufficiently large sample would enable investigation of the fully established MCSP.

The reasons for the significant improvement of general mental health and reduction in family caregiver distress caused by the symptoms of dementia that were found only in Italy are of interest. Family caregivers from the UK attended the MC on average three times more frequently than caregivers from Italy and Poland. The traditional view of “respite” care would suggest that

family caregivers may be motivated by using such services to take a break from caring. Maybe this was a factor in why caregivers from Italy experienced more significant improvement. It is interesting also to note that admissions to long-term care placement were more frequent in the Italian sample. However, the Polish sample had similar attendance levels to the Italian sample and did not show significant outcomes. Caring and adapting to care and changes in dementia is a complex process. At times family caregivers need some respite, at other times they need to spend time with the person they care for in a supportive environment. These differences between countries may also reflect age differences, different cultures and diverse approaches to providing care and support. Qualitative research and longitudinal research may be more appropriate to help deepen our understanding of the mechanisms involved for the diversity of family caregivers needs across time.

The different outcomes may also be due to variations in how the MCSP was adapted and delivered in the three countries involved. Closely related to this is the difference in the pathways to regular dementia day-care activities and support in the three countries as analysed by Szcześniak et al (2018) and which could influence implementation. In Italy and Poland the pathways to post-diagnostic care are less structured than in the UK and access to interventions is much poorer. Open access to the MCs in Italy and Poland enabled family caregivers the opportunity to make contact with the care network. This aspect could have been the reason for the significant improvement and reduction in distress. This is an area in which further research is required. Although the core MCSP programme was maintained in the three countries there were several contextual and cultural differences in how the MCSP intervention was delivered and received in the three countries involved.

The results for family caregivers shown in our study are in line with the literature relating to dyadic interventions for people with dementia and caregivers. Van't Leven et al. (2013) and Smits et al (2007) conclude that dyadic psychosocial programs are effective, but that outcomes for the person with dementia and the family caregiver vary. In the Brooker et al (2018) MeetingDem study it was found that, building on the evidence of effectiveness from the Netherlands, people with dementia attending MCSPs showed significant wellbeing and health benefits compared with UC. However as has been shown in this paper, a positive effect was not found for their caregivers.

Limitations of study

The current study was designed primarily as an implementation study where much of the time and energy was put in realising at least two MCs in each country who provided the full MCSP (Mangiaracina et al., 2017; Szcześniak et al, 2018), were piloted and evaluated. As a consequence, no detailed screening on type of dementia or specific issues for family caregivers was undertaken. Allocation to the intervention was not random. In order to recruit enough participants to the intervention group it was necessary to compare to a geographical control group (of comparable severity of dementia) where there was not an MC. Pairs were not matched in terms of the type of service they attended for usual care. Assessors were not blind to the intervention that participants received. Baseline measurements took place up to one month after commencing at the MC which could mean that there had been already some impact on participants. However in terms of ethics it was important that involvement in the research was not seen as a pre-requisite of attending the MC. In addition people are adjusting in the first few weeks to attending the Meeting Centre and this transition in itself may have an impact.

Only participants that completed six months of attendance were included in the analyses, we did not conduct an intention-to-treat analysis. Although our study was an explorative trial this can be seen as a limitation of the study. Also, because of the relatively small numbers per country, the data overall (all countries) were combined to assess differences between the MCSP and UC groups. Finally, sample sizes between countries varied and the significant benefit shown in Italy may have been partly an effect of the larger sample size.

Conclusions

Despite the limited findings on the selected outcome measures and the fact that we were not able to replicate the findings from the Netherlands, we were able to replicate the MCSP intervention from one country into three others. Although the study was not sufficiently powered to fully test differences per country and between countries we explored the differences between MCSP and UC groups at a country level (within the countries). On a country level findings suggest, subject to the limitations discussed in the section above, that family caregivers in Italy using MCSP benefitted more regarding their mental health and emotional distress than family caregivers using UC. For a thorough effect study per country separate larger sized RCT's would be required.

Family caregivers provide the vast majority of care worldwide. As the numbers of people living with dementia increases, particularly in low and middle income countries where families bear an even bigger proportion of the impact of dementia care, it is imperative that we understand the mechanisms by which we can support families in their communities over time. However,

implementing a complex intervention and evaluating it presents a number of challenges some of which are identified in the discussion and limitation sections above.

There is a great need for high quality implementation research to demonstrate how care interventions can be put into practice in a variety of settings and how evidence based practices can be effectively disseminated and transferred to other countries to share knowledge and improve dementia care on a European and world wide level.

Word count 8792

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Table 1: Characteristics of Caregiver that completed the study in the Meeting Centre Support Programme (MCSP) and Usual Care (UC) groups at baseline

| | | MCSP group (n=93) | UC group (n=74) | Test statistic | p (two-sided) |
|--|---|----------------------|--------------------|-----------------|---------------|
| Caregivers | | | | | |
| Sex | Male | 25 (26.9%) | 24 (32.4%) | $\chi^2 = 0.61$ | 0.43 |
| | Female | 68 (73.1%) | 50 (67.6%) | | |
| Age | Mean age (SD) | 64.2 (13.3) | 64.2 (13.9) | t = 0.06 | 0.96 |
| | Range | 22-88 years | 34-90 years | | |
| Civil status | Married/co-habiting/ civil partnership | 78 (84.8%) | 56 (76.7%) | $\chi^2 = 1.74$ | 0.19 |
| | Widowed/divorced/ single | 14 (15.2%) | 17 (23.3%) | | |
| Education | Not completed high school | 10 (10.9%) | 14 (19.2%) | $\chi^2 = 2.68$ | 0.26 |
| | Completed high school | 49 (53.3%) | 32 (43.8%) | | |
| | Degree level or higher | 33 (35.9%) | 27 (37.0%) | | |
| Employed | Yes | 31 (33.3%) | 27 (36.5%) | $\chi^2 = 0.18$ | 0.67 |
| | No | 62 (66.7%) | 47 (63.5%) | | |
| Relationship with person with dementia* | Spouse/partner | 50 (54.9%) | 41 (56.9%) | $\chi^2 = 1.54$ | 0.46 |
| | Daughter/son | 31 (34.1%) | 27 (37.5%) | | |
| | Other | 10 (11.0%) | 4 (5.6%) | | |
| Live with person with dementia** | Yes | 62 (66.7%) | 53 (72.6%) | $\chi^2 = 0.68$ | 0.41 |
| | No | 31 (33.3%) | 20 (27.4%) | | |
| People with dementia | | | | | |
| Severity of dementia (GDS score) | Mean Score (standard deviation) | 4.0 (1.1) | 3.8 (1.2) | t = -1.16 | 0.25 |

* Missing data for two MC caregivers and 2 UC caregivers

** Missing data for one UC caregiver

Table 2: Attendance to MCSP data for family caregivers over 6 months from baseline interview.

| Participation of Family Caregivers in activities by number of attendances | Attendances per caregiver | | | | N |
|--|---------------------------|-------------|----------|------------|-----------|
| | Mean | SD | Min | Max | |
| Informative meeting attendances | | | | | |
| Across all 3 countries | 2.3 | 5.2 | 0 | 31 | 93 |
| Italy | 0.8 | 0.8 | 0 | 2 | 44 |
| Poland | 2.1 | 1.8 | 0 | 6 | 21 |
| UK | 4.8 | 8.9 | 0 | 31 | 28 |
| Discussion group attendances | | | | | |
| Across all 3 countries | 5.1 | 7.5 | 0 | 38 | 93 |
| Italy | 5.4 | 5.7 | 0 | 18 | 44 |
| Poland | 2.7 | 2.6 | 0 | 7 | 21 |
| UK | 6.3 | 11.4 | 0 | 38 | 28 |
| Plenary Centre meeting attendances | | | | | |
| Across all 3 countries | 4.5 | 7.3 | 0 | 31 | 93 |
| Italy | 1.5 | 2.4 | 0 | 11 | 44 |
| Poland | 1.6 | 1.1 | 0 | 5 | 21 |
| UK | 11.3 | 10.2 | 0 | 31 | 28 |
| Active participation in MC day club activity | | | | | |
| Across all 3 countries | 2.5 | 7.0 | 0 | 36 | 93 |
| Italy | 1.6 | 3.6 | 0 | 14 | 44 |
| Poland | 1.7 | 7.6 | 0 | 35 | 21 |
| UK | 4.5 | 9.7 | 0 | 36 | 28 |
| Attendances overall | | | | | |
| Across all 3 countries | 14.3 | 22.6 | 0 | 132 | 93 |
| Italy | 9.4 | 10.1 | 0 | 37 | 44 |
| Poland | 8 | 9.6 | 0 | 45 | 21 |
| UK | 26.9 | 35.8 | 0 | 132 | 28 |

Table 3: ANCOVA results of completers in the Meeting Centres Support Program (MCSP) versus Usual Care (UC) based on follow-up measurements (with baseline and severity of dementia as covariates), overall and for the different countries

| Measures (range of scores) | Baseline | | Follow-up | | Follow-up ANCOVA adjusted MC/UC mean | F | p | Effect size d |
|---|----------------|----------------|----------------|----------------|--|------|-------|------------------|
| | MC mean(SD) | UC mean(SD) | MC mean(SD) | UC mean(SD) | | | | |
| GHQ (0-36) Higher score indicates poorer health | | | | | | | | |
| Overall (n=91/72) | 3.3 (3.0) | 2.9 (2.6) | 2.2 (2.7) | 2.9 (2.6) | 2.5/3.3 | 3.38 | 0.07 | 0.29 |
| Italy (n=42/21) | 3.3 (2.7) | 3.5 (2.7) | 1.9 (2.4) | 3.6 (2.7) | 2.0/3.4 | 4.40 | 0.04* | 0.55 |
| Poland (n=21/19) | 3.8 (3.5) | 2.5 (2.6) | 2.2 (3.0) | 2.4 (2.7) | 1.1/1.9 | 0.67 | 0.42 | 0.28 |
| UK (n=28/32) | 2.9 (3.2) | 2.8 (2.4) | 2.8 (3.0) | 2.7 (2.5) | 3.0/3.3 | 0.68 | 0.41# | 0.22 |
| SSCQ (0-7) Higher score indicates greater feeling of competence | | | | | | | | |
| Overall (n=87/69) | 3.7 (1.9) | 4.2 (2.1) | 3.9 (2.0) | 4.4 (1.9) | 4.0/4.2 | 0.55 | 0.46 | 0.13 |
| Italy (n=42/20) | 4.0 (1.7) | 3.4 (1.8) | 4.3 (1.8) | 3.9 (1.7) | 4.0/4.0 | 0.01 | 0.91 | 0.00 |
| Poland (n=21/18) | 3.0 (2.2) | 3.7 (2.4) | 3.4 (2.3) | 4.0 (1.6) | 3.9/4.0 | 0.03 | 0.86 | 0.06 |
| UK (n=24/31) | 3.8 (2.0) | 5.0 (1.8) | 3.5 (2.0) | 4.9 (2.1) | 4.0/4.7 | 1.82 | 0.18 | 0.38 |
| UCLA (3-9) Higher score indicates greater feeling of loneliness | | | | | | | | |
| Overall (n=90/72) | 4.7 (1.8) | 4.2 (1.7) | 4.5 (1.7) | 4.3 (1.9) | 4.3/4.4 | 0.17 | 0.68# | 0.06 |
| Italy (n=42/21) | 4.4 (1.7) | 4.0 (1.1) | 4.2 (1.3) | 4.6 (1.4) | 3.9/4.4 | 1.90 | 0.17 | 0.36 |
| Poland (n=21/19) | 4.5 (1.8) | 3.5 (1.0) | 3.7 (1.2) | 3.1 (0.2) | 3.1/3.0 | 0.62 | 0.44# | 0.26 |
| UK (n=27/32) | 5.2 (2.0) | 4.6 (2.3) | 5.6 (2.0) | 4.8 (2.4) | 5.2/4.8 | 0.93 | 0.34# | 0.26 |
| NPI caregiver distress (0-60) Higher score indicates greater distress | | | | | | | | |
| Overall (n=91/72) | 13.9 (9.0) | 10.6 (8.0) | 12.6 (8.5) | 11.7 (9.1) | 12.1/13.3 | 1.33 | 0.25 | 0.18 |
| Italy (n=42/21) | 16.0 (10.1) | 11.2 (6.4) | 12.7 (8.7) | 14.3 (6.6) | 13.7/17.6 | 5.6 | 0.02* | 0.62 |
| Poland (n=21/19) | 9.9 (6.1) | 11.6 (7.5) | 9.0 (7.0) | 11.6 (9.3) | 8.1/10.1 | 0.65 | 0.43 | 0.27 |
| UK | 13.7 (8.4) | 9.6 (9.2) | 15.1 (8.4) | 10.0 | 13.5/11.5 | 1.25 | 0.27 | 0.30 |

| | | | | | | | | |
|-----------|--|--|--|--------|--|--|--|--|
| (n=28/32) | | | | (10.2) | | | | |
|-----------|--|--|--|--------|--|--|--|--|

* significant difference at 95%, $p < 0.05$. # Levene's test showed that the group variances were not equal, so an assumption of covariance analysis was violated.