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Meeting centres support programme highly appreciated by people with dementia and carers: a European cross-country evaluation

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Title: Meeting Centres Support Programme highly appreciated by people with dementia and carers: a European cross-country evaluation

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Title: Meeting Centres Support Programme highly appreciated by people with dementia and carers: a European cross-country evaluation

ABSTRACT

Background: The Meeting Centres Support Programme (MCSP) offers a combined approach to provide practical, emotional and social support to people living with mild to moderately severe dementia and their family carers in the community.

Methods: A mixed methods explanatory design was used. The evaluation took place within the framework of the international Joint Programme – Neurodegenerative Disease Research (JPND) – MEETINGDEM study in nine Meeting Centres in Italy, Poland and the UK. 87 people with dementia and 81 family carers completed a user evaluation survey after three months and 83 people with dementia and 84 carers after 6 months of participation in MCSP. 32 people with dementia and 30 carers took part in focus groups after nine months.

Results: The percentage of people with dementia who were very satisfied with the programme increased significantly over time ($p=0.05$). The majority of carers reported that they felt less burdened after three months of participation in MCSP (48.1% much less; 35.4% a little less). After six months, this percentage increased significantly to 91% ($p=0.04$, 57.7% much less; 33.3% little less). Focus group analysis showed that participants in all countries/centres improved their ability to maintain emotional balance.

Conclusions: The MCSP is highly appreciated by people with dementia and carers in all countries. It confirms the results of previous research into MCSP in the Netherlands. Our findings indicate that MCSP is a model that can help its users to increase their capacity to deal with the challenges caused by dementia and can promote emotional balance.

Keywords: dementia; carers; social support; day programs; qualitative study

INTRODUCTION

Integrated psychosocial interventions attuned to the needs of both people living with dementia and their carers can support a good quality of life of people with dementia and prevent carers from becoming overburdened (Van't Leven, de Lange, Prick, & Pot, 2019). Various support services and psychosocial interventions (e.g. home care, psychogeriatric day care, occupational therapy, psycho-education and support groups for carers) are available across Europe (Dröes et al., 2017; Moniz-Cook & Manthorpe, 2008). However, services are often fragmented, making it difficult for users to find the 'right service' for them. Additionally, these services are not always known to medical professionals who are often the first contact for the dyad. As a result, many people living with dementia experience unmet needs (Van der Roest et al., 2007). Moreover, the most beneficial programmes for people with dementia and their carers are multicomponent interventions that include information, practical, emotional and/or social support (Van't Leven et al., 2013).

In order to promote independent and active living in the community for people with dementia, and to counteract the fragmentation of dementia services, the Dutch Meeting Centres Support Programme (MCSP) offers an integrated package of care and support for both people with mild to moderate dementia and their informal carer(s) (Dröes, Breebaart, Meiland, Van Tilburg, & Mellenbergh, 2004; Dröes, Meiland, Schmitz, & van Tilburg, 2004). For the person with dementia a social club is organised three days each week, where they can participate in (re)creational activities and psychomotor therapy. For carers, there are ongoing discussion groups to support psychological and emotional adjustment and to prevent carers from becoming overburdened and a series of information meetings (lectures) that help them to understand how to deal with the consequences of dementia. For both, there are social activities and a weekly consultation hour for practical and emotional support. Regular 'centre meetings' that allow all participants, staff and volunteers to share experiences and to exert influence on the support programme ensure the voice of participants is central to the model. This psychosocial intervention is based on the theory of the Adaptation-Coping model developed in the late 1980s (Dröes, Van Der Roest, Van Mierlo, & Meiland, 2011). It has its theoretical origins in the Lazarus & Folkman's stress-appraisal-coping model (Lazarus & Folkman, 1984) and the crisis model of Moos and Tsu (Moos & Tsu, 1977). The Adaptation-Coping model focuses on adjustment to the consequences of dementia, by dealing with a number of adaptive tasks, such as: (1) dealing

with disabilities, (2) preserving an emotional balance, (3) maintaining a positive self-image, (4) preparing for an uncertain future, (5) dealing with the (day) care environment, (6) developing an adequate care-relationship with health care professionals and staff, and (7) developing and maintaining social relationships (Dröes, Van der Roest, et al., 2011). An assessment of how individual people deal with these different adaptive tasks results in a psychosocial diagnosis. Depending on the psychosocial diagnosis which is made for the person with dementia and for the carer as an integrated part of the MCSP, several support strategies and interventions are applied focussing at three main strategies: 1. (re-)activation, 2. (re-)socialisation and/or 3. promotion of the emotional functioning of the person with dementia, and the provision of information and practical, emotional and social support for their carers.

Despite the solid theoretical background and evidence from research conducted into the implementation and effectiveness of MCSP in different European Countries which showed that the combined MCSP model has added value compared to regular Day care services (Dröes et al, 2004; Brooker et al, 2018), MCSP and its support strategies require further evidence-based evaluation primarily of its users in the different countries. The importance of Patient and Public Involvement (PPI) is increasingly promoted and recognized as essential in politics, care practice and research by the Global and European Alzheimer Societies (Gove et al., 2018). It is recommended that people with dementia and carers are involved in all decisions to be made in these areas rather than being 'talked about' and 'decided for'. When focusing on care evaluation this implies that not only objective outcomes measures should be taken into consideration, but also the opinions of care receivers, or in other words the users' satisfaction. According to the latest guidelines for care evaluation research therefore mixed-methodology is recommended (Bangerter, Griffin, Zarit, & Havyer, 2017).

People living with dementia and their informal carers can make a unique and valuable contribution in every stage of research, having clear ideas about what contributes best to their quality of life (Dröes et al., 2006). People with dementia emphasise the importance of living their life as normally as possible and remaining active, independent and equally valued members of society, while carers underline their need to receive diverse forms and levels of support to maintain their caring role for as long as possible (Alzheimer Europe, 2014).

Within the framework of a European Joint Programme for Neurodegenerative Diseases (JPND) Research project, called MEETINGDEM, the Dutch Meeting Centres Support

Programme was adapted, implemented and evaluated in three other countries in Europe: Italy, Poland and the United Kingdom (Dröes et al., 2017; Mangiaracina et al., 2017; Van Mierlo et al., 2017). In this paper, we will report on how people with dementia and their carers in these countries experienced the programme. More specifically, the objectives of the present study were to 1) evaluate the user satisfaction with the different structural and theoretical elements of MCSP; 2) to identify key factors determining the level of satisfaction of the participants and 3) to analyse the relationship between user satisfaction and theoretical assumptions defined as crucial (adaptive tasks and strategies) for the MCSP model.

METHODS

Study design

A two-phase mixed method explanatory design (Ivankova, Creswell, & Stick, 2006) was used in the study. All users of the support programme (both people with dementia and their carers) who agreed to take part in the study and had used MCSP for at least three months completed a questionnaire in order to assess the opinions of the people with dementia and their carers about the support they received. The quantitative evaluation took place after three months and after six months of participation in MCSP. In addition, separate focus groups for people with dementia and carers were held in all three countries to explore their experiences with MCSP after six months. Data collection took place over a period of 14 months (May 2015 – October 2016).

The appropriate Ethics Committees in each country approved the study protocol (Dröes et al., 2017). All participants provided informed consent.

Study sample and setting

The research took place in nine new Meeting Centres that were implemented within the framework of the JPND – MEETINGDEM Project (Dröes et al., 2017) in three EU countries: Italy (Milan and Bologna), Poland (Wroclaw) and the United Kingdom (Worcester).

Of the 141 people with dementia and their carers who originally participated in MCSP, 87 people with dementia completed the user evaluation questionnaire after three months and 83 after six months.

[Figure 1]

81 informal carers took part in the first survey after three months, and 84 in the second survey after six months. Figure 1 summarizes the number of participants who took part in the various stages of the study together with information on the reasons for non-participation in the study.

A purposively selected sample of 32 people with dementia and 30 carers (from all three countries) with various backgrounds, who participated in the quantitative evaluation, also took part in the focus groups. This sample selection method maximised variation within the study sample to gain as wide a range of perspectives as possible.

Measuring instruments and data collection procedure

Trained interviewers gathered the background characteristics of all participants, such as socio-demographic data and the severity of dementia based on the Global Deterioration Scale – GDS (Reisberg, Ferris, De Leon, & Crook, 1982).

User satisfaction of people with dementia and carers was measured with two questionnaires (one for people with dementia and one for their carers) originally developed in the Netherlands (Dröes, Meiland, Schmitz, & van Tilburg, 2011), which were translated into the native languages (Italian, Polish and English) of the participating countries. The Italian and Polish versions were translated from the English version of the questionnaire. Two junior researchers worked together on the translation, which was then revised by senior researchers experienced in English-Italian and English-Polish translation of scientific instruments. For the participants with dementia, independent researchers completed the questionnaire during an interview in the Meeting Centres. To ensure understanding of some questions text cards were used in the interview with people with dementia. Informal carers received the written questionnaire and were asked to fill it in and to send it directly to the researchers via the Meeting Centres, after three months and six months of MCSP participation. The 13-items questionnaire for the people with dementia focused on, among other things, location characteristics, staff, atmosphere, food, the activities on offer in the programme and their general feeling about the centre. The carers' questionnaire consisted of 30 questions related to reasons for participation in the support programme, their satisfaction with different programme elements, feelings of burden and their experiences of

emotional and practical support. Responses were recorded on a scale from not being satisfied to being very satisfied.

In addition to the quantitative survey, separate focus groups for people with dementia and for their carers were held in each country to explore the participants' experiences of the Meeting Centre and the support programme. Focus groups were conducted in at least one Meeting Centre in each region in Italy (Milan n=2, Bologna n=1), Poland (Wroclaw n=1) and the UK (Worcester n=1) based on common focus group guidelines and predefined open questions specifically developed for this study.

FOCUS GROUP QUESTIONS for people living with dementia:

- | | |
|----|--|
| 1. | What is your opinion on the Meeting Centre? |
| 2. | Which factors/what influences your level of satisfaction with participation in the Meeting Centre Support Programme? |
| 3. | What is important to you in the Meeting Centre? |
| 4. | What in your opinion makes this place different from others? |
| 5. | What impact does participation in the Meeting Centre Support Programme have on your life? |
| 6. | What do you not like about the Meeting Centre /or what could be improved in your opinion? |
| 7. | Do you have any difficulties during your stay at the Centre? |
| 8. | Is there anything else you would like to say about Meeting Centre? |

FOCUS GROUP QUESTIONS for carers

- | | |
|----|---|
| 1. | What is your opinion on the Meeting Centre? |
| 2. | Which factors/what influences your level of satisfaction with participation in the Meeting Centre Support Programme? |
| 3. | What is important to you in the Meeting Centre? |
| 4. | What in your opinion makes this place different from others? |
| 5. | What impact does the Meeting Centre have on the life of your relative? |
| 6. | What impact does the Meeting Centre have on your life? |
| 7. | What is missing in the Meeting Centre program for carers? And what for your relative? / Or (if not missing) what could be improved? |
| 8. | What does not satisfy you at the Meeting Centre? |
| 9. | Is there anything else you would like to say about the Meeting Centre? |

Two researchers, a moderator and an assistant moderator/scribe, attended the meetings. A small comfortable room at the Meeting Centre was used for the focus groups. Focus group

members were welcomed, reminded of the purpose of the discussion, informed that what they said would be anonymised, but quotes could be used in a report and that discussions would be recorded. All focus groups were tape recorded and transcribed.

Focus group analysis

The texts were analysed according to a concept-driven thematic analysis based on

a) the theoretical framework of the Adaptation-Coping Model (Dröes, Van Der Roest, et al., 2011) defined by the following adaptive tasks:

AT1: Dealing with disabilities, AT2: Develop an adequate care and relationship with professional carers, AT3: Maintain an emotional balance, AT4: Preserve a positive self image, AT5: Deal with an uncertain future, AT6: Stay in contact with family and friends, AT7: Deal with the day care environment

b) the operationalization of the quality of life concept based on the QoL – AD questionnaire (Logsdon, Gibbons, McCurry, & Teri, 2002):

QoL_1.1: physical health, QoL_1.2: energy, QoL_1.3: mood, QoL_1.4: living situation, QoL_1.5: memory, QoL_1.6: family, QoL_1.7: marriage closest relationship, QoL_1.8: friends, QoL_1.9: self as whole, QoL_1.10: ability chores, QoL_1.11: ability fun, QoL_1.12: money financial, QoL_1.13: life as whole

c) previous research on quality of life aspects seen as important by people living with dementia (Dröes et al., 2006):

QoL_2.1: affect, QoL_2.2: self esteem/self-image, QoL_2.3: attachment, QoL_2.4: social contact, QoL_2.5: enjoyment of activities, QoL_2.6: sense of aesthetics in living environment, QoL_2.7: physical and mental health, QoL_2.8: financial situation, QoL_2.9: security and privacy, QoL_2.10: self-determination and freedom, QoL_2.11: being useful/giving meaning to life, QoL_2.12: spirituality.

The above-defined sets of categories were used to assess the statements of people with dementia, while the first two sets (a and b) to assess also the statements of carers. Based on these principles, theoretical categories were identified and two researchers in each of the

three countries coded the fragments of the text independently. Discrepancies were discussed until agreement was reached and finally all fragments and quotes for each category were summarised. The categories were then grouped into themes that, according to the adopted methodology, corresponded to the theoretical basis of the MCSP model defined as three strategies: S1. (re-)activation, S2. (re-)socialisation, S3. improving emotional functioning. The findings were reworked until all researchers were satisfied with the final description of the results. The aim was to elicit the variety of experiences, attitudes and views of MCSP users.

Statistical analysis

To analyse the differences on background characteristics between the countries Chi squared tests were used for nominal variables and Kruskal-Wallis tests with multiple comparison with Holm correction as a post-hoc analysis for interval variables. For the results of the user evaluation questionnaires percentages were calculated. A Spearman rank correlation coefficient was used to determine the relation between burden and satisfaction of carers with various elements of the MCSP programme.

Changes in survey responses between three and six months of participation were analysed using McNemar tests for the qualitative variables, and Wilcoxon matched pairs signed rank tests for the quantitative variables. Analysis was performed using R for Windows version 3.3.3 (R Core Team, 2017).

Results

Quantitative research

Participant characteristics

[Table 1]

Table 1 shows the characteristics of the 87 people with dementia who participated in the first assessment after three months of participation in the user evaluation study per country. There were no significant differences between the countries on the gender, age, or marital status of people with dementia: the mean age was 78.1 years (± 7.3 , range 63 to 93) and overall the majority was female (62.1%, n=54), married (57.5%, n=50). However, the country samples differed significantly in terms of level of education

distribution and severity of dementia. Among the Italian participants, the primary level of education was the most prevalent (45.6%, n=21), in the Polish sample higher education predominated (90%, n=18) and in the UK the education was varied, but nearly half of the sample (47.6%, n=10) was classified as 'highly educated' (IT vs. PL $p=0.0001$, IT vs. UK $p=0.000$, PL vs. UK $p=0.005$). Moreover, there was a statistically significant difference in severity of dementia between the Italian and UK sample ($p=0.002$): Compared to the UK, where more participants had moderate dementia, in Italy more participants had mild cognitive impairments and mild dementia.

81 carers took part in the first survey after 3 months. Overall, the majority were women (70.4 %, n=57), with a mean age of 63.73 years (± 13.89 , range 22 to 87) and married or cohabiting (83.9%, n=68). Most of them were the spouse (55.6%, n=45) of the person with dementia. There were no significant differences between the countries on carers' gender, age and marital status. However, the carers in the three countries differed significantly in their level of education: in Poland the majority of carers (66.7%, n=14) were more highly educated in comparison to Italy 16.3% (n=7) and the UK 33.3% (n=5) (IT vs. PL $p=0.0002$, IT vs. UK $p=0.02$, PL vs. UK $p=0.008$). The reason why carers had chosen to participate in MCSP in all countries was, first and foremost, the possibility of receiving combined support (80.0% in Italy, 81.0% in Poland and 100% in the UK). Secondly in Poland and the UK the integration of MCSP in the local community (71.4% in Poland and 100% in the UK) and in Italy the location (55.6%) was mentioned as important. According to 88.9% carers from the UK the reason for MCSP participation was the feeling of being overburdened, while for Italian and Polish carers this was the least frequently mentioned reason (38.1% in Poland and 44.4% in Italy).

Sometimes participants, both people with dementia and their carers, did not answer all questions in the questionnaire, as some of them did not use all elements of the MCSP. Consequently, there are some differences in the number of respondents for the subsequent findings.

[Here Table 2]

Perspectives of people with dementia

In general, the people with dementia were very positive about their participation in the MCSP, both during the first measurement, after three months of participation, and during

the second measurement after six months. After six months 98.7% of the users described the Meeting Centres in the different countries as cosy, while only one person was dissatisfied with the atmosphere (see Table 2). Moreover, after six months, 74.1% of the study sample evaluated the staff as very friendly and 25.9% as friendly. Over time significantly more people with dementia felt that the staff really listened to them: In the first survey 67.4% indicated that the staff listened very well and 31.4% sufficiently; at the second measurement these percentages were changed to 78.8% and 21.3%. ($p=0.04$), respectively. 92.5% of the persons with dementia said they felt they could do what they enjoyed in the social club. Moreover, the percentage of people very satisfied with the activities offered in the club increased significantly over time ($p=0.05$) from 44.4% to 58.1%. However, after three months 48.8% of participants and after six months 39.5% reported that they were never asked what they wanted to do, 20.0% (and 28.9%) said that they were sometimes asked and the rest of the participants said that they were often or always asked (31.2%, 31.6% respectively).

Carers' perspective

Over time the percentage of carers participating in the information meetings of the MCSP increased significantly ($p=0.04$) from 52.5 % to 67.5 %. The number of people using the other elements of the programme did not change in time: after six months of MCSP participation, 68.8% ($n=53$) of the carers participated in the discussion groups, 61.7% ($n=50$) had used the consultation hour, and over half of them (51.2%, $n=41$) had taken part in the day club at least once. Most informal carers (73.1%, $n=57$) also used the opportunity to attend the monthly meetings organised for both people with dementia and carers as well as staff.

Carers who participated in the MCSP expressed their satisfaction with the information meetings as well the discussion groups (see Table 2). After six months of participation they pointed out that the information meetings always (50.9%, $n=29$), often (35.1%, $n=20$) or sometimes (14.0%, $n=8$) had supplied them with new information. Additional paired analyses among participants who completed both surveys, showed a significant improvement ($p=0.005$) in the level of satisfaction with the discussion groups: after six months of MCSP participation four informal carers changed their opinion from not being satisfied or moderately satisfied to satisfied or very satisfied. Moreover, at that time a majority of the discussion group participants emphasised that after the discussion group

they felt a lot (68.2%, n=36) or sufficiently (25.0%, n=13) emotionally supported by other informal carers, and a lot (69.2%, n=36) or sufficiently (25.0%, n=13) supported by the discussion leader. 91.6% of carers indicated that the practical advice they received was useful, two people (4.2%) considered the advice as not very useful and another two (4.2%) felt they were not useful.

After six months of MCSP participation the consultation hours were evaluated by 95.6% (n=65) of the carers as practical and by 4.4% (n=3) as not practical. A majority of informal carers (88.0%, n=66) described the tailored activities for people with dementia as stimulating, seven participants (9.3%) did not have an opinion on this subject, and two (2.3%) evaluated them as not stimulating.

After three months 83.5% of the carers said they already felt less burdened (48.1% much less and 35.4% little less) and after six months this percentage increased to 91% (57.7% much less and 33.3% little less). The calculation of Spearman rank correlations did not show a relationship between burden and satisfaction with the different elements of MCSP, such as the discussion groups ($\rho=0.16$, $p=0.5$) and information meetings ($\rho=0.17$, $p=0.2$). However, those carers who felt greater satisfaction with the discussion group as well as with the information meetings appeared to have experienced a lot of emotional support from other carers ($\rho=0.34$, $p=0.05$ and respectively $\rho=0.43$, $p=0.003$).

Qualitative research

Participant characteristics

A total of 62 participants, comprising 32 persons with dementia (with age range 65-93 years) and 30 carers (with age range 28-80 years) in five different Meeting Centres in three EU countries took part in the focus groups. All these participants had previously participated in the quantitative research. The focus groups lasted from 34 to 70 minutes for people with dementia, and from 58 to 90 minutes for informal carers. 53.1% (n=17) of people with dementia and 60.0% (n=18) of informal carers taking part in focus groups were female.

Overall, the results of the qualitative part of the study confirm the results obtained in the quantitative research. However, they give more insight and in depth understanding of the factors affecting the positive MC approach and its effectiveness.

Key factors for satisfaction with Meeting Centre Support Programme

- (Re)activation, (re)socialisation and improved emotional functioning

The focus group comments were generally very positive, and illustrated that the MCSP had a beneficial impact on both the people with dementia and their carers. It helped to reduce feelings of isolation and provided an important means for social and emotional interaction as well as for stimulation in daily life. This is wonderfully illustrated by the statement of one of the carers from Poland:

"Thanks to MC, he [person living with dementia] is simply not excluded from social life. Dad's daily functioning was that he slept and ate. It was even difficult to mobilize him to watch TV. Zero interests. He was always very talkative, but as a consequence of the disease he closed himself. At the moment, these 3 days in MC simply allow him to live a normal life. What I like here - the activities are conducted so nicely that these old habits, what they once learned are activated."

Another quote of an Italian MC user referred to all three strategies:

"Now we play burraco, with trump rules but ... (everyone laughs)".

For people with dementia and the informal carers the overarching themes of *(re)activation*, *(re)socialisation*, and *improved emotional functioning* were identified in the statements of the participants (see Figure 2 and 3).

[Figure 2]

[Figure 3]

- Dealing with adaptive tasks

People with dementia as well as the carers indicated that the MCSP helped them to cope with adaptation tasks described in the Adaptation-Coping Model, which is the theoretical basis for the MCSP. The most prominent adaptive tasks indicated by persons with dementia in each Meeting Centre in each country were:

Maintaining an emotional balance as illustrated by the following statement of a Polish participant:

"I am very pleased. I am very happy that I can leave the house and be among other people. As I come here it is always possible to talk and to laugh"

Preserving a positive self-image, as pointed out by one of the UK members:

"I did a pretty technical job, and I was very active, but now it's all stopped. Everything's stopped, and I just feel 'is that the end of the world?' because I can't do any more, and I can't even remember things. But in this group it doesn't seem to matter. I can come along and make a fool of myself and it doesn't matter, because we're all in the same way now. You're all lovely people, and I've never met such a friendly bunch of people as there is here."

Informal carers emphasised the impact of the MCSP on tasks such as:

Maintaining an emotional balance:

"I felt that my mood has improved definitely, and this is one of the most important things here."

"When I come here I do not take the antidepressant drugs. Really, you know?!" (Carer from Italy, Bologna)

Dealing with disabilities:

"MC helps to change carers. Get out of desperation and helplessness. I personally had hateful feelings to my mom. Thanks to MC we start to accept the way things go. We accept the consequences of the disease and we start to enjoy every day." (Carer from Poland)

However, they also pointed out that worrying related to the decline of the disease could affect people with dementia's participation at the programme, which links to the *dealing with uncertain future* adaptive task:

"My question is: how long does she attend this Centre? There will be a decline such that my mother couldn't stay here any more." (Carer from Italy, Milan)

The analysis found no evidence for the impact of the MCSP on *dealing with an uncertain future* for the participants with dementia.

- Improved quality of life

The satisfaction of the MC participants appeared associated with the improvement in some aspects of their quality of life. From the perspective of people with dementia, the most frequently mentioned aspects of quality of life in relation to the MCSP were: *mood, enjoyment of activities, self – esteem, energy and social contact*.

Below are some examples that illustrate these findings.

"We are very happy, we spend a very good time here, we laugh, we relax" (Italian member, Milan)

"Activities are very important. Especially those that develop thinking. Besides, it is important to have company with which it is pleasant and compatible." (Polish member)

“The benefit of it is in its title, it’s a ‘Meeting Centre’. Once you retire, and you don’t go to work, you stop seeing the people you worked with, ‘cause it’s miles away from where you worked. So you’re stuck at home and you either watch the television, which is boring, or listen to the radio, which is sometimes interesting, or you get a book. You’re stuck in an isolated situation. The benefit of the Meeting Centre is that you meet other people.” (The UK member)

For carers, the most important changes reported in each country for the quality of life of people with dementia were in such areas as: *mood, physical health, energy, living situation and friends*.

The quotes below show the MCSP's impact on aspects of quality of life.

“My husband has serious motor problems, despite this, he comes to MC with pleasure, he wakes up early in the morning, otherwise he wouldn’t get up before noon”. (Carer from Italy, Milan)

“Now there are new challenges, new activities and actually new life for her.” (Carer from Poland)

“She has changed so much: she is not silent any more, you have to cover her mouth to make her shut up! [laughing]”. (Carer from Italy, Bologna)

The contrast between the Meeting Centre and living at home was noted by the carers, mainly in terms of the (re)activation that the Meeting Centre provides and the impact this has on the members. As one carer from the UK said:

“They come to life. The rest of the time it’s like, there is just nothing there much at all. It’s stimulation”.

Moreover, it was recognised that the Meeting Centre has an important role to play in terms of addressing the social isolation experienced by many people. As one carer said:

“Before we came here, we were very much isolated. Ok, you’d go and see the consultant, and the nurse comes round, or the occupational therapist comes round, that’s really very nice, but I still had this isolated feeling.” (Carer from the UK)

With regard to the quality of life categories developed by (Logsdon et al., 2002), people with dementia did not mention anything about MCSP participation and satisfaction in relation to their *financial situation and life as a whole*. Furthermore, no remarks were made by people with dementia about some specific aspects of quality of life reported by Dröes et al. (2006) as experienced as important by people with dementia, such as: *sense of aesthetics in the living environment, physical and mental health, financial situation, security and privacy and spirituality*.

- *Informational, practical, emotional and social support for carers*

In addition to the results described above, qualitative analyses also underline the value of the support received in the MC by carers and their satisfaction with the programme. In each country, the carers who took part in a focus group described the support they received in terms of *informational, practical, emotional and social support*. The following quotes illustrate these findings.

"The fact that activities are not just for people living with dementia but also for us is important. This is a new experience, the new knowledge that we gain." (Carer from Poland)

"They can always recommend somebody, or recommend something that you might want to try. And that's the other thing, it's not like a prescription, it's 'well you might want to...' and it's the 'might want to' bit that's quite important." (Carer from the UK)

"There was a moment when I didn't want to live anymore (...) When I came here, I came to life again" (Carer from Italy, Bologna)

"The fact that we have the possibility to share our impressions and difficulties helps us very much. "
"We feel like one big family." (Carer from Italy, Milan)

Discussion

Theoretical framework of the MCSP

Living with dementia entails dealing with a progressive loss of abilities by the person with dementia and also has a major impact on their informal carers. Having dementia often leads to forgetfulness, increased dependency on others, and a lack of meaningful activities and social relationships. It can also lead to concerns about the progression of the disease and how to be prepared for the changes that will occur (Söderhamn, Aasgaard, & Landmark, 2014). According to the Adaptation-Coping Model people living with dementia and their carers have to deal with seven adaptive tasks to stay emotionally in balance (Dröes, Van Der Roest, et al., 2011). This model is the theoretical foundation of the MCSP developed in the Netherlands (Dröes, Meiland, Lange, Vernooij-Dassen, & Tilburg, 2008).

Findings of the study and implications

The objectives of our study were to assess the satisfaction of people with dementia and their carers regarding Meeting Centres (and the different elements of MCSP) in Italy, Poland and the United Kingdom, as well as to identify key factors determining their level of satisfaction. Overall, both quantitative and qualitative data suggested a high degree of satisfaction among MC users. All except one person with dementia across the three countries rated the

Meeting Centres atmosphere positively, and everyone appreciated the attitude of the staff towards them. These results suggest an effective adaptation and implementation of the successful Dutch MCSP model in the three countries involved in this study. The MEETINGDEM project included a long exploration and preparation phase of 18 months in each country, which allowed both involved in setting up the MCs in the three countries and those working in them to correctly learn and apply the integrated person-centred MCSP model, which focuses on social integration and participation for people with dementia. At this point, it should be noted that the preparation of the staff was based on training developed in the Netherlands. Within the MEETINGDEM project this training was translated and adapted to the conditions and context of each of the participating countries. The training consists of 8 modules and lasts four full days, followed by five supervision meetings on a monthly basis, and was delivered by experts in the field of dementia care. It is also important to emphasize the role of the MC coordinator, who, apart from formal qualifications (psychologist, psychomotor therapist, music therapist etc.) should possess appropriate interpersonal and organizational competences enabling work in the Meeting Center.

High satisfaction with activities, which was expressed by less than half of the participants after three months of participation, increased significantly over time, indicating that the staff was able to effectively personalise the service (Söderhamn et al., 2014). This personalisation can be considered as a result of the specific approach applied in the MCSP model, which starts with making an individual psychosocial diagnosis which allows the staff to gain insight into the specific needs of each individual participant. Another important issue related to personalisation is the open and friendly atmosphere in the MC and the principle of addressing each other by the first name, which proved to be particularly important for MC users even in countries where this culturally is not a usual custom (for example in Poland).

However, although the majority of people with dementia felt that the staff listened very well to them, a relatively high percentage reported that they were never asked what they would like to do. This highlights the need to educate professional carers dealing with people with dementia to better take into account their individual needs and wishes. A similar result was described in a previous multicentre study into MCSP conducted in the Netherlands (Dröes, Meiland, et al., 2011), which confirms the importance of the finding in the present study. Also, a Norwegian qualitative study, dealing with social and physical activities for people

with early stage dementia, showed the importance of highly qualified staff with competence in caring for and about people with dementia. This highlights the importance of having staff trained to provide person-centred care and that are able to meet the needs of both the people living with dementia and their informal carers in order to maximise their quality of life (Söderhamn, Landmark, Eriksen, & Söderhamn, 2013). In recent years, psychosocial researchers have increasingly involved people with dementia in the planning phase of their studies, e.g. through focus groups (Spector, Gardner, & Orrell, 2011), even if the mental functionality of older people with dementia might impact on their ability to be involved in research and to have a 'voice' in terms of their experience of the care they receive (Vaismoradi, Wang, Turunen, & Bondas, 2016).

As far as carers are concerned, their participation in different elements of the programme specifically designed for them was high (about two thirds of them participated in information meetings, the discussion groups and the monthly centre meetings after six months, while a slightly lower percentage used the consultation hour), especially when considering how difficult and busy a carer's life is (Dröes, Meiland, et al., 2011). Both the information meetings and the discussion groups were positively evaluated. The fact that a significant improvement in the level of satisfaction with the discussion groups was observed after six months of MCSP participation may be explained by the improved knowledge of carers needs by the staff (psychologists, therapists and coordinators), involved in guiding the groups which is reflected in a psychosocial diagnosis carers receive, but also by the growing relationships with other participants in the group. Having opportunities to get to know each other better and the development of an open and friendly atmosphere over time may be important elements of the positive evaluation by informal carers. It is possible that the development of a sociable atmosphere was also facilitated by the social integration and location of the Meeting Centres in the community, which was mentioned by many carers as an important reason to choose the MCSP.

Consultation hours represented a very innovative service in all countries and were positively evaluated by the majority of carers. They allow individual case management, thus representing a valuable tool for translating the psychosocial diagnosis of the person with dementia and carer into practice. Data about carers' burden are striking, particularly in terms of the increased benefits that were seen over time. We must remember that the main reason why carers had chosen to participate in MCSP in all countries was mainly the

possibility of receiving combined support: according to the present data, it seems that this was indeed achieved.

It is important to consider whether traditional scales have sufficient sensitivity to identify all aspects of the positive impact of psychosocial care on users. This can be seen by comparing user satisfaction results with data obtained using the traditional outcome instruments in the MEETINGDEM project, which primarily showed significant positive effects for some aspects of QoL (self-esteem, positive affect and feelings of belonging) in people with dementia (Brooker et al., 2018), and heterogeneous results for carers in the three countries (Evans et al., 2018). As stated in a recent editorial, the improvement of clinical practice requires the accumulation of understanding gained from qualitative research (Vaismoradi et al., 2016) to capture the subjective experience of care, beyond biological information, investigated and collected through standardised scales (Gaugler, 2016).

A majority of informal carers described the activities for people with dementia as functionally activating, i.e. that they stimulated the user's cognition and mental activities (memory, language, perception, action) as well as instrumental skills which are essential to maintain functioning in daily life and as such improved the physical, social, and psychological functioning. This was clearly confirmed by findings from the focus groups, where many carers also noted the contrast between the Meeting Centre and their life at home in terms of stimulation and activation. This point is very important because reduced independence and activity are common symptoms in mild to moderate dementia. This is also in line with a literature review, which emphasised how dementia involves numerous losses and restrictions that often lead to social isolation (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). Qualitative data from the focus groups also underlined that the Meeting Centre provides an important means for social and emotional interaction. They also confirmed, as far as people with dementia are concerned, the data obtained with the QoL scales, more specifically regarding improved self-esteem and feelings of belonging (Brooker et al., 2018).

When considering the adaptive tasks described in the Adaptation-Coping Model (Dröes, Van Der Roest, et al., 2011), the theoretical basis for MCSP, the most prominent aspect that emerged from the focus groups in all countries for both the persons with dementia and carers was 'maintaining an emotional balance'. This is not surprising when considering the plethora of media and news items suggesting that dementia is feared by elderly people

more than cancer (Spencer, 2016), largely due to a loss of identity and independence that is inherent to this condition. On the other hand, the fact that only carers were worried about future participation in the MCSP (feelings related to the adaptive task dealing with an uncertain future) could be related to cognitive disabilities of people with dementia, which can prevent them from precisely visualising their future.

Strengths and limitations

A key strength of this study is that we elicited the views of many people with dementia. Studies in which people with dementia actively participate are still relatively rare and in most of them only a small number of people are recruited (de Boer et al., 2007; Steeman, Godderis, Grypdonck, De Bal, & De Casterlé, 2007; van Haeften-van Dijk, Hattink, Meiland, Bakker, & Dröes, 2017).

Our study had some methodological limitations: a risk of satisfaction surveys is that respondents tend to give socially desirable answers (Edwards, Staniszevska, & Crichton, 2004). We tried to reduce this risk by asking detailed questions on all elements of MCSP and by employing independent interviewers not connected to the Meeting Centre. At the start of the interview and focus groups, the interviewers also underlined their independent status and explained that all information collected would be processed anonymously. However, a bias due to the utilisation of this kind of evaluation cannot be completely excluded. Another limitation is that sometimes participants, both people with dementia and their carers, did not answer all questions of the questionnaire, because they did not participate in some elements of the programme. In addition, some of the MC participants were not included in our study, due to drop-out and withdrawn consent. A possible explanation for the limited use of the programme by some carers may be that they preferred having some extra free time rather than utilising support activities. For persons with dementia, limited or lack of participation in some activities may have been linked to dementia severity or comorbidities. A further limit is the absence of a control group (e.g. a group of users from a comparable service) as opposed to a very recent Dutch study in which users' satisfaction of MCSP was compared with users' satisfaction of traditional day care in nursing homes (van Haeften-van Dijk et al., 2017).

On the other hand, the results of the present research confirms previous Dutch studies (Dröes, Meiland, et al., 2011; van Haeften-van Dijk et al., 2017) where in general the people

with dementia and the carers were satisfied to very satisfied with the different elements of the support programme, the contact with personnel and the atmosphere at the MC. Also, carers valued the communication with, and expertise of, staff in the community-based day care higher than in traditional day care in the nursing home, and were more satisfied with the received emotional, social and practical support (van Haften-van Dijk et al., 2017). This confirms the reliability of our study results.

Implications for practice and research

Gaining knowledge about how care is experienced by users is of great value for professional and political stakeholders who oversee the planning of care for frail persons. Too frequently care is planned only on the basis of the professionals' point of view, cost estimation and calculation of existing service use. From the present user evaluation, it appears that the Dutch model has been successfully implemented in the three countries participating in the MEETINGDEM project, although there is potential to provide more opportunities for the people with dementia to be consulted on what activities they would like to do in the centre. The present study did not show a relationship between carers' burden and satisfaction with the specific elements of MCSP. Further research is needed on this point, in order to understand whether strengthening some elements rather than others might be useful to further improve the efficacy of the MCSP model. A recent explorative study into an additional individualized programme (iMCSP) for people with dementia and carers, connected to a number of Meeting Centres in the Netherlands showed promising results (Dröes et al., 2019).

It is also clear that further qualitative research is required to identify psychosocial interventions that have a positive impact on older adults with dementia and their family members. As clearly stated by Gaugler (2016, p. 371), truly person-centred research must 'identify and include outcomes the population of interest notices and cares about' and 'results of this research must be used to inform health decisions' ("PCORI," 2019)(see <http://www.pcori.org>).

The study into MCSP across the three countries involved in the MEETINGDEM project reported on in this paper provides a powerful and consistent description of the satisfaction of the users of the Meeting Centres with the support and assistance they received, thus stimulating interest in further appropriate actions to disseminate the MCSP model in other

European countries and beyond. The user experiences and the findings of a previous study within the MEETINGDEM project into the facilitators and barriers of adaptive implementation of MCSP in the three countries (Mangiaracina et al., 2017; Mierlo et al., 2018) were therefore integrated in practical country-specific guides which together with the developed training courses for staff can help care and welfare organisations and professionals to set up Meeting Centres in their own country and region. In the past few years this resulted already in further dissemination of Meeting Centres in Italy, Poland, the UK and Spain (www.meetingdem.eu). Also several initiatives are undertaken outside Europe in other parts of the world, such as Australia, the United States, Chilli and Japan, to develop Meeting Centres there.

Conflict of Interest: none

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Table 1. Background characteristics of people with dementia (N=87) per country

		People with dementia % (N)			χ^2 , df	p-value
Characteristics	Nationality	Italy (IT) N=46	Poland (PL) N=20	UK N=21		
Gender						
Male		34.8 (16)	25.0 (5)	57.1 (12)	4.906, 2	0.09
Female		65.2 (30)	75.0 (15)	42.9 (9)		
Age		78.86 (±6.46)	78.05 (±5.67)	76.32 (±10.25)	0.104, 2	0.9
Marital status						
Married		58.7 (27)	40.0 (8)	71.5 (15)	7.565, 6	0.3
Widowed		34.8 (16)	55.0 (11)	19.1 (4)		
Divorced		2.2 (1)	-	4.7 (1)		
Single		4.3 (2)	5.0 (1)	4.7 (1)		
Level of education						
Higher education		4.4 (2)	40.0 (8)	47.6 (10)	40.34, 8	IT vs. PL 0.0001 IT vs. UK 0.0000 PL vs. UK 0.005
Vocational level 2		23.9 (11)	50.0 (10)	14.3 (3)		
Vocational level 1		15.2 (7)	-	23.8 (5)		
Primary education		45.7 (21)	10.0 (2)	-		
No qualification		4.3 (2)	-	9.5 (2)		
No data		6.5 (3)	-	4.8 (1)		
Severity of dementia (GDS)						
No cognitive decline		2.2 (1)	-	-	19.49, 10	IT vs. PL 0.64 IT vs. UK 0.002 PL vs. UK 0.07
Age Associated Memory Impairment		4.3 (2)	15.0 (3)	9.5 (2)		
Mild Cognitive Impairment		36.9 (17)	30.0 (6)	4.8 (1)		
Mild Dementia		39.1 (18)	35.0 (7)	28.6 (6)		
Moderate Dementia		13.1 (6)	20.0 (4)	47.6 (10)		
Moderately Severe Dementia		2.2 (1)	-	9.5 (2)		
Severe Dementia		-	-	-		
No data		2.2 (1)	-	-		

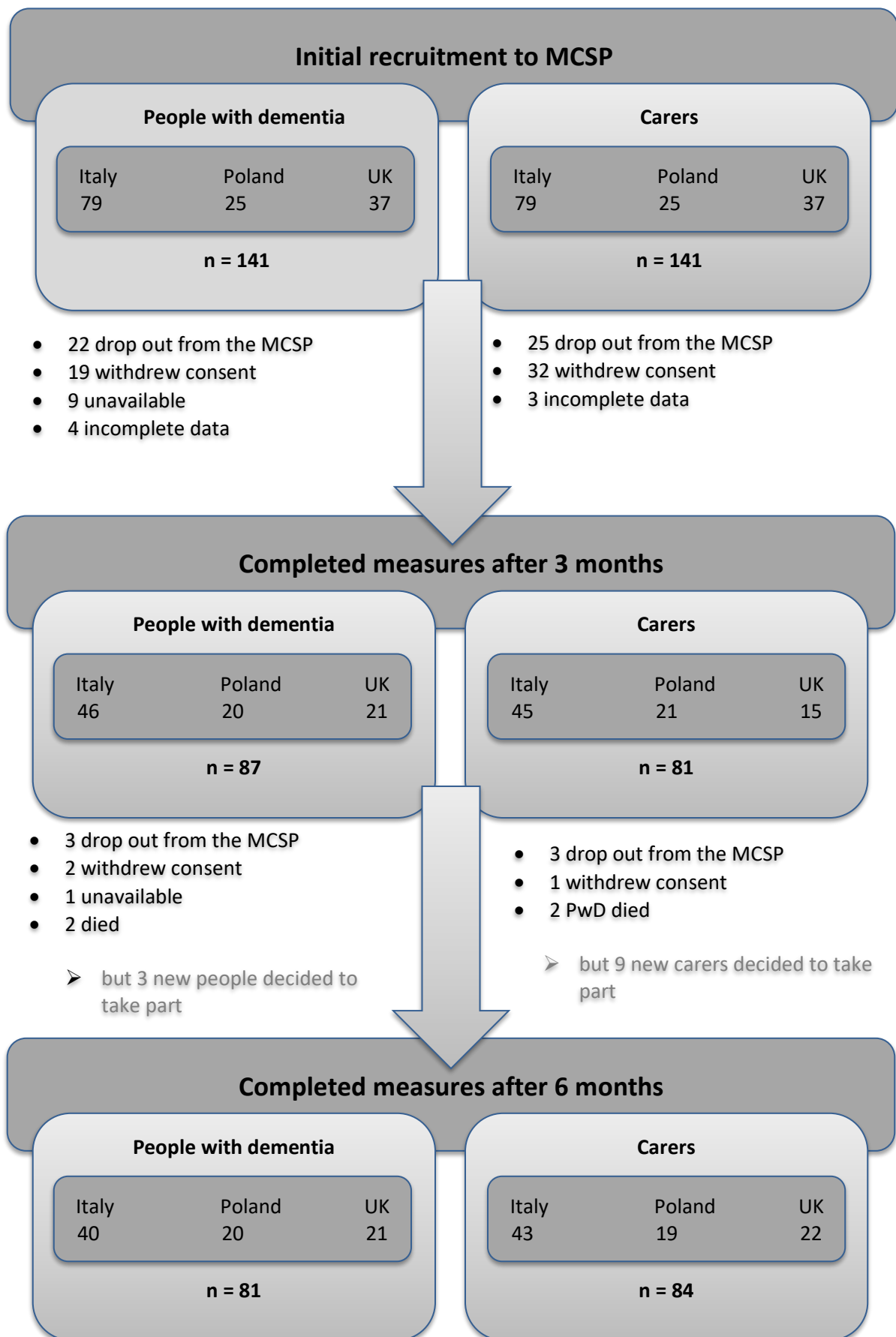
* Kruskal-Wallis chi-squared

Table 2. Opinion of people with dementia and their carers on selected factors of MC after three and after seven months of participation

PEOPLE WITH DEMENTIA								
Content	After 3 months %(N)				After 6 months %(N)			
Atmosphere in MC	cosy 95.3 (81)	not cosy 4.7 (4)			cosy 98.7 (78)	not cosy 1.3 (1)		
Contact with staff	very friendly 63.5 (54)	friendly 36.5 (31)	unfriendly -		very friendly 74.1 (60)	friendly 25.9 (21)	unfriendly -	
Does the staff listen?*	very well 67.4 (58)	sufficiently 31.4 (27)	insufficiently 1.2 (1)		very well 78.8 (63)	sufficiently 21.3 (17)	insufficiently -	
General Opinion*	very satisfied 44.4 (36)	satisfied 55.6 (45)	not satisfied -		very satisfied 58.1 (43)	satisfied 40.5 (30)	not satisfied 1.4 (1)	
INFORMAL CARERS								
	very satisfied	satisfied	moderately satisfied	not satisfied	very satisfied	satisfied	moderately satisfied	not satisfied
Information meetings	80.5 (33)	14.6 (6)	4.9 (2)	-	78.3 (47)	18.3 (11)	3.3 (2)	-
Discussion groups*	55.6 (20)	33.3 (12)	8.3 (3)	2.8 (1)	52.9 (27)	39.2 (20)	5.9 (3)	1.9 (1)

* $p < 0.05$ (Wilcoxon paired test) conducted in additional paired analyses among participants who completed both surveys

Figure 1 Numbers of research participants recruited by country and reasons of drop out during the user evaluation study



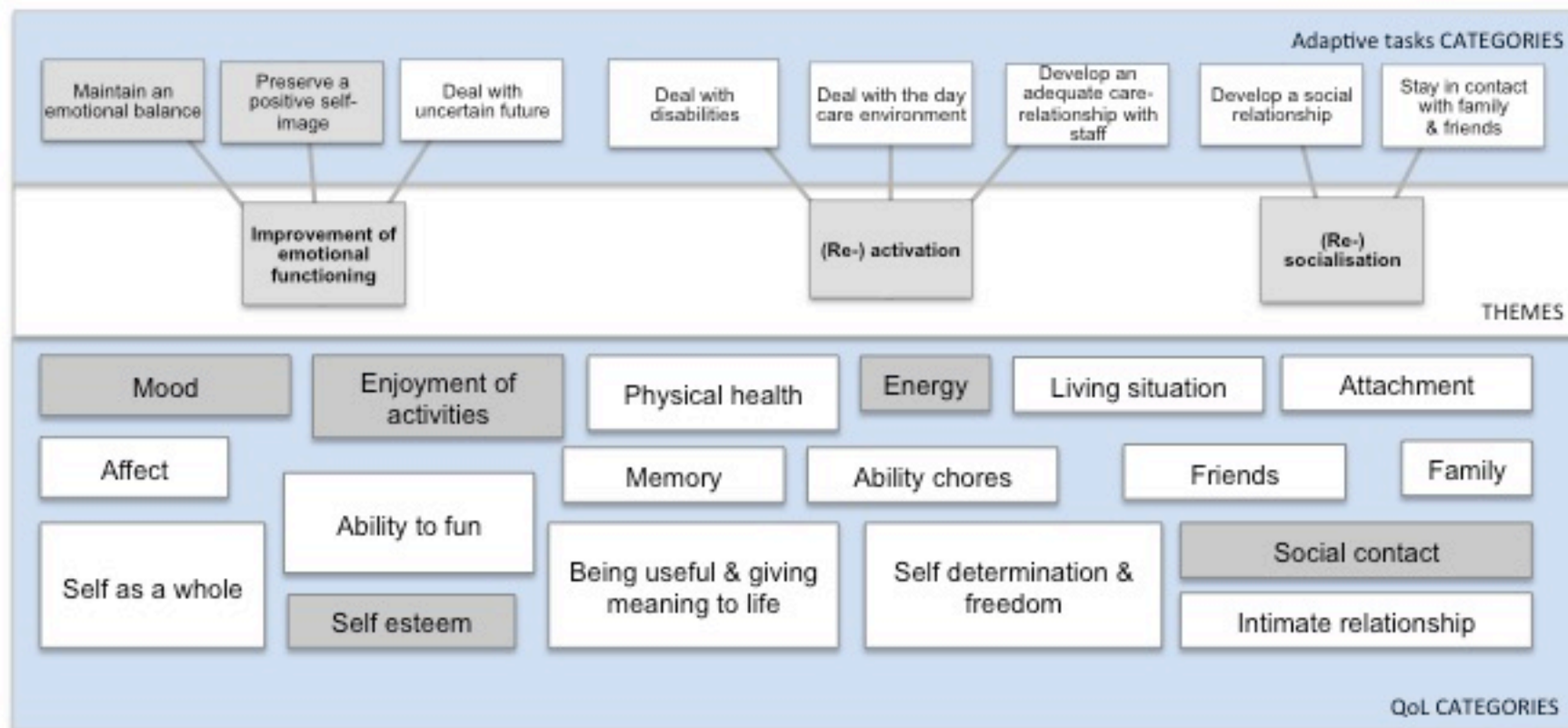


Figure 2. MCSP impact on people with dementia according to its users.

Gray categories have been identified in each of the Meeting Centers

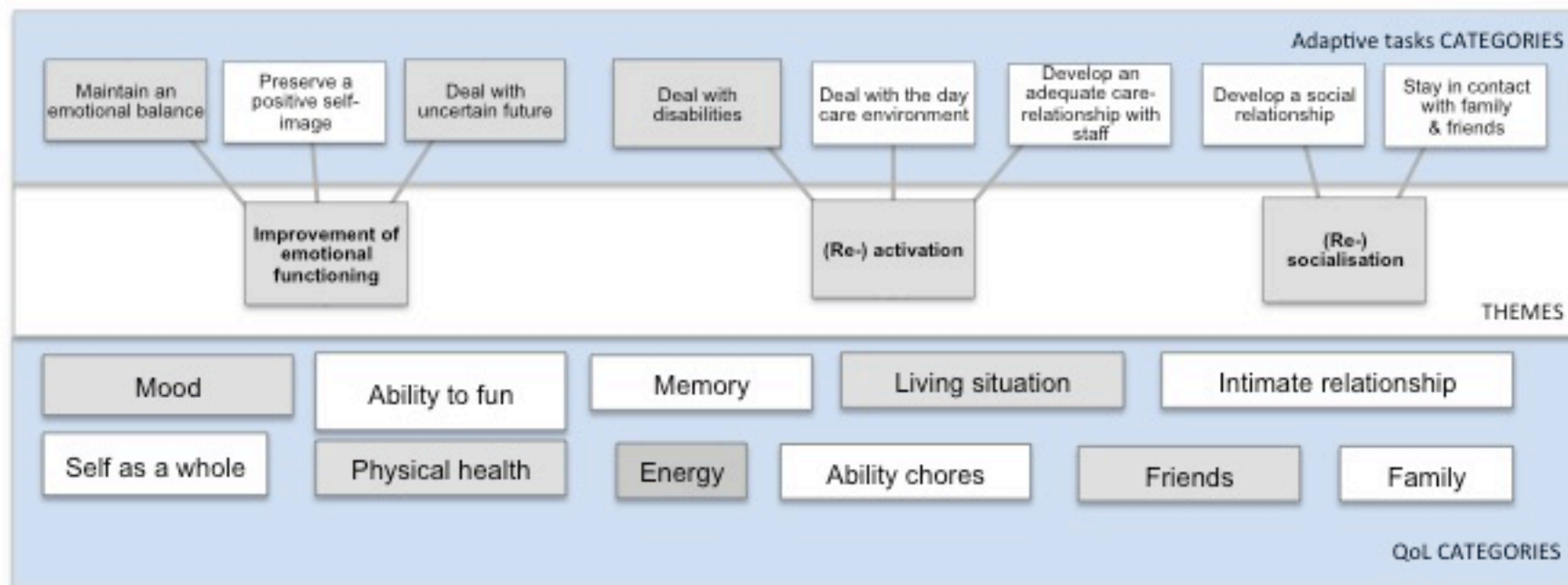


Figure 3. MCSP impact on people with dementia according to their carers.

Gray categories have been identified in each of the Meeting Centers