Adaptive Implementation and validation of the Meeting Centers Support Programme for people with dementia and their carers in Europe

How do people with dementia and their caregivers in Italy, Poland and the UK evaluate the Meeting Centre Support Programme?

RYMASZEWSKA, Joanna, SZCZEŚNIAK, Dorota, URBAŃSKA, Katarzyna, BROOKER, Dawn, EVANS, Shirley, EVANS, Simon, CHATTAT, Rabih, SCOROLLI, Claudia, FARINA, Elisabetta, D’ADARMA, Alessia, SAIBENE, Francesca Lea, MEILAND, Franka, DRÖES, Rose-Marie

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Introduction

The importance of Patient and Public Involvement (PPI) is increasingly promoted and recognized as essential in conducting research.

The JPND- MEETINGDEM project aimed to adapt, implement and evaluate an innovative, person-centered approach to support community dwelling people with mild to moderate dementia and their carers called Meeting Centre Support Programme (MCSP).
Meeting Centre Support Programme

Person with dementia: social club, psychomotor group therapy, creative and recreational activities

Carer: informative meetings, support group, care coordination

For both: consulting hour, monthly center meeting, social activities

Community centres
Socially integrated
MeetingDem Project

**Phase I: Exploration and preparation**

- **WP1**: Project management (VUmc)

- **WP2**: Exploration, mapping and recruitment of organisations for initiative group in participating countries (WMU)

- **WP3**: Inventory and analysis of conditions for successful implementation of MCSP in participating countries (UNIBO)

- **WP4**: Preparation of country specific implementation plans with strategies and materials (VUmc)

**Phase II: Implementation and Evaluation**

- **WP5**: Implementation of MCSP (UNIBO)
  - At least one MC in each of the participating countries, i.e. Italy, Poland, the United Kingdom
  - Train the trainer course in each country
  - Courses for personnel in each country

- **WP6**: Evaluation of implementation (UW)
  - Cost-effectiveness on behaviour, mood and quality of life of people with dementia, sense of competence of carers and care costs; **User satisfaction**, Implementation process

- **WP7**: Dissemination of project results (VUmc)
**User Satisfaction Evaluation**

**Aim**
To evaluate the satisfaction of MSCP users: people with dementia & their carers

**Procedure**
a mixed methods explanatory design

- **M3**
  - User satisfaction questionnaires among Italian, Polish and English MC participants
  - for 87 PwD & 81 carers

- **M6**
  - User satisfaction questionnaires among Italian, Polish and English MC participants
  - for 83 PwD & 84 carers

- **M9**
  - FOCUS GROUPS
    - in 5 Meeting Centres in Italy, Poland and the UK
    - 32 PwD & 30 carers

**Qualitative research**

**Quantitative research**
User satisfaction – quantitative methods

Instruments

- 2 questionnaires developed in the Netherlands (Dröes et al, 2011)
- Language adaptation (Italy, Poland, the UK)
- Performed with:
  - People with dementia
  - Carers
## Study sample characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>People with dementia % (N)</th>
<th>(X^2, df)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationality</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Italy (IT)</td>
<td>N=46</td>
<td></td>
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</tr>
<tr>
<td>Poland (PL)</td>
<td>N=20</td>
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</tr>
<tr>
<td>UK</td>
<td>N=21</td>
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<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34.8 (16)</td>
<td>25.0 (5)</td>
<td>57.1 (12)</td>
</tr>
<tr>
<td>Female</td>
<td>65.2 (30)</td>
<td>75.0 (15)</td>
<td>42.9 (9)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>78.86 (±6.46)</td>
<td>78.05 (±5.67)</td>
<td>76.32 (±10.25)</td>
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<tr>
<td><strong>Marital status</strong></td>
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<tr>
<td>Married</td>
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<td>40.0 (8)</td>
<td>71.5 (15)</td>
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<tr>
<td>Widowed</td>
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<td>55.0 (11)</td>
<td>19.1 (4)</td>
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<tr>
<td>Divorced</td>
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<td>-</td>
<td>4.7 (1)</td>
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<tr>
<td>Single</td>
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<td>5.0 (1)</td>
<td>4.7 (1)</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
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<td></td>
<td></td>
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<tr>
<td>Higher education</td>
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<td>40.0 (8)</td>
<td>47.6 (10)</td>
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<tr>
<td>Vocational level 2</td>
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<td>50.0 (10)</td>
<td>14.3 (3)</td>
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<tr>
<td>Vocational level 1</td>
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<td>-</td>
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<td>Primary education</td>
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<td>10.0 (2)</td>
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<tr>
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<td>9.5 (2)</td>
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<tr>
<td>No data</td>
<td>6.5 (3)</td>
<td>-</td>
<td>4.8 (1)</td>
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<tr>
<td><strong>Severity of dementia (GDS)</strong></td>
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<td>No cognitive decline</td>
<td>2.2 (1)</td>
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<td>-</td>
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<tr>
<td>Age Associated Memory Impairment</td>
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<td>Mild Cognitive Impairment</td>
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<td>30.0 (6)</td>
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<tr>
<td>Mild Dementia</td>
<td>39.1 (18)</td>
<td>35.0 (7)</td>
<td>28.6 (6)</td>
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<tr>
<td>Moderate Dementia</td>
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<td>20.0 (4)</td>
<td>47.6 (10)</td>
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<td>Moderately Severe Dementia</td>
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<tr>
<td>No data</td>
<td>2.2 (1)</td>
<td>-</td>
<td>-</td>
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</tbody>
</table>
Why did carers choose MCSP?

1. THE POSSIBILITY OF RECEIVING COMBINED SUPPORT
   - 80.0% - Italy; 81.0% - Poland; 100% - the UK

2. THE INTEGRATION OF MC IN THE LOCAL COMMUNITY
   - 71.4% - Poland; 100% - UK

3. THE FEELING OF BEING OVERBURNTED
   - 88.9% - UK; 38.1% - Poland; 44.4% - Italy

4. LOCATION
   - Italy - 55.6%
# Results on user satisfaction

## PEOPLE WITH DEMENTIA

<table>
<thead>
<tr>
<th>Content</th>
<th>After 3 months %(N)</th>
<th>After 6 months %(N)</th>
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</thead>
<tbody>
<tr>
<td><strong>Atmosphere in MC</strong></td>
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<td></td>
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<tr>
<td>Cozy</td>
<td>95.3 (81)</td>
<td>98.7 (78)</td>
</tr>
<tr>
<td>Not cozy</td>
<td>4.7 (4)</td>
<td>1.3 (1)</td>
</tr>
<tr>
<td><strong>Contact with staff</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very friendly</td>
<td>63.5 (54)</td>
<td>74.1 (60)</td>
</tr>
<tr>
<td>Friendly</td>
<td>36.5 (31)</td>
<td>25.9 (21)</td>
</tr>
<tr>
<td>Unfriendly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very friendly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friendly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unfriendly</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Does the staff listen?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very well</td>
<td>67.4 (58)</td>
<td>78.8 (63)</td>
</tr>
<tr>
<td>Sufficiently</td>
<td>31.4 (27)</td>
<td>21.3 (17)</td>
</tr>
<tr>
<td>Insufficiently</td>
<td>1.2 (1)</td>
<td>-</td>
</tr>
<tr>
<td><strong>General Opinion</strong></td>
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<td></td>
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<tr>
<td>Very satisfied</td>
<td>44.4 (36)</td>
<td>58.1 (43)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>55.6 (45)</td>
<td>40.5 (30)</td>
</tr>
<tr>
<td>Not satisfied</td>
<td></td>
<td>1.4 (1)</td>
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## CARERS

<table>
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<tr>
<th>Information meetings</th>
<th>very satisfied</th>
<th>satisfied</th>
<th>moderately satisfied</th>
<th>not satisfied</th>
<th>very satisfied</th>
<th>satisfied</th>
<th>moderately satisfied</th>
<th>not satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>80.5 (33)</td>
<td>14.6 (6)</td>
<td>4.9 (2)</td>
<td>-</td>
<td>78.3 (47)</td>
<td>18.3 (11)</td>
<td>3.3 (2)</td>
<td>-</td>
</tr>
<tr>
<td>Satisfied</td>
<td>14.6 (6)</td>
<td>54.8 (22)</td>
<td>14.6 (6)</td>
<td>5.8 (2)</td>
<td>18.3 (11)</td>
<td>52.9 (22)</td>
<td>5.8 (2)</td>
<td>14.6 (6)</td>
</tr>
<tr>
<td>Moderately satisfied</td>
<td>4.9 (2)</td>
<td>3.3 (1)</td>
<td>4.9 (2)</td>
<td>3.3 (1)</td>
<td>5.8 (2)</td>
<td>3.3 (1)</td>
<td>3.3 (1)</td>
<td>4.9 (2)</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>-</td>
<td>2.8 (1)</td>
<td>-</td>
<td>2.8 (1)</td>
<td>-</td>
<td>2.8 (1)</td>
<td>-</td>
<td>2.8 (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discussion groups*</th>
<th>very satisfied</th>
<th>satisfied</th>
<th>moderately satisfied</th>
<th>not satisfied</th>
<th>very satisfied</th>
<th>satisfied</th>
<th>moderately satisfied</th>
<th>not satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>55.6 (20)</td>
<td>33.3 (12)</td>
<td>8.3 (3)</td>
<td>2.8 (1)</td>
<td>52.9 (27)</td>
<td>39.2 (20)</td>
<td>5.9 (3)</td>
<td>1.9 (1)</td>
</tr>
<tr>
<td>Satisfied</td>
<td>33.3 (12)</td>
<td>55.6 (20)</td>
<td>8.3 (3)</td>
<td>2.8 (1)</td>
<td>39.2 (20)</td>
<td>52.9 (27)</td>
<td>5.9 (3)</td>
<td>1.9 (1)</td>
</tr>
<tr>
<td>Moderately satisfied</td>
<td>8.3 (3)</td>
<td>8.3 (3)</td>
<td>55.6 (20)</td>
<td>33.3 (12)</td>
<td>8.3 (3)</td>
<td>55.6 (20)</td>
<td>8.3 (3)</td>
<td>55.6 (20)</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>2.8 (1)</td>
<td>2.8 (1)</td>
<td>2.8 (1)</td>
<td>55.6 (20)</td>
<td>2.8 (1)</td>
<td>55.6 (20)</td>
<td>2.8 (1)</td>
<td>55.6 (20)</td>
</tr>
</tbody>
</table>
Results on user satisfaction

Over time significantly more people with dementia:

• felt that the personnel listened to them: 67.4% $\rightarrow$ 78.8% very well and 31.4% $\rightarrow$ 21.3% sufficiently (p=0.04)

• felt very satisfied with the activities offered in the club 44.4% $\rightarrow$ 58.1% (p=0.05)
User satisfaction - qualitative methods

Procedure

- Focus group interviews (n=5-7; 45-90 min)

→ 5 CS (2 Milan, Bologna, Worcester, Wrocław)

→ concept driven coding - analysis

people with dementia

cares
MCSP impact on people with dementia - their own perspective

- Improvement of emotional functioning
  - Maintain an emotional balance
  - Preserve a positive self-image
  - Deal with uncertain future
- (Re-) activation
  - Deal with disabilities
  - Deal with the day care environment
  - Develop an adequate care-relationship with staff
- (Re-) socialisation
  - Develop a social relationship
  - Stay in contact with family & friends

Quality of Life

- Mood
- Enjoyment of activities
- Physical health
- Energy
- Living situation
- Affect
- Ability to fun
- Memory
- Ability chores
- Friends
- Self as a whole
- Self esteem
- Being useful & giving meaning to life
- Self determination & freedom
- Family
- Social contact
- Intimate relationship

Red categories have been identified in each of the Meeting Centers
MCSP impact on people with dementia – carers’ perspective

- Improvement of emotional functioning
  - Maintain an emotional balance
  - Preserve a positive self-image
  - Deal with uncertain future
  - Deal with disabilities

- (Re-) activation
  - Deal with the day care environment
  - Develop an adequate care relationship with staff

- (Re-) socialisation
  - Develop a social relationship
  - Stay in contact with family & friends

Quality of Life

- Mood
- Ability to have fun
- Memory
- Energy
- Living situation
- Intimate relationship
- Self as a whole
- Physical health
- Ability chores
- Friends
- Family

Red categories have been identified in each of the Meeting Centers
Maintaining emotional balance & QoL improvement:
‘We are very happy, we spend a very good time here, we laugh, we relax.’
(Italian member, Milan)
Enjoyment of activities & social contact:
‘Activities are very important. Especially those that develop thinking. Besides, it is important to have a company with which it is pleasant and compatible. (Polish member)

‘You’re stuck in an isolated situation. The benefit of the Meeting Centre is that you meet other people.’ (UK member)
Dealing with disabilities:
‘MC helps to change carers. Get out of desperation and helplessness (…) Thanks to we accept the consequences of the disease and we start to enjoy every day.’
(Carer from Poland)
Emotional support:
‘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)
Conclusions

MCSP is **highly appreciated** by people with dementia and carers in Italy, Poland and the UK.

MCSP is a **model** that can help people living with dementia and their carers to increase their capacity to deal with the challenges caused by dementia and promotes **emotional balance, enjoyment of activities and social relationships**.
Summary

‘Because of the MC we have started to accept the disease. We accept this and we are happy with every single day which gives us something (...) I have stopped hating my mum. We learned again how to love them. It is a big change in our minds (...) They are still people and we can do a lot for them.’

(MC participant from Poland)