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ABSTRACT (250/250 words)

Objectives:

This is the first study to focus at the role and impact of a psychosocial intervention, the Meeting Centre Support Programme (MCSP), for people living with dementia and mild cognitive impairment (MCI), on the experience of stigmatisation across three different European countries.

Method:

A pre/post-test control group study design compared outcomes for 114 people with dementia (n=74) and MCI (n=40) in Italy, Poland and the UK who received either the MCSP or usual care (UC). The 'Stigma Impact Scale, neurological disease' (SIS) was administered at two points in time 6 months apart. The Global Deterioration Scale (GDS) was used to assess the level of cognitive impairment.

Results:

Although statistical analysis did not show any significant differences between MCSP and UC at pre/post-test for the 3 countries combined, there were significant results for individual countries. In Italy, the level of SIS was significantly lower ($p=0.02$) in the MCSP group following the intervention. The level of Social Isolation increased significantly ($p=0.05$) in the UC group at follow up in Poland. The level of Social Rejection was significantly higher ($p=0.03$) over time for UK participants receiving MCSP compared to UC.

Conclusion:

The experience of stigma by people living with dementia and MCI is complex and there may be different country specific contexts and mechanisms. The results do not enable us to confirm or disconfirm the impact of a social support programme, such as MCSP, on this experience. Difficulties in directly measuring the level of stigma in this group also requires further research.

Keywords: stigma, aging, dementia, discrimination, social support, care, attitude

ARTICLE HIGHLIGHTS

- 1.** The experience of stigma by people living with dementia and MCI is a complex and country specific issue.
- 2.** The results of this study do not confirm or disconfirm the impact of a social support programme, such as MCSP, on the experience of stigma.
- 3.** There is a great need for further research in this area and developing more reliable stigma measuring tools.

INTRODUCTION

As the population worldwide is getting older issues that are linked to old age are getting increased attention, not only in medical practice and scientific research, but also in policy, everyday conversations, social campaigns etc. One of the most common issues connected with old age is dementia. As a neurodegenerative disease it leads to many consequences including changes in the private, social, financial and emotional lives of people diagnosed with dementia and their relatives¹. Even though more and more countries implement national dementia strategies, there is still not enough knowledge and support for people with dementia and mild cognitive impairments (MCI). The issue of stigmatisation is being raised in many ways worldwide. There are language guidelines to use in official documents by researchers, politicians and media²⁻⁴, publications debating on stigma in dementia⁵⁻⁸, and scientific articles describing the views of GPs and other medical and non-medical professionals, as well as the informal carer and societal perspective⁹⁻¹¹. However, the perspective of people with dementia¹²⁻¹⁶ is still rarely investigated. According to Werner⁵ people with dementia experience stigma on an emotional, cognitive and behavioural level. The experienced stigmatisation is negatively correlated with social support and quality of life and the diagnosis of dementia may lead to lower self-esteem, loss of self-control, negative mood like feeling ashamed, embarrassed, guilty and worried^{5,13-15,17}.

Also very little is known about the stigmatisation experience of people living with dementia and MCI in different countries and cultures. A study we conducted recently showed that people in the UK experienced a higher level of stigmatisation than people in Italy and Poland¹⁵. These differences may be connected with the economic development level of countries, ways of social support, family beliefs or media images¹⁸⁻²⁰. The prevalence of behavioural and psychological symptoms of dementia seems to be also higher in more developed countries²¹. This fact may be linked to a higher level of unmet needs, and lead to higher levels of discrimination and stigmatisation^{21,22}.

An important aspect in the research on stigma is trialling different social interventions to find out which could lower the stigmatization experience level among people living with cognitive impairment and dementia. There are various programmes supporting people with dementia, such as Cognitive Stimulation Therapy²³, community based occupational

therapy²⁴, the Meeting Centre Support Programme (MCSP)^{25,26} and dedicated post diagnostic support offered by some countries or regions, which may not only improve the quality of life but also help to reduce the experience of stigma¹⁴. This issue is also raised in the WHO 2017-2025 global action plan on the public response to dementia²⁷.

MCSP aims to deliver tailored care for people with dementia and their families based on their individual needs, wishes and psychosocial diagnosis^{25,26,28,29}.

This article is the first one describing the impact of a social intervention, i.e. the Meeting Centre Support Programme on the experience of stigmatisation by people with dementia.

MATERIALS AND METHODS

Participants and setting

114 people living with dementia (n=74) and MCI (n=40) in Italy, Poland and the United Kingdom, responded to the 'Stigma Impact Scale, neurological disease' (SIS) at two measure points in time. All participants met the inclusion criteria: having a diagnosis of mild cognitive impairment or mild to moderately severe dementia, living in their own home and having a family carer. There were no exclusion criteria regarding age or type of cognitive impairments/dementia.

Study design

A pre/post-test control group study design comparing outcomes for people living with dementia in the participating European countries was applied. People recruited from the MCSP were considered as the experimental group (MCSP) while those receiving usual care (mostly support at home only and/or day care) were considered as the control group (UC).

The study was conducted within the framework of the European, JPND funded, MEETINGDEM – project (2014-2017)²⁸ and approved by the Medical Ethical Committees in all participating countries.

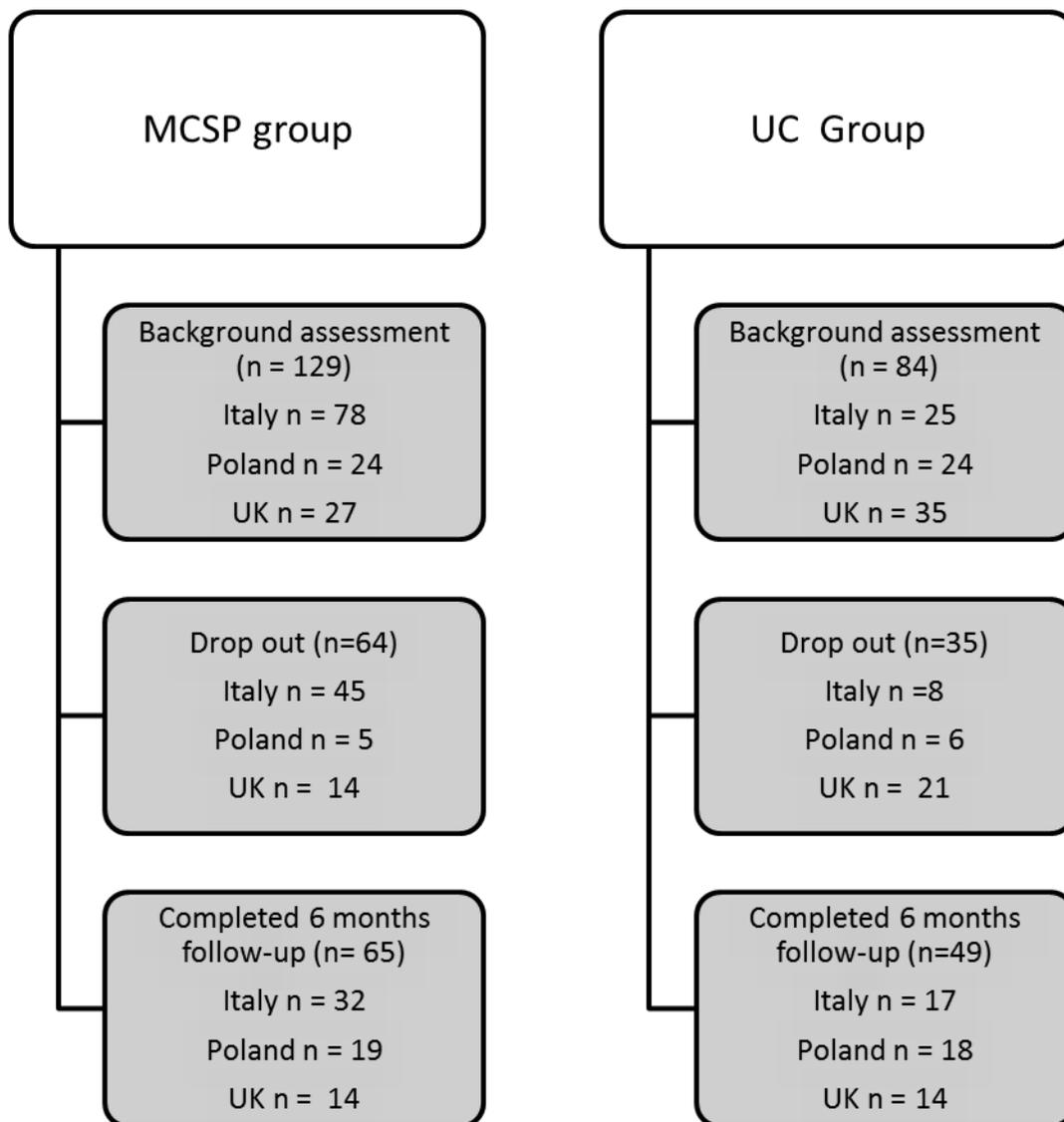


Figure 1 Recruitment process of participants for the study in Italy, Poland and the UK

Meeting Centre Support Programme intervention

The Meeting Centre Support Programme (MCSP) concept was developed 26 years ago in the Netherlands in collaboration with people living with dementia and their carers. It operates on the border of care and welfare based on the theoretical framework of the Adaptation-Coping model^{25,26,30,31}. According to this model, people with dementia and their informal caregivers have to cope with several adaptive tasks (such as dealing with disabilities, maintaining an emotional balance and positive self-image and maintaining social relationships). Depending on the individual adaptation challenges, coping abilities and needs of people with dementia, the support focuses on the cognitive, emotional and/or social

adaptation by means of (re-)activation, promoting the emotional functioning and/or (re-)socialization. The MCSP offers person-centred care, based on the individual wishes, needs and abilities to support people in living well with dementia. Usually, the Meeting Centre (MC) supports about 15 people with dementia plus their families in easily accessible, socially integrated, community locations by means of a variety of support activities like psychomotor therapy, cognitive stimulation and music therapy and by providing informative, practical, emotional and social support for their informal carers (family support groups, psychoeducation and counselling).

MCSP was shown to be effective for people with dementia and their carers in research and practice. Compared to those using traditional day care, after 7 months of participation in MCSP, people with dementia showed fewer behavioural and mood problems (less inactivity, unsocial and depressed behaviour, higher self-esteem) and nursing home admission²⁶ was delayed. There was a correlation noticed between increased levels of attendance and a significant reduction in symptoms of distressing behaviour and greater feelings of support^{25,26,32}.

MCSP was successfully implemented in Italy, Poland and the UK after a 12-month preparation phase involving collaboration between local organisations working for elderly people and those living with dementia^{28,33,34}. Five Meeting Centres (MC) were opened in Italy (Lombardia and Emilia-Romagna regions), two in Poland (Wroclaw region), and two in the UK (Central England). MCSP was offered three days per week in Poland and the UK and 3 half-days to 2 days per week in the Meeting Centres in Italy. Usually, 10 to 15 dyads (people with dementia/family members) participated in the support programme in each MC. The MCSP in each country was implemented to a high degree of accuracy conforming to the original Dutch model. However, several cultural adaptations were made in each participating country²⁵.

Instruments

The 'Stigma Impact Scale (SIS), neurological impairments'¹² was used to measure the level of stigmatisation. This instrument consists of 21 items divided into 3 subscales: Social Rejection (SR; 9 items), Internalised Shame (IS; 5 items) and Social Isolation (SI; 7 items). The Financial Insecurity subscale (3 items) was not included in this study as it is supposed to be less

relevant for a retired, older population and had low internal consistency¹². A higher score (range 0-84) indicates a higher level of perceived stigmatisation.

The internal consistency of the SIS and its subscales was tested for all translated measurements. The obtained Cronbach's alphas varied from 0.85 for the British version UK to 0.92 for the Italian version. Detailed values for all subscales are presented in Table 1.

[Table 1]

Additionally the Global Deterioration Scale (GDS) was used to assess the severity of cognitive impairment where 1 indicates no cognitive problems and 7 - very severe cognitive problems³⁵.

Procedure

All participants received information about the aim of the study, and expressed written consent before the start of the data collection. Self-report questionnaires were used and people living with dementia or mild cognitive impairments were interviewed twice by trained researchers, at the beginning of participation in the MCSP or UC and after 6 months between May 2015 and November 2016. Interviews were conducted in one or two sessions. Total Interview duration was between 30 minutes and two hours. Level of cognitive impairment was assessed by the researchers based on an interview with the informal carers of the people with living with dementia. To be able to detect moderate statistical significant differences between countries with a power of 0.80 and alpha of 0.05 64 participants per country were required³⁶. Taking into account an expected dropout of 20% in 6 months we aimed to recruit at least 80 participants per group (experimental/control).

Statistical analysis

The analysis was done using R for Windows (version 3.5.3)³⁷. A significance level of alpha smaller or equal than 0.05 was used. Differences between MCSP and UC groups were analysed for all participants and each country separately using the Kruskal-Wallis test with Conover post-hoc analysis (for ordinal and interval variables) and Fisher exact test with multiple comparisons post-hoc analysis or Pearson's Chi squared test with Yate's continuity (for nominal variables). The analysis of the impact of the interventions (MCSP vs. UC) on the changes in the level of stigmatisation (SIS and its subscales) was made with the linear mixed

models, with subject id as a random effect, taking into account differences in background characteristics (GDS level for Italian participants and education level for the whole group) at baseline. Additionally Cohen's f^2 was used to calculate the clinical effect sizes. The analysis was conducted only on participants who completed SIS at baseline and follow-up in each group.

RESULTS

Background characteristics

From the recruited participants (n=114) 65 participated in the Meeting Centre Support Programme (MCSP) while 49 received the usual care (UC). In both groups over 60% of participants were women (61.54% for MCSP and 63.27% for UC). There were no significant statistical differences in age between MCSP and UC participants. The mean age was 78.01 ± 7.46 (median 78.92) for the MCSP participants and 78.13 ± 7.37 (median=78) for UC participants ($p=1$).

Participants recruited to MCSP and UC groups statistically differed ($p=0.04$) in education level. More people from MCSP obtained secondary or higher education (56.25%) than from UC (51.02%). Vocational, primary or less than primary education was obtained respectively by 43.75% and 48.98% of participants.

The majority people with dementia in both groups were married (60% in MCSP and 55.1% in UC) or widowed (33.85% and 34.69% respectively). The Italian population was overrepresented in the MCSP group (n=32 in MCSP and n=17 in UC), where Polish (n=19 in MCSP and n=18 in UC) and British (n=14 in MCSP and n=14 in UC) groups were more equal in number. Detailed background characteristics are presented in the Table 2.

[Table 2 here]

The mean level of cognitive decline among people recruited into MCSP group was 3.75 (± 1.09) and 3.73 (± 1.09) into UC which indicates the border between mild cognitive decline and moderate cognitive decline/mild dementia according to GDS stages. Participants in Italy scored respectively 3.67 (± 1.02) and 4.41 (± 0.62). The mean GDS scores of people recruited in Poland was 3.74 (± 0.99) in MCSP and 3.39 (± 1.20) in UC and of people in the UK

respectively 4 (± 1.41) and 3.31 (± 1.03). There was no significant differences between the MCSP and UC groups in the level of cognitive decline among the whole group. However, a significant difference in GDS scores was noticed for Italian participants ($p=0.006$). Detailed GDS characteristics are presented in Table 3.

[Table 3 here]

Level of the experienced stigmatisation among people with dementia and MCI at baseline

The mean level of stigmatisation (SIS total) among study participants from MCSP was 32.25(± 9.33) and 34.41(± 10.96) from UC.

People with dementia and MCI in the UC group (mean= 13.47 ± 4.87 ; median=13; $Q_1=10$; $Q_3=16$) showed a statistically significantly higher level ($p=0.02$) of Social Rejection than those from MCSP (mean= 11.71 ± 3.77 ; median=11; $Q_1=9$; $Q_3=14$) at baseline. At baseline, people using UC (mean= 17.64 ± 3.89 ; median 16.5; $Q_1=14.25$; $Q_3=20$) in the UK showed a statistically higher level ($p=0.003$) of Social Rejection (mean= 12.07 ± 3.25 ; median=12; $Q_1=9.25$; $Q_3=15.5$) than those using MCSP. People living with dementia and MCI in Poland and Italy participating in the MCSP or UC group did not differ from each other on the level of stigma and its subscales.

The mean level of Social Isolation was 13.11(± 4.41) for those participating in MCSP and 13.31(± 4.42) in UC. The mean level of Internalised Shame was 7.43(± 2.66) for MCSP group and 7.63(± 2.88) for UC.

There were no other statistically important differences between MCSP and UC overall and in the general level of reported stigmatisation between people living with dementia and MCI in the different countries at baseline. Detailed description of the stigma results are presented in Table 4.

Comparison of stigma outcome measures of MCSP and UC groups

Overall group level

Overall statistical analysis did not show any significant differences between MCSP and UC at pre/post-test analyses, neither in the Stigma Impact Scale or its subscales. Detailed results

are presented in Table 4. There were also no statistical significant differences after including the education level as a covariate in the analysis.

[Table 4 here]

Italy

In participants in Italy, the analysis did not show a statistical difference between MCSP and UC in time, although the level of SIS total score ($p=0.02$) and Social Isolation ($p=0.03$) were significantly lower in the MCSP group after (SIS mean= 28.41 ± 9.75 ; SI mean= 11.5 ± 4.57) the intervention than before (SIS mean= 32.41 ± 9.37 ; SI mean= 13.38 ± 4.27). There were no other statistically significant changes in time, also after including differences in cognitive decline level between participants as a covariant in the analysis.

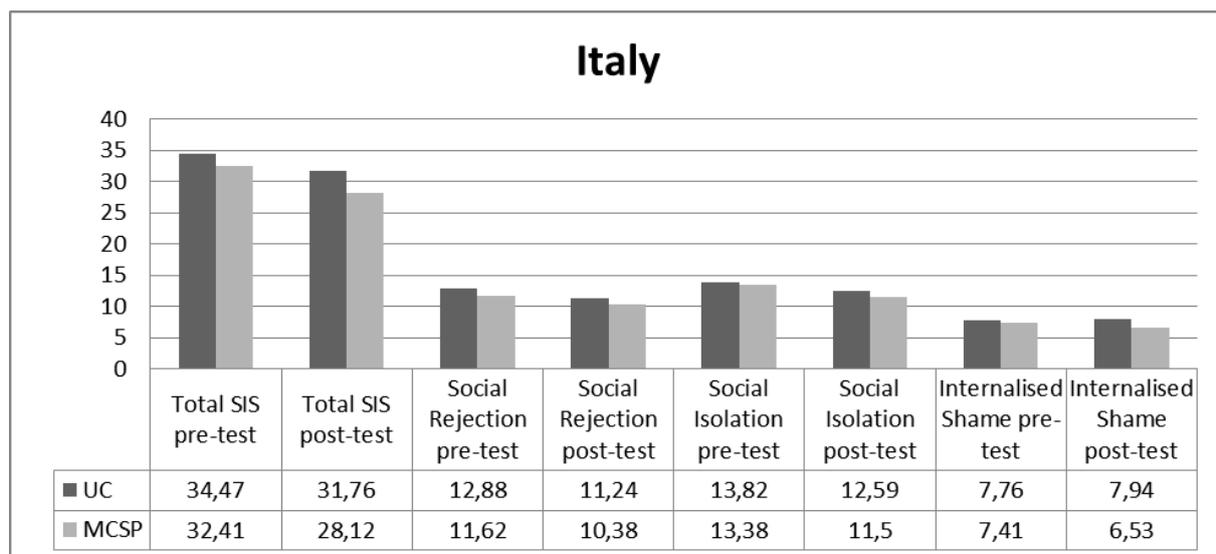


Figure 2 The mean results on Social Impact Scale (SIS) and its subscales in Italy (UC n=17; MCSP n=32)

Poland

Among participants from Poland, statistical significant differences were found between MCSP and UC at pre/post-test analysis in Social Isolation among people living with dementia and MCI. The level of Social Isolation increased statistically significantly more ($p=0.05$) in the UC group between baseline and follow-up (*pre-test* mean= 11.61 ± 3.01 ; *post-test* mean= 13.33 ± 3.51) than in the MCSP group (mean= 12.53 ± 4.57 ; *post-test* mean= 13.58 ± 5.08).

Additionally, it was observed that the overall level of stigmatisation raised in time in both, MCSP and UC groups, but these changes were not statistically significant.

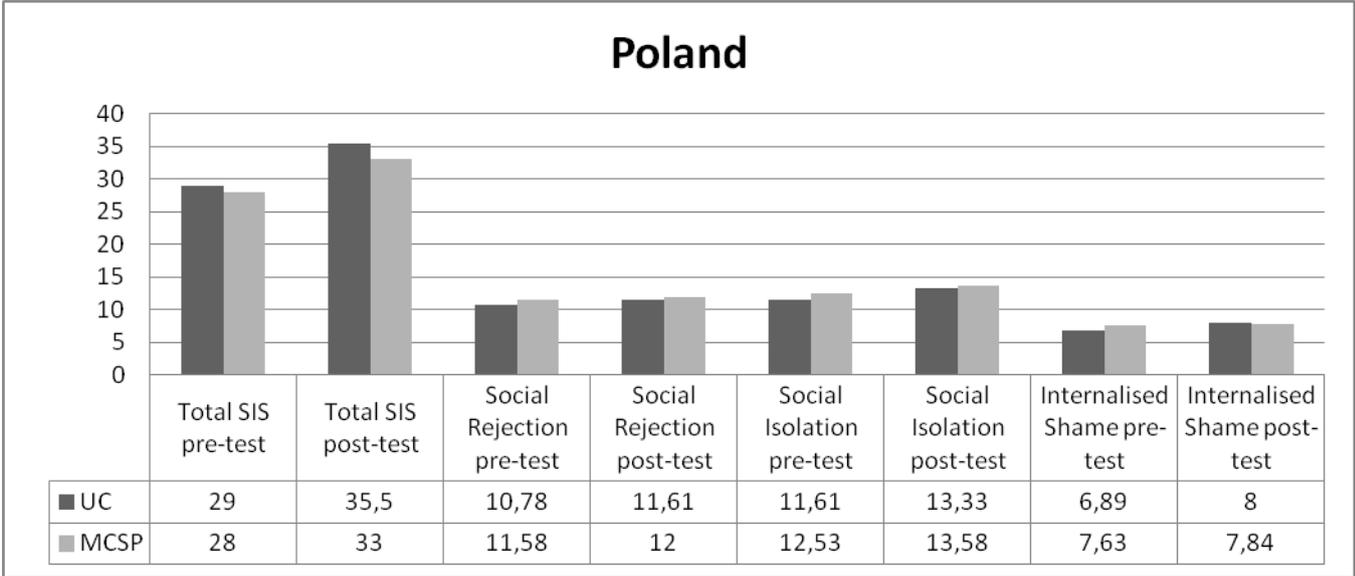


Figure 3 The mean results on Social Impact Scale (SIS) and its subscales in Poland (UC n=18; MCSP n=19)

The United Kingdom

Pre/post-test analysis showed that the level of Social Rejection in participants in the United Kingdom significantly raised ($p=0.03$) among participants in MCSP (*pre-test* mean=12.07±3.25; *post-test* mean=13.86±4.87) compared to the UC group (*pre-test* mean=17.64±3.89; *post-test* mean=16.29±4.51). There were no other statistically significant changes in the level of stigmatisation in the UK.

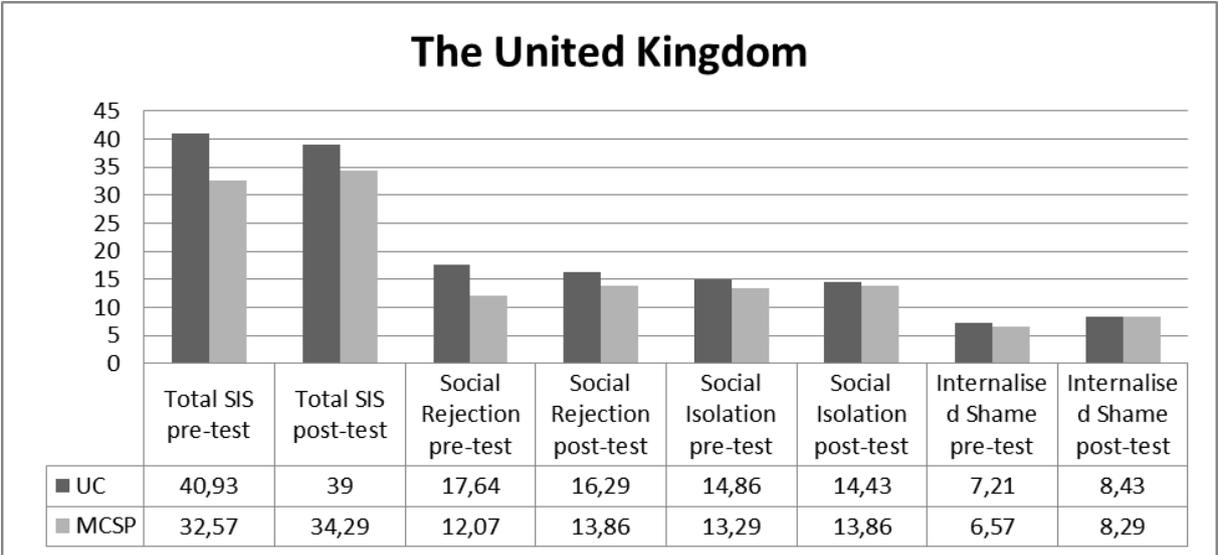


Figure 4 The mean results on SIS and its subscales in the UK (UC n=14; MCSP n=14)

DISCUSSION

This is the first study which focused at the role and impact of a psychosocial intervention, i.e. the Meeting Centre Support Programme for people living with dementia and MCI, on the experienced stigmatisation in three different European countries.

Participants recruited from Italy, the UK and Poland were comparable regarding their sociodemographic characteristics, except for the level of education. Participants in the UK overall had a lower level of education than those from Poland and Italy. Similar to previous findings no relationship was found between the level of stigmatisation and educational level in these countries ¹⁵.

Except for social rejection, people living with dementia and MCI participating in MCSP and UC experienced a comparable level of stigmatisation, overall and on the SIS subscales. The overall greater experienced social rejection in the UC group was mainly caused by the higher experienced social rejection of UC participants in the UK, which influenced the results in the whole sample.

The obtained levels of experienced stigmatisation in this study seems to be relatively low (taking into account the 0-84 range of the SIS). However, the results are similar to the data obtained in studies previous studies conducted in the USA, the UK, Poland and Italy that used the Stigma Impact Scale among people with dementia ^{12,14,15,38,39}. For example, the recently published study by Ashworth (2017) describing the stigmatisation experience of people living with dementia in Scotland (UK) using the Stigma Impact Scale presented comparable results to those obtained in our sample. In general, people with dementia and MCI from Poland, Italy and the UK enrolled into this study scored even lower on all subscales. Only people participating in the UC group in the UK scored slightly higher, comparing reported means, on the whole scale than presented by Ashworth (2017) (UK 40.93±7.49 vs. 38.4±6.4) as well as on Social Rejection (UK: 17.64±3.89 vs. 15.7±3.7) and Social Isolation (UK: 14.86±3.8 vs.13±2.5)¹⁴. Other research suggests that people with dementia may give more positive (social desirable) answers and only detailed interview may

provide a clear answer about their real experience⁴⁰ and this may explain the relatively low scores in SIS.

There is no evidence from this study that the level of stigma decreased or increased after six months of participating in the MCSP compared to UC, taking into account the whole study sample. However, it seems that the stigmatisation is closely related to cultural aspects⁴¹ and it is therefore important to look more in detail to the analysis on a country level. In Poland, the level of stigmatisation raised (not statistically significantly) in time among all people living with dementia and MCI. People participating in the UC in Poland scored statistically significantly higher on Social Isolation in the post-test than people using MCSP. Similarly, in the Italian group using MCSP the total level of stigmatisation and social isolation was reduced after 6 months period. However, the difference was not statistically significant when compared to the UC group. These results may suggest that the MCSP intervention, even if it did not help to reduce the overall level of stigmatisation, may help to prevent an increase in the feeling of social isolation by providing tailored social support²⁵. This is particularly notable in Poland, where the topic of stigma in dementia was not discussed in the scientific and clinical context until recently^{1,15} and still does not exist in public discussion. This is a positive outcome which needs further investigation as social isolation, apart from being associated with depression, is correlated with accelerated cognitive decline and feelings of loneliness which may, in turn, lead into higher mortality risk^{42,43}.

Interesting and surprising results were obtained in the UK. The level of experienced social rejection increased over time among people using MCSP compared to those participating in UC.

Given the small country sample size it is most likely that these effects were not directly attributable to the intervention itself. There is the possibility, however, that attending the MCSP may actually lead people to become more aware of feelings of social rejection. Paradoxically, the cultural differences between countries related to the acceptance of people living with disabilities, including dementia, may be a possible explanation. People in the UK generally have much easier access to movies, books and other media in the English language presenting cultural metaphors of dementia^{18,19} than people in Italy and Poland. These images often do not present disabilities in a positive way. Living in a more traditional

society, where dementia may be still treated as a normal part of ageing (more likely to happen in Poland or Italy) may prevent people living with this disease from social rejection and the feeling of being socially isolated^{18,20}.

The obtained results from this study do not provide a clear answer, if a social support programme like MCSP reduces the experienced stigmatisation among people living with dementia and MCI. However, it gives ground for further intercultural investigations.

STUDY LIMITATIONS

The study had several limitations. It was conducted within a European research project and people with dementia and MCI involved in the study may have been more motivated and more involved in the society as they volunteered to join the project. Therefore the sample can be considered as selective, which limits the possibility to generalise the results to all people living with cognitive impairments in Italy, Poland and the United Kingdom. There might be other reasons why people with dementia and MCI participating in the MCSP programme may present lower levels of experienced stigmatisation. One of them may be the fact that they have accepted living with this disease and they are telling the “positive story”⁴⁰. On the other hand, using MCSP and obtaining “special” and a dedicated type of care might make some people feel more stigmatised.

The sample was also relatively small and the minimum of 64 participants on a country level to show statistical significant moderate differences was not obtained³⁶. This means that on a country level the study was underpowered. Calculations based on Cohen’s f^2 shows that for the obtained small effects of 0.02 around 500 observations would be needed to have a power of 0.8 to show statistical significant differences; for the medium effect of 0.15 around 67 observations would be needed, and for the large effect of 0.2 around 50 observations would be needed per group³⁶. This is important to take into account in future studies into the effect of psychosocial interventions on stigma.

The awareness of people with dementia’s condition was not taken into account in this study. As other research has raised this as an important issue^{40,44,45} this variable would be an important addition to further research on the subject of stigma. As suggested in other

research¹⁴, the results on questionnaires may be also lower than the stigma experiences revealed in individual face to face interviews.

Another limitation of the study is the quality of the Stigma Impact Scale questionnaire. It is the only standardised measurement available for assessing stigma experience among people living with dementia worldwide to date. SIS was developed from the HIV stigma questionnaire and adapted into a version for people living with neurological disorders – the first study with SIS compared the stigma experience of people with Alzheimer’s disease and Parkinson’s diseases¹². People with different neurological disorders face different difficulties which may influence their stigmatisation experience as well, even dementia is a wide term and each person living with this diagnosis experiences difficulties in different ways. This need for research which better identifies and measures stigma was also raised by other authors¹⁶.

The SIS scale contains items that reflect the negative aspects of living with dementia. Other research investigating psychosocial interventions suggests the improvement in positive aspects of quality of life, positive emotions, support from the social network, met needs^{25,46,47}, social inclusion⁴⁸ or learning more about oneself⁴⁹ are relevant for dealing with the consequences of dementia and therefore may also impact the experience of stigmatisation.

CONCLUSIONS AND FUTURE DIRECTIONS

There is a need for more comprehensive research describing the experience of stigmatisation from the perspective of people living with dementia in different countries and an investigation of how support programmes dedicated to people with dementia influence this issue. Also the experienced stigma by informal carers is not yet widely investigated in European Countries.

The research results suggest the need of developing a better tool to measure the stigma experience by people with dementia and MCI, to investigate in detail their perception of stigma and stigmatisation and if and how they experience stigmatising behaviours, feelings and attitudes in their everyday life. Asking people with dementia about their perspective, about their experiences, their needs in interviews or while designing a new questionnaire will help them to express their perspective more clearly. This, in turn, will help to prepare

solutions in social care, to inform social campaigns and finally to reduce the stigma of dementia⁵⁰.

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