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Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits?

This is the final peer-reviewed author's accepted manuscript (postprint) of the following publication:

*Published Version:*

Lion K.M., Szczesniak D., Bulinska K., Mazurek J., Evans S.B., Evans S.C., et al. (2021). Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits?. *AGING & MENTAL HEALTH*, 25(1), 160-169 [10.1080/13607863.2019.1683815].

*Availability:*

This version is available at: <https://hdl.handle.net/11585/741932> since: 2020-02-29

*Published:*

DOI: <http://doi.org/10.1080/13607863.2019.1683815>

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(Article begins on next page)

This is the final peer-reviewed accepted manuscript of:

**Lion KM, Szcześniak D, Bulińska K, Mazurek J, Evans SB, Evans SC, Saibene FL, d'Arma A, Scorolli C, Farina E, Brooker D, Chattat R, Meiland, FJM, Dröes RM, & Rymaszewska J. (2019). Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits? *Aging & Mental Health* 2019.**

**Accepted 18 Oct 2019, Published online: 07 Nov 2019**

The final published version is available online at:

<https://doi.org/10.1080/13607863.2019.1683815>

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**Title:** Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits?

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## **CONFLICT OF INTEREST**

None

## **ACKNOWLEDGEMENTS**

The authors would like to highly appreciate the effort in collecting data by Mateusz Babicki and Katarzyna Osyra among people with dementia in Poland.

## **DECLARATION OF SOURCES OF FUNDING**

1. The work was supported by the framework of research aimed at promoting young scientists, funded by the Ministry of Science and Higher Education, Poland under the grant number STM.C230.16.020.
2. The MeetingDem project was supported by the following funding organisations under the aegis of Joint Programme - Neurodegenerative Disease Research (JPND\_HC-559-018):

The Netherlands: ZonMw under grant number: 733051002,

Italy: Ministero dell'Istruzione, dell'Università e della Ricerca (MIUR) (Ministry of Education, University and Research) under grant number: CUP: B32I14000470001 and Ministero della Salute - Codice Progetto (Ministry of Health) under grant number RRC-2013-2353248

Poland: Narodowe Centrum Badań i Rozwoju (National Centre for Research and Development) under grant number: DZP/1/JPND-II/2014

The United Kingdom: Economic and Social Research Council under grant number: ES/L00920X/1.

## **ABSTRACT**

**OBJECTIVES:** This is the first study to focus on 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, social support, attitude

## 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 diagnosed people and their relatives (Urbańska, Szcześniak, & Rymaszewska, 2015). Even though more and more countries implement national dementia strategies, there is still not enough public knowledge about dementia, its prevention, diagnosis and available support for people living with dementia and mild cognitive impairments (MCI) (Alzheimer's Disease International, 2019). This seems closely related to the still existing taboo on dementia and the issue of stigmatisation. Worldwide actions are undertaken to counteract the stigmatisation in dementia in many ways. For example, in many countries dementia-friendly language guidelines to be used in official documents by researchers, politicians and media were published (e.g. Dementia Australia, 2009). The number of scientific publications on stigma in dementia is growing (Milne, 2010; Swaffer, 2014; Werner, 2014), including articles describing the views of GPs and other medical/non-medical professionals (Gove, Downs, Vernooij-Dassen, & Small, 2016; Gove, Small, Downs, & Vernooij-Dassen, 2017) or informal carers' and societal perspectives (Herrmann, Udelson, et al., 2018). To date however, the perspective of people with dementia is still rarely investigated (Ashworth, 2017; Burgener & Berger, 2008; Herrmann, Welter, et al., 2018; Lion et al., 2019; Riley, Burgener, & Buckwalter, 2014; Swaffer, 2014). According to Werner (2014) 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 (Ashworth, 2017; Devlin, MacAskill, & Stead, 2007; Lion et al., 2019; Riley et al., 2014; Werner, 2014).

Very little is known about the stigmatisation experience of people with dementia in different countries and cultures. A study we conducted recently showed people in the UK experienced a higher level of stigmatisation than people in Italy and Poland (Lion et al., 2019). These differences may be connected with the economic development level of countries, ways of social support, family beliefs or media images (Hillman & Latimer, 2017; Lasalvia et al., 2015; Zeilig, 2014).

Despite the increasing number of research and publications on stigma in dementia there are still no clear definitions of the terms *stigma* and *stigmatisation* (see Urbańska et al., 2015). The complexity of stigma in dementia definition was also raised by Alzheimer's Disease

International Report: Attitudes to Dementia (Alzheimer's Disease International, 2019). For the purpose of this study The Modified Labelling Theory by Link and colleagues (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) and its operationalisation in dementia (Burgener & Berger, 2008; Fife & Wright, 2000) was used. This theoretical framework takes into account the individual perception of being stigmatised as well as the experience of being treated with stigmatising behaviour. Based on this theory, the stigmatisation is composed of four elements: financial insecurity, social rejection, internalised shame and social isolation (Burgener & Berger, 2008; Fife & Wright, 2000; Link et al., 1989).

An important aspect in the research on stigma is trialling different psychosocial interventions to find out which could decrease the stigmatization experience level among people with cognitive impairment. There are various programmes supporting people with dementia, such as the Meeting Centre Support Programme (MCSP) (Brooker et al., 2018; Dröes, Meiland, Schmitz, & van Tilburg, 2004), and dedicated post diagnostic support offered by some countries/regions, which may improve quality of life and help to reduce the experience of stigma (Ashworth, 2017). This issue is also raised in the WHO 2017-2025 global action plan on the public response to dementia (WHO, 2017a).

This article is the first one describing the impact of a psychosocial intervention, the MCSP, on the experience of stigmatisation by people with dementia.

## **METHODS**

### *Participants and setting*

114 people with dementia (n=74) and MCI (n=40) in Italy, Poland and the UK, 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 MCI 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.

### *Recruitment*

The study was conducted within the framework of the European, JPND funded, MEETINGDEM – project (2014-2017) (Dröes, Meiland, et al., 2017) and approved by the Medical Ethical Committees in all participating countries. Participants for the study on stigmatisation were recruited from those participating in the MEETINGDEM project willing to take part in the study. From the 213 people assessed on background characteristics at baseline 99 people dropped out from the study because of different reasons including withdrawing consent, health deterioration or death as illustrated in Figure 1.

### *Study design*

A pre/post-test control group study design comparing outcomes for people 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).

[Figure 1]

### *Meeting Centre Support Programme intervention*

The Meeting Centre Support Programme (MCSP) concept was developed 26 years ago in the Netherlands in collaboration with people with dementia and their carers. It operates on the border of care and welfare based on the theoretical framework of the Adaptation-Coping model (Brooker et al., 2018; Dröes, 1991; Dröes et al., 2004; Dröes, Van Der Roest, Van Mierlo, & Meiland, 2011). According to this model, people with dementia and their informal caregivers have to cope with several adaptive tasks (such as dealing with disabilities and maintaining an emotional balance, positive self-image and social relationships). Depending on the individual adaptation challenges, coping abilities and participants' needs, 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, music therapy and by providing informative, practical, emotional and social support for their carers (family support groups, psychoeducation and counselling).

MCSP was shown to be effective for people with dementia and 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 admission (Dröes et al., 2004) was delayed. A correlation was found between increased levels of attendance and a reduction in symptoms of distressing behaviour and greater feelings of support (Brooker et al., 2018; Dröes, Meiland, Schmitz, & Van Tilburg, 2005; Dröes et al., 2004).

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 people with dementia (Dröes, Meiland, et al., 2017; Mangiaracina et al., 2016; Van Mierlo et al., 2017). In the MEETINGDEM project five MCs 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 Italy. Usually, 10-15 dyads (people with dementia/family members) participated in the programme in each MC. The MCSP in each country was implemented to a high degree of accuracy corresponding to the original Dutch model. However, several cultural adaptations were made in each participating country (Brooker et al., 2018).

### *Instruments*

The 'Stigma Impact Scale, neurological impairments' (SIS) (Burgener & Berger, 2008) was used to measure the level of stigmatisation. The 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 consistency (Burgener & Berger, 2008). A higher score (range 0-84) indicates a higher level of perceived stigmatisation. This also applies for the subscales: Social Rejection (range 0-36), Social Isolation (range 0-28) and Internalised Shame (range 0-20).

The Stigma Impact Scale was translated and adapted into the Polish and Italian language based on the formal criteria of the translation of psychological questionnaires following the WHO recommendations (WHO, 2017b). The translated versions used in this study were also used in our previous study into stigma (Lion et al., 2019). The internal consistency of the SIS and its subscales was tested: Cronbach's alphas varied from 0.85 for the British version 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 problems (Reisberg, Ferris, De Leon, & Crook, 1982). For the Polish and Italian participants existing Polish and Italian versions of the GDS were utilized (Barcikowska, 2011; Brooker et al., 2018).

### *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 with dementia or MCI 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. The level of cognitive impairment was assessed by researchers based on an interview with informal carers of people 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 required(Cohen, 1988). 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)(R Core Team, 2019). 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  $78.01 \pm 7.46$  (median 78.92) for the MCSP participants and  $78.13 \pm 7.37$  (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 of 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 Table 2.

[Table 2 here]

The mean level of cognitive decline among people recruited into MCSP group was 3.75( $\pm$ 1.09) and into UC 3.73( $\pm$ 1.09), which indicates on the border between mild cognitive decline and moderate cognitive decline/mild dementia according to the GDS stages. Participants in Italy scored respectively 3.67( $\pm$ 1.02) and 4.41( $\pm$ 0.62). The mean GDS scores of people recruited in Poland was 3.74( $\pm$ 0.99) in MCSP and 3.39( $\pm$ 1.20) in UC and of people in the UK respectively 4( $\pm$ 1.41) and 3.31( $\pm$ 1.03). On the whole there was no significant difference in the level of cognitive decline between the MCSP and UC group. However, a significant difference in mean GDS score was noticed for the Italian group ( $p=0.006$ ). 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( $\pm$ 9.33) and from UC 34.41( $\pm$ 10.96).

People with dementia and MCI in the UC group (mean=13.47 $\pm$ 4.87; median=13;  $Q_1=10$ ;  $Q_3=16$ ) showed a statistically significant higher level ( $p=0.02$ ) of Social Rejection than those from MCSP (mean=11.71 $\pm$ 3.77; median=11;  $Q_1=9$ ;  $Q_3=14$ ) at baseline. At baseline, UC users (mean=17.64 $\pm$ 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 $\pm$ 3.25; median=12;  $Q_1=9.25$ ;  $Q_3=15.5$ ) than those using MCSP. People 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 levels of Social Isolation was 13.11( $\pm$ 4.41) for MCSP participants and for UC users 13.31( $\pm$ 4.42). The mean level of Internalised Shame was 7.43( $\pm$ 2.66) for the MCSP group and 7.63( $\pm$ 2.88) for the UC group.

Overall there were no other statistically significant differences between MCSP and UC p or in the general level of reported stigmatisation between people with dementia and MCI in the different countries at baseline. Detailed description of the stigma results is 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 SIS 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 levels of SIS total score ( $p=0.02$ ) and Social Isolation ( $p=0.03$ ) were significantly lower in the MCSP group after (SIS mean= $28.41\pm 9.75$ ; SI mean= $11.5\pm 4.57$ ) the intervention than before (SIS mean= $32.41\pm 9.37$ ; SI mean= $13.38\pm 4.27$ ). There were no other statistically significant changes in time, nor after including cognitive decline level as a covariate in the analysis.

[Figure 2]

### *Poland*

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

Additionally, the overall level of stigmatisation raised in time in both groups, but these changes were not statistically significant.

### *The United Kingdom*

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

## **DISCUSSION**

This is the first study which focused on the role and impact of a psychosocial intervention, MCSP for people with dementia and MCI, on the experienced stigmatisation in three different European countries.

Participants recruited from Italy, Poland and the UK were comparable regarding their sociodemographic characteristics, except for the level of education. British participants 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 (Lion et al., 2019).

Except for social rejection, participants 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 levels of experienced stigmatisation in this study seems to be relatively low (taking into account the 0-84 SIS range). However, the results are similar to the data obtained in previous studies conducted in the USA, the UK, Poland and Italy that also used the SIS (Ashworth, 2017; Burgener & Berger, 2008; Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015; Lion et al., 2019). For example, the recently-published study by Ashworth (2017). In general, people with dementia and MCI from Poland, Italy and the UK enrolled into our study scored even lower on all subscales. On the whole scale only the British UC participants from our sample scored slightly higher than the sample presented by Ashworth (2017) (UK:  $40.93 \pm 7.49$  vs.  $38.4 \pm 6.4$ ), on Social Rejection (UK:  $17.64 \pm 3.89$  vs.  $15.7 \pm 3.7$ ) and Social Isolation (UK:  $14.86 \pm 3.8$  vs.  $13 \pm 2.5$ ) (Ashworth, 2017). Other research suggests that people with dementia may give more positive (social desirable) answers when questionnaires are used and only in depth interviews may provide a clear answer about their real experience (Steeman, Godderis, Grypdonck, De Bal, & De Casterlé, 2007) This may explain the relatively low scores in SIS.

Although 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, there seemed to be cultural differences in stigmatisation experience between the participants in the three countries (see also Cipriani & Borin, 2015). In Poland, the level of stigmatisation (although not statistically significantly) raised in time among all participants. However, the UC users in Poland scored statistically significantly higher on Social Isolation in the post-test than the MCSP participants. In the Italian MCSP group the total level of stigmatisation and social isolation reduced after 6 months intervention. However, the decrease was not statistically significant compared to the UC group. These results 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 support (Brooker et al., 2018). This is particularly notable in Poland, where until recently the topic of stigma in dementia was not at all discussed in the scientific and clinical context (Lion et al., 2019; Urbańska et al., 2015) and still does not exist in the 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 a higher mortality risk (Luo, Hawkey, Waite, & Cacioppo, 2012).

Interesting and surprising results were obtained in the UK. The level of experienced social rejection increased over time among MCSP users 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 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 (Hillman & Latimer, 2017; Zeilig, 2014) 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 still be treated as a normal part of ageing (more likely to happen in Poland or Italy) may prevent people with this disease from social rejection and the feeling of being socially isolated (Hillman & Latimer, 2017; Lasalvia et al., 2015).

The obtained results from this study do not provide a clear answer, if a support programme like MCSP reduces the experienced stigmatisation among people 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 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 with cognitive impairments in Italy, Poland and the UK. There might be other reasons why the MCSP participants 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” (Steeman et al., 2007). 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 obtained (Cohen, 1988). 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 group (Cohen, 1988). 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 (Aalten, Van Valen, Clare, Kenny, & Verhey, 2005; Steeman et al., 2007) this variable would be an important addition to further research on the subject of stigma. As mentioned before and suggested by other researchers (Ashworth, 2017), the results on questionnaires may also be 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 with dementia worldwide to date. SIS was developed from the HIV stigma questionnaire (Fife & Wright, 2000) and adapted into a version for people with neurological disorders – the first study compared the stigma experience of people with Alzheimer's and Parkinson's diseases (Burgener & Berger, 2008). People with different neurological disorders face other difficulties which may influence their stigmatisation experience as well, even dementia is a wide term and each person with this diagnosis experiences difficulties in different ways. The quality of the instrument could be a possible explanation of the relatively low levels of stigma observed in research using SIS (Ashworth, 2017; Burgener & Berger, 2008; Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu, et al., 2015; Lion et al., 2019). The need for research into instruments that better identify and measure stigma in dementia was also raised by other authors (Herrmann, Welter, et al., 2018).

The SIS scale contains items that reflect the negative aspects of having dementia. Other research investigating psychosocial interventions in dementia suggests that the improvement in positive aspects of quality of life, positive emotions, social support and inclusion (Dröes, Chattat, et al., 2017), met needs (Brooker et al., 2018; Mazurek et al., 2019) or learning more about oneself (Clare, 2002) are relevant for dealing with the dementia consequences and therefore may impact the experience of stigmatisation.

## **CONCLUSIONS**

There is a need for more comprehensive research describing the experience of stigmatisation from the perspective of people 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 instrument to measure the stigma experience by people with dementia and MCI, to investigate in detail their perception of stigmatisation, and if and how they experience discriminating behaviours, feelings and attitudes in their everyday life. Asking people with dementia about their perspective, their experiences, their needs in interviews or while designing a new questionnaire will help them to express their view more clearly. This, in turn, will help to prepare solutions in social care, to inform social campaigns and finally to reduce the stigma of dementia (Øksnebjerg et al., 2018).

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## **FIGURE/TABLE LEGENDS:**

**Table 1** Internal consistency analysis: Stigma Impact Scale and its subscales.

**Table 2** Demographical description of the recruited participants (n=114).

**Table 3** Stage of cognitive decline of study participants based on GDS scale at baseline (Reisberg et al., 1982).

**Table 4** The level of experienced stigmatisation (SIS total) among people living with dementia from Italy, Poland and the UK (n=114) and results of the linear mixed models analysis.

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

**Figure 2** The mean results on Social Impact Scale (SIS) and its subscales in Italy (UC n=17; MCSP n=32), Poland (UC n=18; MCSP n=19) and the UK (UC n=14; MCSP n=14).

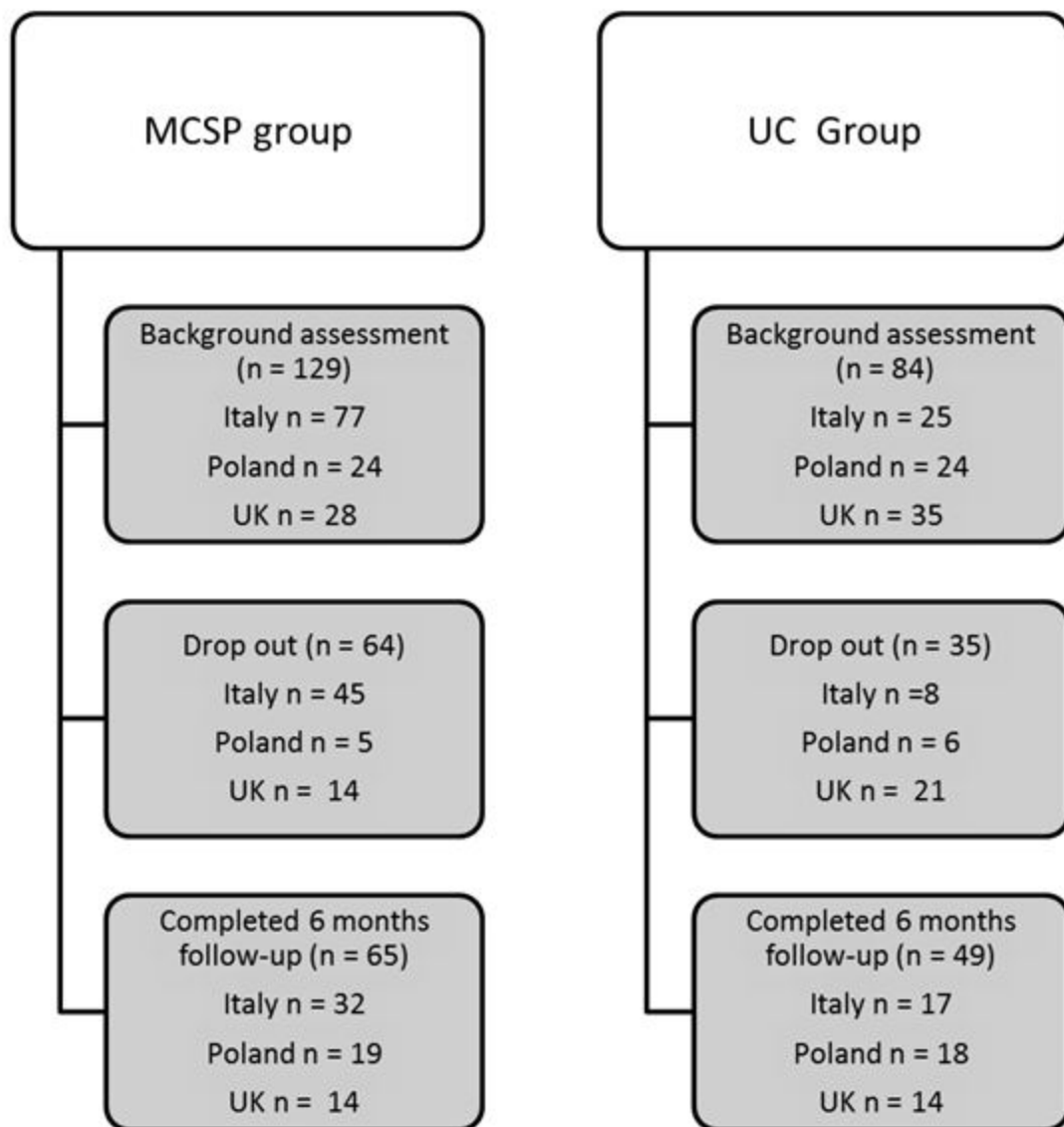
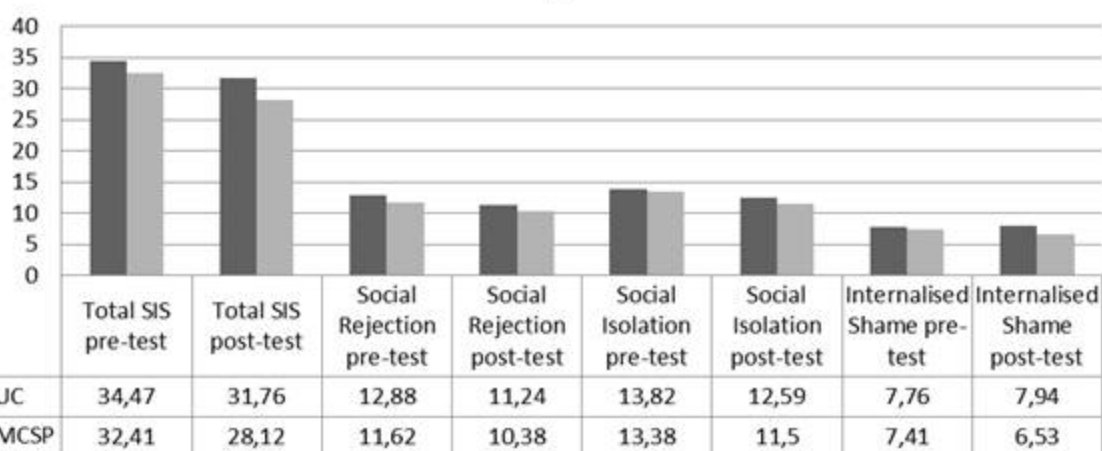
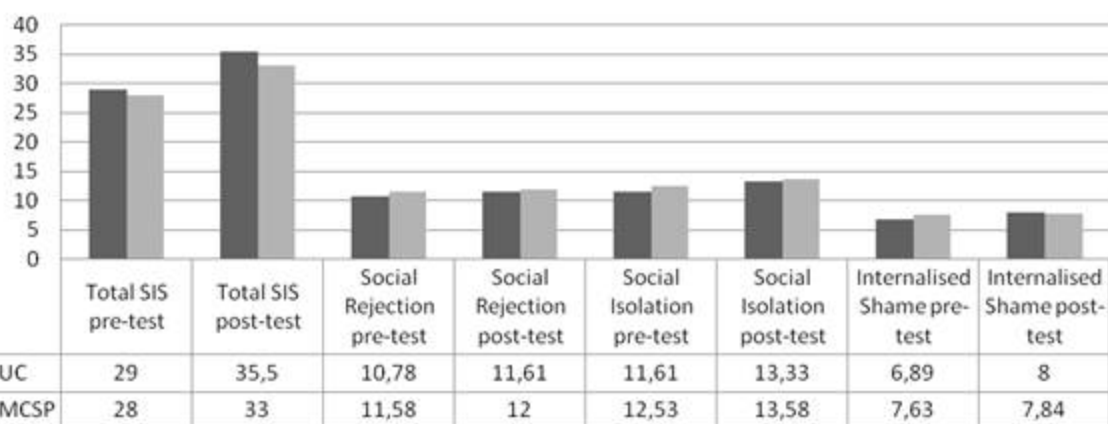


Figure 1 Recruitment process of participants for the study in Italy, Poland and the UK

## Italy



## Poland



## The United Kingdom

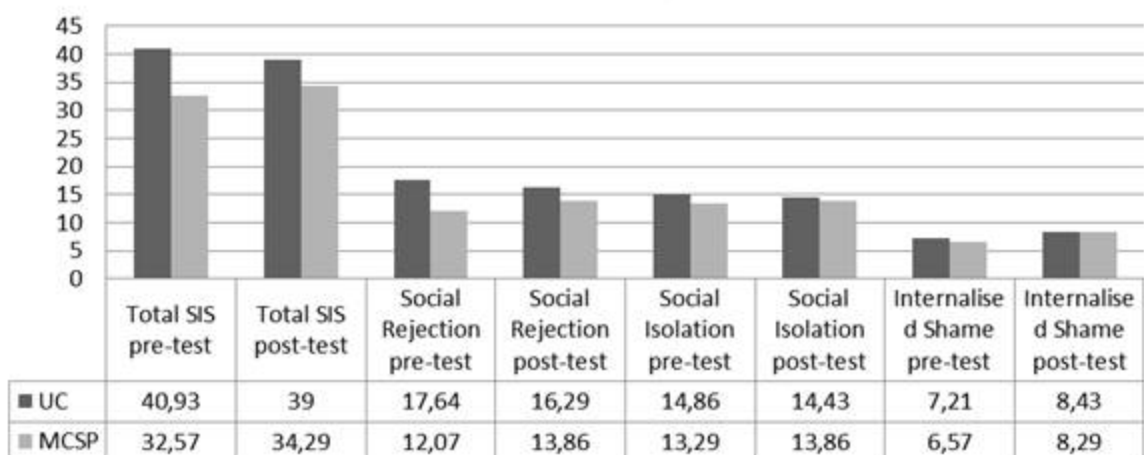


Figure 2 The mean results on Stigma Impact Scale (SIS) and its subscales in Italy (UC n=17; MCSP n=32), Poland (UC n=18; MCSP n=19) and the UK (UC n=14; MCSP n=14).

**Table 1 Internal consistency analysis: Stigma Impact Scale and its subscales**

	Cronbach's alpha			
	Total Sample	Italy	Poland	UK
<b>Stigma Impact Scale</b>	0.90	0.92	0.90	0.85
Social Rejection (9 items)	0.80	0.82	0.80	0.65
Internalized Shame (5 items)	0.76	0.80	0.75	0.69
Social Isolation (7 items)	0.80	0.81	0.84	0.67



**Table 2 Demographical description of the recruited participants (n=114)**

Variable		MCSP		UC		p-value
		N=65	%	N=49	%	
<b>Gender</b>	Female	40	61.54%	31	63.27%	1
	Male	25	38.46%	18	36.83%	
<b>Nationality</b>	Italian	32	49.23%	17	34.69%	0.3
	Polish	19	29.23%	18	36.73%	
	British	14	21.54%	14	28.57%	
<b>Marital status</b>	Married	39	60%	27	55.1%	0.6
	Widowed	22	33.85%	17	34.69%	
	Divorced	1	1.54%	3	6.12%	
	Single	3	4.62%	2	4.08%	
<b>Education</b>	Higher education	19	29.69%	9	18.37%	0.03*
	Secondary education†	17	26.56%	16	32.65%	
	Vocational education‡	10	15.62%	9	18.37%	
	Primary education	15	23.44%	6	12.24%	
	No qualification	3	4.69%	9	18.37%	
		Mean(±SD)	Median(Q <sub>1</sub> -Q <sub>3</sub> )	Mean(±SD)	Median(Q <sub>1</sub> -Q <sub>3</sub> )	p-value
<b>Age</b>	Italy	78.88(±6.78)	80.67(74.62-84)	81.42(±6.57)	81.42(78-85.75)	0.3
	Poland	78.39(±5.23)	77.88(75.15-88.31)	77.34(±7.66)	76.54(71-83.75)	0.6
	UK	75.57(±10.72)	72.5(65.25-84.75)	74.92(±6.66)	77(71-80)	0.9
	All	78.01(±7.46)	78.92(73.21-84)	78.13(±7.37)	78(73.25-84)	1

\*p≤0.05

†secondary education in Poland and Italy/ vocational level 2 in the UK; ‡vocational education in Poland and Italy/vocational level 1 in the UK;

**Table 3 Stage of cognitive decline of study participants based on GDS scale at baseline (Reisberg et al., 1982)**

	MCSP					UC					p-value
	GDS Stage			GDS	GDS	GDS Stage			GDS	GDS	
	<4 (n[%])	4 (n[%])	>4 (n[%])	mean (±SD)	median (Q1-Q3 range)	<4 (n[%])	4 (n[%])	>4 (n[%])	mean (±SD)	median (Q1-Q3 range)	
<b>Italy</b>	14 (43.8%)	12 (37.5%)	6 (18.8%)	3.66 (±1.04)	4 (3-4)	0 (0%)	11 (64.7%)	6 (35.3%)	4.41 (±0.62)	4 (4-5)	0.006*
<b>Poland</b>	8 (42.1%)	6 (31.6%)	5 (26.3%)	3.74 (±0.99)	4 (3-4.5)	7 (38.9%)	9 (50%)	2 (11.1%)	3.39 (±1.20)	4 (3-4)	0.5
<b>UK</b>	5 (35.7%)	2 (14.3%)	7 (50%)	4 (±1.36)	4.5 (3-5)	6 (46.2%)	6 (46.2%)	1 (7.6%)	3.31 (±1.03)	4 (2-4)	0.1
<b>All</b>	27 (41.5%)	20 (30.8%)	18 (27.7%)	3.75 (±1.09)	4 (3-5)	13 (27.1%)	26 (54.2%)	9 (18.7%)	3.73 (±1.09)	4 (3-4)	0.9

Detailed description of cognitive decline stages by Reisberg et al. (1982): 1. no cognitive decline; 2. very mild cognitive decline; 3. mild cognitive decline (MCI); 4. moderate cognitive decline (mild dementia); 5. moderately severe cognitive decline (moderate dementia); 6. severe cognitive decline (moderately severe dementia); 7. very severe cognitive decline (severe dementia); \*p<0.05

**Table 4** The level of experienced stigmatisation (SIS total) among people living with dementia from Italy, Poland and the UK (n=114) and results of the linear mixed models analysis.

	Stigma Impact Scale	Group (n)	Pre-test		Post-test		Linear mixed models analysis – interaction effect			Cohen’s <i>f</i> <sup>2</sup>	
			Mean(SD)	Median (Q1- Q3)	Mean (SD)	Median (Q1- Q3)	Estimate	Std Error	p-value		
Total Score (0-84)	Overall	MCSP(65)	32.25 (9.33)	30(26-40)	31.14(10.41)	29(24-39)	Group MCSP	-2.162	1.97	0.273	0.02
		UC (49)	34.41(10.96)	35(29-40)	34.27(11.11)	35(29-42)	Time follow-up	-0.143	1.31	0.914	
							<b>Group MCSP x time</b>	<b>-0.965</b>	<b>1.74</b>	<b>0.580</b>	
	Italy	MCSP(32)	32.41(9.37)	30 (26-38)	28.41(9.75)	28 (23-32.5)	Group MCSP	-2.06	3.43	0.549	0.01
		UC (17)	34.47(14.05)	39 (29-41)	31.76(14.7)	34(25-44)	Time follow-up	-2.71	2.31	0.248	
							<b>Group MCSP x time</b>	<b>-1.29</b>	<b>2.86</b>	<b>0.653</b>	
	UK	MCSP (14)	32.57(9.14)	33.5(24.25-39.75)	34.29(11.49)	36 (24.75-45.25)	Group MCSP	-8.36	3.50	0.022	0.14
		UC (14)	40.93(7.49)	39(35.5-46.5)	39(8.40)	39.5(34.25-43.5)	Time follow-up	-1.93	2.31	0.411	
							<b>Group MCSP x time</b>	<b>3.64</b>	<b>3.26</b>	<b>0.275</b>	
	Poland	MCSP (19)	31.74(9.88)	28 (24.5-40.5)	33.42(10.01)	33 (24.5-42)	Group MCSP	2.46	2.91	0.401	0.01
		UC (18)	29.28(6.91)	29 (24.25-32.7)	32.94(8.02)	35.5 (25.75-39)	Time follow-up	3.67	1.91	0.063	
							<b>Group MCSP x time</b>	<b>-1.98</b>	<b>2.67</b>	<b>0.463</b>	
Social Rejection (0-36)	Overall	MCSP (65)	11.71(3.77)	11 (9-14)	11.60(4.1)	10 (8-13)	Group MCSP	-1.762	0.824	0.034	0.03
		UC (49)	13.47(4.87)	13 (10-16)	12.82(4.85)	13 (9-16)	Time follow-up	-0.653	0.543	0.232	
							<b>Group MCSP x time</b>	<b>0.545</b>	<b>0.719</b>	<b>0.450</b>	
	Italy	MCSP (32)	11.62(4.19)	10 (8.75-13)	10.38(3.54)	9.5 (8-13)	Group MCSP	-1.257	1.321	0.345	0.01
		UC(17)	12.88(5.17)	13 (11-16)	11.24(5.38)	11 (8-15)	Time follow-up	-1.647	0.961	0.093	
							<b>Group MCSP x time</b>	<b>0.397</b>	<b>1.189</b>	<b>0.740</b>	
	UK	MCSP(14)	12.07(3.25)	12 (9.25-15.5)	13.86(4.87)	14.50 (10-17.75)	Group MCSP	-5.57	1.578	0.001	0.27
		UC (14)	17.64(3.89)	16.5 (14.25-20)	16.29(4.51)	16 (13.25-19.2)	Time follow-up	-1.36	0.954	0.167	
							<b>Group MCSP x time</b>	<b>3.14</b>	<b>1.350</b>	<b>0.028*</b>	
	Poland	MCSP (19)	11.58(3.53)	11 (8.5-13)	12(3.8)	12 (9-14)	Group MCSP	0.801	1.098	0.469	0.09
		UC (18)	10.78(2.78)	10.5 (9-11)	11.61(3.11)	12(9-14)	Time follow-up	0.833	0.784	0.295	
							<b>Group MCSP x time</b>	<b>-0.412</b>	<b>1.094</b>	<b>0.709</b>	
Social Isolation (0-28)	Overall	MCSP(65)	13.11(4.41)	13(10-16)	12.62(4.96)	12 (9-17)	Group MCSP	-0.198	0.870	0.820	0.00
		UC (49)	13.31(4.42)	14 (12-16)	13.39(4.54)	14 (11-17)	Time follow-up	-0.082	0.647	0.90	
							<b>Group MCSP x time</b>	<b>-0.574</b>	<b>0.857</b>	<b>0.505</b>	
	Italy	MCSP(32)	13.38(4.27)	12(11-16)	11.50(4.57)	11.5 (8-14.25)	Group MCSP	-0.449	1.51	0.767	0.01
		UC (17)	13.82(5.62)	14(12-17)	12.59(6.41)	13(9-18)	Time follow-up	-1.235	1.10	0.269	
							<b>Group MCSP x time</b>	<b>-0.640</b>	<b>1.37</b>	<b>0.642</b>	
	UK	MCSP(14)	13.29(4.75)	13.5(9.5-17.75)	13.86(5.40)	15.50(11.25-17.75)	Group MCSP	-1.571	1.62	0.337	0.02
		UC (14)	14.86(3.8)	15(12.25-17.7)	14.43(2.71)	14(13.25-16.5)	Time follow-up	-0.429	1.31	0.747	
							<b>Group MCSP x time</b>	<b>1.000</b>	<b>1.86</b>	<b>0.595</b>	
	Poland	MCSP(19)	12.53(4.57)	11(9-16.5)	13.58(5.08)	14(9-17.5)	Group MCSP	0.915	1.365	0.506	0.01
		UC (18)	11.61(3.01)	12(9-14)	13.33(3.51)	14(11.25-15.7)	Time follow-up	1.722	0.888	0.061	
							<b>Group MCSP x time</b>	<b>-0.67</b>	<b>1.239</b>	<b>0.592</b>	
Internalised Shame (0-20)	Overall	MCSP (65)	7.43(2.66)	7(5-9)	6.92(2.35)	7(5-8)	Group MCSP	-0.202	0.506	0.690	0.02
		UC (49)	7.63(2.88)	7(6-10)	8.06(2.88)	9(6-10)	Time follow-up	0.429	0.407	0.295	
							<b>Group MCSP x time</b>	<b>-0.936</b>	<b>0.539</b>	<b>0.085</b>	
	Italy	MCSP (32)	7.41(2.59)	7(5-9)	6.53(2.38)	6(5-8)	Group MCSP	-0.358	0.898	0.691	0.03
		UC (17)	7.76(3.91)	8(6-10)	7.94(3.65)	9(7-10)	Time follow-up	0.176	0.716	0.806	
							<b>Group MCSP x time</b>	<b>-1.051</b>	<b>0.886</b>	<b>0.241</b>	
	UK	MCSP(14)	7.21(1.93)	7.5 (5-8.75)	6.57(1.99)	5.50 (5-8)	Group MCSP	-1.214	0.835	0.153	0.12
		UC (14)	8.43(2.14)	8.5(7-10)	8.29(2.7)	9.5 (6-10)	Time follow-up	-0.143	0.685	0.836	

						<b>Group MCSP x time</b>	<b>-0.500</b>	<b>0.969</b>	<b>0.610</b>	
<b>Poland</b>	MCSP (19)	7.63(3.29)	<u>7 (5-10)</u>	7.84(2.39)	<u>7 (6.5-8)</u>	Group MCSP	0.743	0.844	0.382	0.01
	UC (18)	6.89(2.08)	6(5-8.5)	8(2.3)	9(5.25-10)	Time follow-up	1.111	0.691	0.117	
						<b>Group MCSP x time</b>	<b>-0.901</b>	<b>0.964</b>	<b>0.357</b>	

*Scale ranges are presented under the scale titles with the most positive value underlined.*

\* $p \leq 0.05$  – statistically significant change between MCSP and UC groups in time;  $f^2 \geq 0.02$ ,  $f^2 \geq 0.15$ , and  $f^2 \geq 0.35$  represent small, medium and large effect sizes (respectively) (Cohen, 1988)