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Title: Do people with dementia experience Stigma? A cross country comparison between Italy, Poland and the UK

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Title: Do people with dementia experience Stigma? A cross country comparison between Italy, Poland and the UK

Abstract:

Introduction: Until now little research has been done to answer the question of whether people with dementia experience stigma and if so how they experience this. Also, no previous studies were conducted into possible differences between countries and cultures regarding the experience of stigma in dementia.

Objectives: The aims of this study were to compare the experience of stigma (with social isolation, social rejection and internalised shame as components) among people with dementia (n=180) in three European countries: Italy, Poland and the United Kingdom (UK); and to investigate possible determinants in background characteristics, quality of life aspects, social support, mood and cognitive functioning.

Material and Methods: A one group multinational cross-sectional design was used. Stigma was measured with the Stigma Impact Scale (SIS).

Results: The results showed that people in the UK experience a higher level of stigmatisation than people in Italy and Poland. The experienced stigmatisation negatively correlated with obtained social support (DSSI; $\rho=-0.42$, $p=0.000$) and quality of life aspects (QOL-AD; $\rho=-0.39$, $p=0.000$). Positive correlations were found between experiencing stigma and negative mood ($\rho=0.28$, $p=0.0002$). There was no significant correlation between level of cognitive functioning and stigmatisation (GDS, $\rho=0.02$; $p=0.98$) although people rating their own memory lower reported a higher level of stigmatisation (QoL-AD, memory item; $\rho=-0.29$; $p=0.001$).

Conclusion: There is a strong need for research into the individual experience of people with dementia across Europe and the world. This could help in providing support and care services that match their experience, needs, preferences; and designing well informed awareness campaigns based on their voice.

Keywords: dementia, stigma, awareness, shame, quality of life

Introduction

While the stigma of serious mental illnesses like depression, schizophrenia (Corrigan, 2004; Świtaj, 2005; Tyszkowska, Podgrodzka, 2013) or physical problems, such as AIDS, leprosy and skin diseases (Sartorius, 2007), has been examined in scientific research in the past decade, relatively little has been done on stigmatisation in dementia (Burgener et al., 2015a; Burgener et al., 2015b; Burgener, Berger, 2008; Wermer, 2014; Swaffer, 2014; Devlin et al., 2007; Riley et al., 2014; Gove et al., 2016a; Gove et al., 2016b).

Dementia is a serious medical disease with consequences causing difficulties for the diagnosed person, their relatives and close friends (ADI, 2015). It affects not only cognitive functioning but also psychological well-being and social life (Burgener et al., 2015a; Burgener et al., 2015b; Burgener, Berger, 2008; Wermer, 2014; Swaffer, 2014; Devlin et al., 2007; Riley et al., 2014; Gove et al., 2016a; Gove et al., 2016b, ADI, 2015).

Stigma spans different areas. These include the individual experience of people with dementia (internalised stigma, self-stigma), families (courtesy/family stigma) and the societal level involving the prejudice of segments of society towards those with dementia (public stigma) (Corrigan, 2004; Świtaj, 2005, Wermer, 2014).

Despite some empirical and theoretical studies on stigma in dementia, mostly focussing on social aspects and carers' or professionals' perspective, there is still relatively little known about people with dementia's individual experience of stigma (Urbanska et al., 2015). According to Wermer (2014) people with dementia experience stigma on the emotional, cognitive and behavioural levels. The diagnosis can lead to lower self-esteem, loss of self-control (Devlin et al., 2007; Riley et al., 2014), feeling ashamed, embarrassed, guilty and worried about the progress of the disease (Wermer, 2014).

Some studies show that lower cognitive functioning goes together with increased experiences of social rejection and social isolation (Burgener et al., 2015a; Burgener et al., 2015b) and that negative attitudes towards people with dementia are related to behavioural and cognitive symptoms and their loss of ability taking care of themselves (Wermer, 2014; Riley et al., 2014; Urbanska et al., 2015).

The aim of this study was to investigate the experience of stigmatisation among community-dwelling people with dementia in three European countries (Italy, Poland,

the United Kingdom). The study focused on identifying social, clinical and psychological factors related to stigma. This article addresses three research questions:

1. Do people with dementia in Italy, Poland and the UK experience stigma?
2. Are there any differences between the experience of stigmatisation among people living with dementia in these three European countries?
3. Is the level of experienced stigma by people with dementia related to their background characteristics, quality of life, social support, mood and/or cognitive functioning?

Methods

Study design

A one-group multinational cross-sectional study design was applied in three European countries.

Participants and setting

The study was conducted within the European, JPND funded, MEETINGDEM – project (2014-2017), which evaluated the implementation of the Meeting Centres Support Programme (MCSP), originally developed in the Netherlands, in Italy, Poland and the UK (Dröes et al., 2017). MCSP aims to deliver timely information and emotional, practical and social support for people with dementia and their carers, adjusted to individual participants' needs and values (Dröes et al., 2004). The inclusion criteria were having mild cognitive impairment or mild to moderately severe dementia, independent of age or type of dementia, living at home and having an informal carer. All participants were recruited within the MEETINGDEM study and met criteria to participate in the MCSP. The study was approved by the Ethical Committees in the participating countries.

Instruments

The level of stigmatisation was measured with the 'Stigma Impact Scale (SIS), neurological impairments' (Burgener and Berger, 2008), which consists of 21 items and 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 omitted based on the Burgener and Berger's (2008) recommendations. A higher score (range 0-84) indicates a higher level of perceived stigmatisation.

Besides background characteristics of the person with dementia (such as age, sex, education, marital status), the 30-items Dementia Quality of Life scale (DQoL) (Brod et al., 1999) and the 13-items Quality of Life Alzheimer's Disease scale (QOL-AD) (Longsdon et al., 2002) were administered to measure their quality of life. DQoL contains 5 subscales: Self Esteem, Positive Affect/Humor; Negative Affect; Feelings of Belonging and Sense of Aesthetics as well as an additional item to assess the overall experienced QoL (Brod et al., 1999). Both scales have good psychometric properties (Moniz-Cook et al., 2008). Social support was measured by the Duke Social Support Inventory (DSSI) (George et al., 1989), mood/depressive symptoms by the Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al., 1988) and the level of cognitive impairment by the Global Deterioration Scale (GDS) (Reisberg et al., 1982).

In Italy and Poland the psychometric measures, not yet existing in the native language, were translated and adapted into the native languages based on the formal criteria of psychological questionnaires' translation following the WHO recommendations (WHO. Process of Translation and Adaptation Documents, 2017).

Procedure

All participants that met the inclusion criteria for the MCSP intervention or the control group were asked to participate in the study. Those who agreed, provided informed consent before the start of the data collection. All questionnaires were administered by trained researchers between May 2015 and July 2016. People with dementia and carers were separately interviewed during one or two sessions, which in total took from half an hour until two hours.

Statistical analysis

Because the data were not distributed normally, nonparametric statistics were used to answer the research questions. Differences between countries (question 1) were analysed using the Kruskal-Wallis test (for ordinal and interval variables) and Fisher exact test with multiple comparisons post-hoc analysis (for nominal variables).

Analyses were done using R for Windows (version 3.3.3). A significance level of alpha smaller or equal to 0.05 was used.

Relationships between SIS (and its subscales) and background characteristics and other quantitative outcome measures (question 3) were assessed using Spearman rank correlation coefficient. For ordinal variables the relation with stigma (SIS and subscales) was assessed using Mann-Whitney U test or Kruskal-Wallis test (for 3 or more categories) with post-hoc analysis using the Conover method with Holm adjustment to test differences between categories. Background characteristics that differed among participants from the three countries and were related to the experience of stigma (potential cofounding variables) were included as covariates in the ANCOVA to test country differences in experienced stigma.

Results

Data from 180 people with dementia, from whom the SIS was administered, were included in the final analysis. Some of them did not answer all questions from the other instruments which explains the differences in numbers in Tables 1, 2 and 3.

Background and clinical characteristics

101 (56.11%) women and 79 (43.89%) men between 62 and 95 years old (mean=78.66±7.24) participated in the study. 44% was from Italy, 26% from Poland and 30% from the UK. The majority of people with dementia were married (almost 60%), 34% were widowed. Almost half of them (46%) achieved the vocational level 1 or 2. There were no statistical differences between countries in background characteristics except for educational level. In Italy the majority achieved vocational level 2 (31%) or primary education (36%). In Poland the majority had higher education (32%) or vocational level 1 (49%). 37% of British people had higher education level and 25% of them no education. More detailed demographic characteristics are presented in Table 1.

[Table 1 about here]

The median for dementia severity (GDS) was 4, indicating moderate cognitive decline.

The overall quality of life means were 3.38 ± 0.97 for DQoL and 34.17 ± 5.52 for QOL-AD. On two DQoL subscales differences between participants from Italy, Poland and the UK were found. People from Poland scored higher in Negative Affect than people from Italy and the UK. They also had significantly lower scores for Positive Affect than in the UK. Results for other clinical outcome measures are also presented in Table 2.

[Table 2 about here]

The level of stigmatisation

The level of stigmatisation (SIS total) among study participants varied from 2 to 65 (mean= 34.18 ± 10.50 ; median=33.5). The SIS level in the UK (mean= 39.04 ± 9.58) was higher than in Poland (mean= 30.72 ± 8.99 ; $p=0.00$) and in Italy (mean= 32.92 ± 10.85 ; $p=0.001$). Participants from the UK felt more socially rejected (SR) (mean= 15.52 ± 4.42) than Italian (mean= 12.27 ± 4.43 ; $p=0.00$) and Polish people (mean= 11.23 ± 3.30 ; $p=0.00$). Similar results were obtained for social isolation (SI) in the UK (mean= 15.06 ± 4.34) compared with Italy (mean= 13.29 ± 4.72 ; $p=0.04$) and Poland (mean= 11.94 ± 4.07 ; $p=0.005$). The level of internalised shame (IS) was significantly higher in the UK (mean= 8.46 ± 2.35) than in Italy (mean= 7.37 ± 2.96 ; $p=0.03$), but not compared to Poland. Table 2 and Chart 1 present more details.

[Chart 1 about here]

Stigma and background characteristics

Kruskalis-Wallis test showed that people with dementia with no education in all countries reported a higher ($p=0.04$) level of stigmatisation (mean= 37.67 ± 12.3) than people with vocational level 2 (mean= 31.59 ± 9.5). There were no other significant correlations between background characteristics and the level of stigmatisation. Because education level differed between the countries and the education level appeared to be related to the level of experienced stigmatisation, we included education as a covariate in the ANCOVA. The ANCOVA showed significant differences between the three countries on SIS ($F=9.94$, $p=0.000$), SR ($F=14.63$, $p=0.000$) and SI ($F=6.69$, $p=0.0016$). Only the effect of nationality on IS became statistically insignificant ($F=2.95$, $p=0.055$). There were no other background characteristics appeared to impact on the level of experienced stigma.

Stigma and other outcome measures

The level of experienced stigmatisation (SIS total) correlated negatively with QoL (QoL-AD $\rho=-0.39$; $p=0.000$; DQoL (overall rate) $\rho=-0.20$; $p=0.008$). Lower QoL was related to higher SR (QoL-AD $\rho=-0.32$; $p=0.000$; DQoL (overall rate) $\rho=-0.15$; $p=0.05$), SI (QoL-AD $\rho=-0.45$; $p=0.000$; DQoL (overall rate) $\rho=-0.22$; $p=0.003$) and IS (QoL-AD $\rho=-0.25$; $p=0.0007$; DQoL (overall rate) $\rho=-0.16$; $p=0.03$).

People with lower SR ($\rho=-0.21$; $p=0.004$), SI ($\rho=-0.31$; $p=0.000$), IS ($\rho=-0.21$; $p=0.004$) and total SIS level ($\rho=-0.27$; $p=0.0003$) had higher Self Esteem scores. People with lower SI had higher Positive Affect ($\rho=-0.21$; $p=0.006$). Other negative relationships were found between SIS ($\rho=-0.18$; $p=0.02$), SI ($\rho=-0.22$; $p=0.004$), IS ($\rho=-0.15$; $p=0.049$) and Feelings of Belonging. Positive correlations were found between SIS ($\rho=0.28$; $p=0.0002$), SR ($\rho=0.20$; $p=0.008$), SI ($\rho=0.37$; $p=0.00$), IS ($\rho=0.17$; $p=0.02$) and Negative Affect.

The SIS score correlated weakly negatively with the level of energy ($\rho=-0.26$; $p=0.0005$) and mood ($\rho=-0.24$; $p=0.01$) from QoL-AD. However, no significant relationship between the experience of stigmatisation ($\rho=0.0$; $p=0.98$) and mood (CSDD) was found.

People who experienced a higher SI ($\rho=-0.37$; $p=0.000$) and SIS ($\rho=-0.29$; $p=0.001$) declared more severe memory problems and worse physical health (SI $\rho=-0.33$; $p=0.000$; SIS $\rho=-0.28$; $p=0.0002$). However, the study did not show a significant relationship between the SIS total and overall cognitive functioning (GDS; $\rho=0.02$; $p=0.98$). Moreover, there appeared to be no correlation ($\rho=0.02$, $p=0.8$) between the level of subjective decline in memory (QoL-AD; memory item) and a proxy measure on cognitive decline (GDS).

People declaring higher SIS reported lower QoL (QoL-AD) in areas such as: family relationships ($\rho=-0.29$; $p=0.0001$) and friends ($\rho=-0.16$; $p=0.03$). There was no correlation between stigma (subscales) and other aspects of QoL-AD, like the living situation or financial situation of people with dementia (Table 3).

A negative relationship was found between SIS ($\rho=-0.41$; $p=0.000$) IS ($\rho=-0.3$; $p=0.001$), SI ($\rho=-0.35$; $p=0.000$) and SR ($\rho=-0.42$; $p=0.000$) and the experienced social support (DSSI).

[Table 3 about here]

Discussion

This study is the first describing and comparing the stigmatisation levels among people with dementia living in the community in three European countries. The samples of participants in Italy, Poland and the UK differed from each other only on educational level. People in the UK had a lower mean level of education than those in Italy and Poland.

Overall the level of experienced stigma among study participants was not as high as results published by Burgener and Berger (2008), who collected data from 26 people diagnosed with Alzheimer's Disease receiving care at two diagnostic centres located in rural and non-rural areas in the USA. The SIS instrument that was used in their study consisted of 24 items (including the Financial Insecurity subscale) (Burgener and Berger, 2008). A significant difference was found between lower (low/no education) and higher education level (vocational level 2) with the experience of stigma (the lower the education the higher experienced stigma). This finding partly differs from the results published by Burgener et al. (2015a) who found that educational level was positively related to stigma. There were no other findings which could explain this difference.

Results obtained in our study showed that the level of stigmatization varied significantly between participants in different countries. British people living with dementia felt significantly more stigmatised than Italian and Polish. Also after adjusting for country differences in educational level in the analysis, there were still differences between the countries in level of experienced stigmatisation (SIS, SR and SI). A possible explanation of this may be cultural differences in acceptance of people with disabilities or openness on cognitive problems/dementia in the three countries. This needs further research.

The finding of Burgener et al. (2005) that stigma is related to the age of people with dementia and cognitive decline as measured with the GDS was not confirmed in this

study. However, a significant relation between stigmatisation and subjective cognitive decline was found: participants who assessed their memory lower reported higher levels of social isolation. This finding could be a result of their own beliefs which may have increased self-isolating behaviour or avoidance of social contacts (Chronister et al., 2013).

The negative relation between experiencing stigmatisation and psychological well-being confirms the previous findings of Burgener et al.(2015a; 2015b), Wermer (2014) and Milne (2010). The positive relation between stigma and more intensive negative feelings is in line with Wermer (2014). This study shows the relation between a lower experienced stigma level and positive emotions, feelings of belonging and self-esteem, which suggests a substantial impact of stigma on the emotional life of people with dementia. This underlines the importance of creating dementia-friendly societies and a positive image of dementia (Devlin et al., 2007; ADI, 2012).

Social support can be seen as a factor that reduces the experience of stigma (Burgener and Berger, 2008; Chronister, et al., 2013). People who ranked relationships with friends and family lower felt more stigmatised. This is an important finding as previous studies showed that with the progress of the disease the social network of people with dementia usually decreases (Corrigan, 2004; Wermer, 2014).

There were some methodological limitations of this study. First, samples in the three countries differed in size and educational level. Second, a selective study sample was used: only people who joined MCSP or control group in the MEETINGDEM study were recruited and it was not an epidemiological cohort. The type of the diagnosis as well as the other characteristics regarding their physical health (such as comorbidities) were not included in the analysis. Furthermore, participants mainly lived in cities (where MCSP was mostly offered), with only a few people attending from local villages. Thus, the study results are not applicable to community-dwelling people with dementia in general. Finally, people experiencing higher internalised stigma may avoid social interactions and using of services and therefore do not participate in research (Burgener and Berger, 2008; Chronister et al., 2013; Garand et al., 2010). This may have caused selection bias, i.e. underestimation of perceived stigmatisation among people with dementia.

The study findings confirm that people with dementia, who experience consequences of the disease and are aware of their situation, are still able to express their feelings and describe their quality of life. Stigmatisation can be experienced on a very basic level and influence the emotional life.

For future research into determinants of stigmatisation it is important to represent both people living in rural and non-rural areas, and in different regions of countries (Burgener et al., 2015a; 2015b). In addition to e.g. the ADI report (2012), which was based mostly on the carer's perspectives, it seems very important to compare the experienced stigma among dyads – people with dementia and family members. Investigation of the relation between societal awareness of dementia and people with dementia's beliefs about this disease and experienced stigma would be also valuable (Wermer, 2014; Clare, 2003). Moreover, qualitative methods like focus groups or semi-structured interviews should be used in addition to quantitative measures. This could provide a more detailed insight in the experience of stigmatisation among people living with dementia.

As this study showed the relationship between stigma and social support, which is a modifiable factor, this finding is very relevant for clinical practice and social work with people with dementia and their carers. Moreover, the fact that experienced stigma is related to quality of friendships and relationships with family could be probably seen as a clue for raising awareness of the importance of creating dementia-friendly environments in all three countries.

Conflict of interests: none

Description of authors' roles:

K. Urbańska wrote the paper, collected the data and conducted the data analysis. D. Szcześniak collected the data and assisted in writing article. K. Bulińska collected the data. S.B Evans collected the data and reviewed the manuscript. D. Brooker and S.C. Evans supervised the data collection and reviewed the manuscript. F. L. Saibene and A. d'Arma collected the data. E. Farina supervised the data collection and reviewed the manuscript. R. Chattat supervised the data collection and reviewed the manuscript. F. Meiland supervised the data collection and reviewed the manuscript. R.M. Dröes supervised the data collection and supervised with and

contributed to writing the article. J. Rymaszewska supervised the data collection, assisted in writing article and reviewed the manuscript.

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