



Public knowledge about dementia in Germany—results of a population survey

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Abstract

Objectives The following research questions are addressed: (1) What does the German public know about dementia? (2) Are social factors, care experience and contact with dementia patients associated with knowledge about dementia? (3) Is knowledge associated with attitudes/beliefs about dementia?

Methods Analyses are based on a German mail survey conducted in 2012. Sample consists of persons aged 18–79 years. 1795 persons filled out the questionnaire (response rate 78 %). Respondents were asked about their knowledge of and attitudes about dementia.

Results Knowledge about cause, prevention, diagnosis, treatment and life impact of dementia is characterized by a relatively high uncertainty. People with care experiences and people from higher status groups know more about dementia. People with more knowledge are less likely to believe that dementia patients have a high quality of life, but tend to be less skeptical about early detection of dementia.

Conclusions To increase knowledge, reduce uncertainty and modify attitudes towards dementia and those who are afflicted, educational programs and contact-based approaches should be considered.

Keywords Dementia · Knowledge · Attitudes · Beliefs · Survey · Germany

Introduction

Dementia is an important present and future challenge in public health (Perrig-Chiello 2007; Piko 2007). As a particularly old-age-correlated disease, the demographic change leads to a rapidly increasing prevalence of dementia (Ziegler and Doblhammer 2009; Mukadam and Sampson 2011). The patients' burden lies in experiencing the cognitive decline, which leads to uncertainty and worries (Jansen 2005). Receiving a dementia diagnosis evokes ambiguous reactions. While some patients feel shocked, angry and depressed, others show a decline of anxiety and depression symptoms (Carpenter et al. 2009). The illness is also connected with negative impacts on caregivers' burden (Brodaty et al. 2005). Because of the growing number of persons afflicted, not only as patients, but also as caregivers' (Bickel 2000; Prince et al. 2013), attitudes and beliefs regarding dementia are also highly relevant in the area of public health.

Knowledge about dementia and Alzheimer's disease (AD) has practical implications. Enhanced dementia knowledge helps families, caregivers and others who care for disordered people to cope better with illness-related behaviours. This also helps in reducing mental and physical caregivers' burden (Cahill and Shapiro 1997; McKee et al. 2003; Kofahl et al. 2009; Jorm 2012). Moreover, greater knowledge of dementia symptoms is positively correlated with the aim to utilize counselling and healthcare services (Werner 2003; Low and Anstey 2009). At least for Germany, however, knowledge about AD symptoms and treatment possibilities is still unsatisfactory (Schwalen and Förstl 2008).

Not only caregivers benefit from dementia knowledge. The recognition of mental disorders facilitates early help seeking (Jorm 2012) and helps planning "getting things done" before dementia symptoms become too burdensome

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(Schwalen and Förstl 2008). Hence, targeting the general population as “potentially affected” should be considered as one prevention strategy. To this end, it is useful to assess knowledge and beliefs about dementia in the general public.

Low and Anstey (2009) adapted the concept of mental health literacy (Jorm 2000) to define the specific case of dementia literacy, which covers domains of knowledge as well as beliefs and attitudes. Attitudes towards persons with mental disorders in general and especially towards people with dementia provoke emotional reactions that play an important role in the stigma process of people concerned (Angermeyer et al. 2010; von dem Knesebeck et al. 2014). A study from France also shows an association between negative attitudes towards AD and burden of caregivers (Zawadzki et al. 2011). Luck et al. (2012) identified gender and beliefs about effective prevention measures to be relevant factors affecting attitudes towards early detection of dementia. In terms of attitudes towards early detection, Hausner et al. (2012) compared general practitioners, family caregivers and persons without contact to people with dementia in Germany. The majority of the general public and family caregivers are favouring an early detection of a possible dementia (72 and 62 % respectively), while general practitioners have rated this slightly less meaningful (59 %).

Experience with dementia patients, defined as having contact to them, is positively correlated with pro-social attitudes like willingness to help or care (Kofahl et al. 2013; von dem Knesebeck et al. 2014). It is also known that mental health of caregivers and dementia literacy are associated with social factors like the socioeconomic status (SES) (Low et al. 2010; Carpenter et al. 2011). However, the relations between social factors, dementia knowledge, attitudes and beliefs have not been much investigated yet. This is particularly true for most German population-based surveys. Usually, only attitudes towards ‘early detection’ and the ‘diagnosis’ are investigated (Schwalen and Förstl 2008; Luck et al. 2012; Hausner et al. 2012). Studies that consider a broader range of attitudes or social factors only focus on general practitioners, not on the general public (Kaduszkiewicz et al. 2009).

Hence, this paper addresses the following research questions: (1) What does the German public know about dementia? (2) Are social factors, care experience and contact with dementia patients associated with knowledge about dementia? (3) Is knowledge associated with attitudes/beliefs about dementia?

Methods

Study design and sampling

Analyses are based on a random sample of an access panel of a German institute for market and social research (GfK)

Table 1 Sample description of selected sociodemographic characteristics ($N = 1795$, weighted, Germany 2012) compared to official statistics

Variables	Sample		Official statistics %
	<i>N</i>	%	
Age			
20–39	563	31.4	31.5 ^a
40–59	679	37.8	40.1
60–79	553	30.8	28.4
Sex, female	930	51.8	50.9 ^b
Level of education			
Low (up to 9 years)	412	30.8	30.8 ^c
Medium (10 years)	502	37.6	29.7
High (12 or 13 years)	422	31.6	39.5

^a https://www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Bevoelkerung/Bevoelkerungsstand/Tabellen/_lrbev01.html

^b https://www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Bevoelkerung/Bevoelkerungsstand/Tabellen/Zensus_Geschlecht_Staatsangehoerigkeit.html

^c <https://www-genesis.destatis.de/genesis/online>

consisting of 32,836 persons aged from 18 to 79 years living in private households. The access panel is conceptualized as a stratified sample of the general public, taking into account a number of sociodemographic characteristics (like gender, age, education, employment status, household size, regional structure, federal state). The aim is to get a representative selection based on comparisons with official statistics (Statistisches Bundesamt 2015). About 25 % of the participants of the panel are replaced every year to match official statistics. For the purpose of a German national mail survey (“Gesundheitsmonitor”, health monitor), a random sample of 2300 persons was drawn from this panel in fall 2012. 1795 individuals participated, reflecting a response rate of 78 %. Survey participation was voluntary; informed consent was considered to have been given when individuals have sent back the filled out questionnaire. Concerning the distribution of gender, age and federal states population-based weights were used to compensate for nonresponse.

Comparisons of sociodemographic characteristics of the used sample with data of official statistics are shown in Table 1. While individuals from 20 to 39 years are well represented in our sample, older person between 60 and 79 years are slightly over-represented. About 52 % are female, which is close to official statistics. In terms of education, high levels are under-represented in our sample.

Measures

Social factors that are assumed to be associated with dementia knowledge and attitudes towards people with dementia are represented by measures of age, gender and

SES. SES was measured as an index of vocational education, occupational position, and income. In terms of vocational education, degrees ranging from no qualification (1) to university degree (9) were differentiated; occupational position ranges between non-skilled worker (1) to free-lanced academic (9); equivalence household income (per month) ranging between less than 500 Euros (1) and more than 2500 Euros (9). SES index was calculated by summing up the values of the three indicators, resulting in a scale ranging from 3 to 27 points. Based on this index, three status groups representing low (3–10), middle (11–19) and high SES (20–27) were defined. Beside social factors, personal contact and care experience with dementia patients is likely to have an impact on knowledge about dementia and attitudes towards people with dementia. Thus, the factor “dementia experience” was also included in the analyses. Dementia experience is represented by two items: contact with dementia patients (yes/no) and care experience (yes/no).

A number of tests exist to assess knowledge about dementia and AD (see Carpenter et al. 2009 for an overview). However, and with respect for our German population sample, most of them are only available in English or are mostly addressing general practitioners or other healthcare professionals rather than the general public (Kaduszkiewicz et al. 2009, Pentzek et al. 2005). Moreover, the existing original scales (Carpenter et al. 2009) turned out to be too long for integration in the health monitor survey. Other instruments used open-ended questions, which do not fit with the health monitor data-collection procedure (Schwalen and Förstl 2008). Hence, based on the concept of one of the most common tests [Alzheimer’s Disease Knowledge Scale (ADKS), Carpenter et al. (2009)], we decided to adapt five items that represent different domains, which were used to analyse dementia knowledge: (1) “In more than 90 %, genes are the cause for development of dementia” (cause); (2) “It has been scientifically proven that mental exercise can prevent a person from getting AD” (prevention); (3) “It is safe

for people with AD to drive, as long as they have a companion on the car at all times” (life impact); (4) “Prescription medications to cure AD are available” (treatment); and (5) “An unambiguous AD diagnosis can only be confirmed after death through a brain examination” (diagnosis). Answer categories were “true”, “false” and “do not know”. For logistic regressions, answer categories were dichotomized (correct answer vs. wrong answer and “do not know” combined, cp. Table 2). Assuming that the general public does not clearly distinguish between “Alzheimer’s Disease” and “dementia”, these terms were used synonymously in the health monitor survey.

To assess public’s attitudes and believes about dementia and AD, three items were used: “In general, people with dementia are better taken care of in nursing homes than at home” (care); “Despite their disorder, dementia patients have a very high quality of life” (quality of life); and “To know early that you have dementia is not good at all” (early detection). Valid item categories range from 1 (“do not agree at all”) to 4 (“strongly agree”). For the analyses, the items were dichotomized [agree (values 3 and 4) vs. disagree (values 1 and 2)].

Statistical methods

Descriptive statistics were chosen to document the sample characteristics and the distribution of item categories. Logistic regressions were applied to analyse the association between social factors, dementia knowledge and attitudes towards dementia patients. Odds ratios, 95 % confidence intervals, significances and Nagelkerkes R^2 are reported. All analyses were conducted using the R statistical package (R Core Team 2014).

Results

About 24 % of the respondents had a low and 61 % mid SES. 15 % of the sample is considered to have a high

Table 2 Knowledge about dementia and Alzheimer’s disease (AD) ($N = 1795$; in %, Germany 2012)

	True	False	Do not know
<i>Treatment</i> “Prescription medications to cure AD are available”	8.8	59.8	31.4
<i>Life impact</i> “It is safe for people with AD to drive as long as they have a companion on the car at all times”	6.1	55.3	38.5
<i>Prevention</i> “It has been scientifically proven that mental exercise can prevent a person from getting AD”	48.5	22.2	29.2
<i>Cause</i> “In more than 90 %, genes are the cause for development of dementia”	22.9	21.6	55.5
<i>Diagnosis</i> “An unambiguous AD diagnosis can only be confirmed after death through a brain examination”	8.7	59.6	31.8

Correct answer categories in bold

Table 3 Association between social factors, care experience and dementia knowledge: odds ratios (OR), 95 % confidence intervals (CI) and significance-values (*p*) (Germany 2012)

	Treatment "Prescription medications to cure AD are available." (false)		Cause "In more than 90 %, genes are the cause for development of dementia." (false)		Prevention "It has been scientifically proven that mental exercise can prevent a person from getting AD." (false)		Diagnosis "An unambiguous AD diagnosis can only be confirmed after death through a brain examination." (true)		Life impact "It is safe for people with AD to drive as long as they have a companion on the car at all times." (false)	
	OR (CI)	<i>p</i>	OR (CI)	<i>p</i>	OR (CI)	<i>p</i>	OR (CI)	<i>p</i>	OR (CI)	<i>p</i>
Gender*										
Female	1.33 (1.07–1.64)	0.009	0.98 (0.77–1.26)	0.899	1.16 (0.91–1.49)	0.232	0.67 (0.46–0.96)	0.032	1.34 (1.09–1.65)	0.005
Age (years)*										
41–59	1.05 (0.81–1.37)	0.696	1.18 (0.87–1.60)	0.287	1.11 (0.82–1.52)	0.487	1.23 (0.78–1.99)	0.376	1.17 (0.91–1.51)	0.228
60+	0.70 (0.54–0.92)	0.011	0.76 (0.55–1.06)	0.104	1.02 (0.74–1.40)	0.913	1.13 (0.71–1.85)	0.609	0.95 (0.73–1.23)	0.703
SES*										
Middle	1.33 (1.03–1.71)	0.030	0.95 (0.70–1.30)	0.761	1.23 (0.90–1.69)	0.203	1.15 (0.72–1.90)	0.565	1.37 (1.07–1.77)	0.013
High	2.00 (1.44–2.80)	0.000	1.19 (0.82–1.73)	0.366	1.62 (1.11–2.37)	0.013	1.83 (1.07–3.20)	0.030	1.33 (0.97–1.83)	0.074
Contact with dementia patients*	1.60 (1.28–1.99)	0.000	1.47 (1.13–1.90)	0.004	1.52 (1.17–1.96)	0.002	1.23 (0.84–1.80)	0.291	1.13 (0.91–1.40)	0.259
Care experience*	2.38 (1.72–3.33)	0.000	1.79 (1.27–2.52)	0.001	2.05 (1.46–2.85)	0.000	1.83 (1.13–2.90)	0.012	1.53 (1.13–2.08)	0.007
Observations	1669		1665		1664		1663		1665	
Nagelkerkes- <i>R</i> ²	0.060		0.024		0.028		0.027		0.022	

* Reference categories: male gender, age 18–40, low SES, no contact, no care experience. *p* values <0.05 are in bold

socioeconomic status. One third had contact with a person with dementia, and 12.3 % were personally caring for a person with dementia. More than half of the sample had no contact to a person with dementia before. 40 % of the respondents agreed to the statement "Dementia patients have a very high quality of life". 47 % of the sample think that people with dementia are better taken care of in nursing homes than at home. About 16 % of the respondents agreed to the statement that it would not be good at all to know early that one has a dementia.

Table 2 provides an overview of the answer distributions of the selected knowledge items. About one-third of the respondents or more stated that they would not know whether the given statements are correct or not. More than half of the respondents correctly answered the items concerning treatment and life impact of AD. The item concerning diagnosis was the most difficult one—about 9 % gave the correct answer.

The associations between social factors, care experience and dementia knowledge are shown in Table 3. Female respondents are more likely to give correct answers concerning treatment and life impact, whereas men know better about an unambiguous diagnosis. Age is weakly and inconsistently associated with dementia literacy. Respondents with a high SES know significantly more about treatment, prevention and diagnosis of dementia than those with a low SES. Care experience is the only factor that is significantly associated with all knowledge items. People with care experience are more likely to give correct answers than people without care experience. Also, contact with dementia patients is positively associated with dementia literacy. Explained variance varies between 2 and 6 %.

In Table 4, attitudes/beliefs about dementia (home care, consequences for quality of life, and early detection) are regressed on gender, age, SES, experiences and the five knowledge items. Compared with men, female respondents are significantly less likely to agree to the statement that dementia patients would be better taken care of in nursing homes than at home. Female respondents are more likely to consider people with dementia to have a high quality of life. Older people are less optimistic concerning quality of life and more sceptical in terms of early detection. Middle and high SES groups are less likely to be sceptical about early detection. Respondents with care experience are less likely to agree to the statement that people with dementia are better taken care of in nursing homes than at home. Moreover, they are more convinced that dementia patients have a high quality of life. Knowledge about dementia is primarily associated with the attitude regarding quality of life of dementia patients. Respondents who know more about treatment, prevention and life impact are less likely to believe that dementia patients have a very high quality

Table 4 Association between social factors, dementia knowledge and attitudes: odds ratios (OR), 95 % confidence intervals (CI) and significance-values (*p*) (Germany 2012)

	“People with dementia are better taken care of in nursing homes than at home.” (agree)		“Despite their disorder, dementia patients have a very high quality of life.” (agree)		“To know early that you have dementia is not good at all.” (agree)	
	OR (CI)	<i>p</i>	OR (CI)	<i>p</i>	OR (CI)	<i>p</i>
Gender*						
Female	0.80 (0.65–0.98)	0.031	1.36 (1.09–1.69)	0.006	0.98 (0.73–1.31)	0.871
Age (years)*						
41–59	0.99 (0.77–1.28)	0.953	0.84 (0.65–1.10)	0.205	1.02 (0.68–1.53)	0.940
60+	0.91 (0.70–1.19)	0.497	0.69 (0.52–0.91)	0.009	2.27 (1.56–3.34)	0.000
SES*						
Middle	0.87 (0.67–1.12)	0.266	0.92 (0.71–1.19)	0.514	0.64 (0.46–0.89)	0.008
High	0.76 (0.55–1.05)	0.100	0.67 (0.47–0.94)	0.021	0.51 (0.32–0.80)	0.003
Contact with dementia patients*	0.86 (0.69–1.07)	0.181	0.92 (0.73–1.16)	0.504	0.99 (0.72–1.35)	0.944
Care experience*	0.61 (0.45–0.83)	0.002	1.65 (1.21–2.26)	0.002	1.09 (0.71–1.64)	0.693
Knowledge items*						
Treatment	0.84 (0.68–1.04)	0.111	0.73 (0.58–0.91)	0.005	0.83 (0.62–1.12)	0.215
Cause	1.01 (0.79–1.29)	0.929	1.10 (0.85–1.42)	0.465	1.10 (0.77–1.54)	0.600
Prevention	1.12 (0.87–1.43)	0.376	0.69 (0.53–0.91)	0.008	0.82 (0.56–1.17)	0.274
Diagnosis	1.20 (0.85–1.70)	0.299	1.03 (0.71–1.48)	0.870	1.24 (0.77–1.95)	0.353
Life impact	1.38 (1.13–1.69)	0.002	0.78 (0.63–0.97)	0.024	0.75 (0.56–0.99)	0.041
Observations	1625		1619		1617	
Nagelkerkes- <i>R</i> ²	0.024		0.054		0.059	

* Reference categories: age 18–40, male gender, low SES, no contact, no care experience, wrong answer given to knowledge item. *p* values <0.05 are in bold

of life. Moreover, knowing more about the life impact of dementia is significantly associated with attitudes about home care and early detection.

Discussion

The aim of this study was to investigate knowledge about dementia, an important component of dementia literacy (Low and Anstey 2009), that can be considered as a variation of mental health literacy (Jorm 2000). Based on a national survey, we particularly analysed what the German public knows about dementia and how social factors as well as contact with dementia patients and care experience are related to this knowledge. Furthermore, associations of people’s attitudes/beliefs about dementia with social factors, dementia experience and dementia knowledge were investigated.

Knowledge about five important aspects of dementia (cause, prevention, diagnosis, treatment and life impact) in the German public is characterized by a relatively high uncertainty. Between one and two-thirds of the respondents stated that they would not know whether the given statements are correct or not. On the other hand, more than 50 % knew that there is no medication to cure dementia and that it

would not be safe for a dementia patient to drive a car. The statement about an unambiguous diagnosis was indeed a rather specific question and therefore the most difficult one, which only 9 % could answer correctly. Compared to results from Carpenter et al., who applied the ADKS, our sample seems to have less knowledge about AD (Carpenter et al. 2011). However, due to a missing “don’t know” option in the ADKS, guessing of participants may lead to better results (Carpenter et al. 2009). Furthermore, Carpenter et al. analysed knowledge about dementia in specific populations (trained students, older adults, senior centre staff, dementia caregivers and dementia professionals) with more experience in dementia and dementia care compared to the general population. A German public survey with 1245 individuals between 14 and 99 years conducted by Schwalen and Förstl (2008) showed that most of the general population is not familiar with AD and dementia. They found a remarkable lack of relevant information about this illness, e.g. only 13 % mentioned memory disturbances, e.g. forgetfulness, as hallmarks of AD, and only 54 % knew that age was a major risk factor. Although the item difficulty is hardly comparable with our questions—Schwalen and Förstl used six open questions—we consider our results to be in line with their study.

Gender and age are inconsistently associated with knowledge about dementia. There is no general pattern indicating that either male or female respondents would have better dementia knowledge. This is consistent with several studies that also found no or only little differences in dementia knowledge according to gender (Carpenter et al. 2011; Nordhus et al. 2012; Scerri and Scerri 2013). In terms of age, there is only one significant association: Older people are less likely to know details about the effectiveness of medication. Thus, older people do not seem to know more about dementia than younger ones, although one could assume that older people are more concerned about dementia due to the increasing probability of being affected—either personally or with respect for their next to kin. People from higher status groups tend to know more about dementia-related issues. In particular, high SES was significantly correlated with knowledge about treatment, prevention and diagnosis. Thus, our findings indicate a social inequality in some aspects of dementia literacy and partly confirm other studies that found associations between SES and mental health literacy (von dem Knesebeck et al. 2013).

Respondents who care or have cared for a person with dementia (12.3 % in our sample) are significantly better off in terms of dementia literacy. This holds true for all five aspects of dementia literacy under study. This finding is similar to the results of the study from Carpenter et al. (2011) who also found that caregivers of dementia patients achieve better scores in knowledge tests. Furthermore, people who had or have contact with dementia patients without caring for them (33.1 % in our sample) also seem to know more about dementia. Regarding attitudes about dementia, women and respondents with care experience are less likely to state that people with dementia are better taken care of in nursing homes than at home. Respondents who know more about dementia are more likely to agree to this statement, although the associations are mostly weak. These respondents with high dementia literacy are less likely to believe that dementia patients have a high quality of life, just like older people and people with a high SES. Women and respondents with care experience hold more positive views in this regard (Bédard et al. 2005; Pinquart and Sörensen 2006; Lüdecke et al. 2012). Finally, higher status groups and respondents with pronounced dementia literacy tend to be less skeptical about early detection of dementia. Early detection of dementia provides benefits for patients, caregivers, and the healthcare system, although currently there are no curative treatments available for the most common form of dementia, Alzheimer's disease (Luck et al. 2012). A recent study with 506 elderly participant showed that 71.2 % indicated that they wanted to be screened for Alzheimer's disease even on a regular basis (Braun et al. 2014). These findings are confirmed by

Hausner et al. (2012), where the general population and even more, the family caregivers approve regular screenings (73, and 78 % respectively). This is also comparable to Schwalen and Förstl's finding that in case of developing AD, more than 70 % wished to be informed together with a close relative or friend (2008). All these studies, however, do not account for social determinants.

Overall, explained variances of dementia knowledge and dementia-related attitudes vary only between 2 and 6 %. In this context, we also have to point out that associations between social factors, dementia knowledge and attitudes are rather weak and inconsistent. Thus, other factors, not considered in our analyses need to be taken into account to understand variations in dementia knowledge and attitudes. We assume that factors which lead to higher dementia knowledge or different attitudes are manifold and individual, most likely depending more on personal interests and awareness, unique events and experiences in social circles and family, rather than on SES or age group. Dealing with and concerning about dementia seems to be only partly concentrated in population groups with higher risks or potential relevance. If we take this more or less unsystematic emergence combined with the relatively little knowledge in dementia as an indicator for the preparedness of a society towards dementia and its challenges, we can conclude that this topic has not entered the public discourse very much so far.

Our study has some limitations to be considered when interpreting the results. First, due to non-response, the sample has a slight selection bias towards higher educated people. A weight factor to compensate for non-response bias was used in the descriptive analyses. However, this weight is not useful for multivariate analyses as it may inflate the variances of the coefficient estimators in regression models, leading to larger standard errors (Fuller 2009; Skinner and Mason 2012). Secondly, we only used five items representing different aspects to assess knowledge about dementia. This cannot be considered a comprehensive measure of knowledge about dementia; however, it is not far-off measures used in other German population surveys (Luck et al. 2012 or Schwalen and Förstl 2008). Moreover, the items used in our study cover important dimensions of dementia literacy, i.e. causes, effectiveness of prevention, certainty of diagnosis, treatment possibilities and (negative) impact on everyday life. Furthermore, we decided to dichotomize the variables and to use logistic regression models as the response scales on knowledge and attitudes are neither metric nor showed normal distributions. Therefore, the results on associations are crude to some extent. Finally, a mail survey containing knowledge items allows respondents looking-up correct answers instead of spontaneously answering based on personal knowledge. However, regarding the distribution

of wrong given and ‘don’t know’ answers, we consider this potential bias as rather low.

Despite these limitations, we think that our results have several implications. Dementia literacy is a factor that has an impact on prevention, recognition and management of dementia (Low and Anstey 2009). A rising awareness of dementia and its consequences for individuals and families are an important matter as it would give people a better chance to talk about their opinions, wishes and fears in order to be prepared better for possible future needs and plans.

Two major and well-established strategies to improve knowledge, change attitudes and to reduce stigma are education and promoting personal contact with dementia patients (Rüsch et al. 2005). In terms of education, public campaigns need to reduce uncertainty and should promote positive views of dementia. Our results indicate that possible messages of such campaigns may be that early detection provides benefits for patients and caregivers (Luck et al. 2012) and that there are marked differences in functioning among individuals with dementia and that their self-rated wellbeing is similar to others of the same age (Mukadam and Livingston 2012). Moreover, our findings suggest that information campaigns should consider information needs of people with a low SES. Finally, results presented here show the importance of care experiences and personal contact with patients for dementia literacy. Therefore, contact-based approaches in which people meet individuals with dementia and/or their relatives may help to increase knowledge. To modify attitudes towards dementia and those who are afflicted directly or indirectly as caregivers, our results suggest that sole contact to persons with dementia without “lived experience” with the disease may be less sufficient. Rüsch et al. (2005) report that, for instance, colleagues or remote relatives with mental illnesses are perceived as not typical for the disease. Therefore, just “having contact” is unlikely to modify attitudes. Hence, contact-based approaches should also focus on including carers’ perspectives, providing a deeper understanding of dementia symptoms and thus reducing fear or stigma against dementia.

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