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Cognitive and emotional attitudes towards dementia and persons with dementia in family carers and individuals with no experience in caring

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Abstract

Introduction: Perception of dementia and direct contact with individuals with dementia seem to be important factors modifying attitudes towards the patient group. The study aims were formulated to assess: (1) the difference between carers for a family member with dementia and those with no experience in caring for a chronically ill person in terms of their perceptions of dementia, competence and warmth ratings of persons with dementia and feelings about them, (2) the influence of dementia representation and experience of caring on warmth, competence ratings and feelings about persons with dementia.

Material and methods: A total of 57 individuals participated in the study, including: 27 family carers (Cg) and 30 controls without caregiving experience (C). The Revised Illness Perception Questionnaire (IPQ-R) and experimental tasks of our own design were used to assess attitudes to dementia itself and persons with dementia.

Results: The study showed significant differences between groups and specific profiles of each group in the range of dementia representation and perception of individuals with dementia. The significant associations between various aspects of dementia perceptions and attitudes towards people with dementia were obtained. Experiences in caring for individuals with dementia partially explained the perception of their efficiency.

Conclusions: Family carers highlight self-confidence as a dominant characteristic of individuals with dementia, which may reflect some dementia deficits. Pity as a substantial characteristic in emotional attitude towards persons with dementia prevails in individuals with no experience in caring, whereas anxiety predominates in family carers.

Keywords: dementia representation, caregiving, feelings about persons with dementia

Streszczenie

Wstęp: Reprezentacja demencji i doświadczenia bezpośredniego kontaktu z osobami z demencją wydają się być istotnymi czynnikami modyfikującymi ustosunkowania wobec tej grupy osób. Celem podjętych badań było oszacowanie: (1) różnic między rodzinnymi opiekunami a osobami bez doświadczenia w sprawowaniu opieki w zakresie: reprezentacji demencji, postrzegania kompetencji osób z demencją w codziennym funkcjonowaniu i w interakcjach społecznych oraz odczuć wzbudzanych przez osoby z demencją; (2) wpływu reprezentacji demencji oraz doświadczenia sprawowania opieki na postrzeganie kompetencji osób z demencją w codziennym funkcjonowaniu i w interakcjach społecznych oraz na odczucia wzbudzone przez osoby z demencją.

Materiał i metody: W badaniu uczestniczyło 57 osób, w tym 27 rodzinnych opiekunów i 30 osób bez doświadczeń w sprawowaniu opieki. Zastosowano zmodyfikowany Kwestionariusz Percepcji Choroby (IPQ-R) w celu oszacowania, czym dla opiekuna jest choroba osoby bliskiej. Dla oceny ustosunkowania się wobec osób z demencją zastosowano zadania własnej konstrukcji.

Dyskusja: Badanie wykazało istotne różnice międzygrupowe oraz specyficzne profile każdej z badanych grup w zakresie reprezentacji demencji oraz postrzegania osób z demencją. Stwierdzono istotne powiązania między różnymi wymiarami reprezentacji demencji oraz ustosunkowania wobec osób z demencją. Percepcja skuteczności osoby z demencją jest częściowo wyjaśniana przez posiadanie doświadczenia w sprawowaniu opieki.

Wnioski: Rodzinni opiekunowie podkreślają pewność siebie jako istotną charakterystykę osób z demencją, co może być powiązane z deficytami charakterystycznymi dla procesu otepiennego. Litość w emocjonalnym ustosunkowaniu względem osób z demencją przeważa u osób bez doświadczenia w sprawowaniu opieki, podczas gdy u rodzinnych opiekunów dominuje obawa i niepokój.

Słowa kluczowe: postrzeganie demencji, sprawowanie opieki, odczucia wobec osób z demencją

1. Introduction

According to the ageing of the population, the number of chronically ill people, including those with dementia, is increasing [1]. The progressive dementia process, resulting from degenerative changes involving the central nervous system, leads to a gradual loss of independence and requires the provision of support in daily functioning. The stereotypical depiction of a person with dementia is that of an old individual, who loses their memory, mind and identity, behaves unpredictably and is suffering [2,3]. Many factors such as health condition of the person, individuals' exposure to people with dementia, their awareness of the nature of dementia, its course and treatment options may be important for social attitudes toward individuals with dementia [4,5,6]. According to Putland and Brookes [3], one in five British adults believes that dementia is an inevitable part of aging, and such misconceptions may contribute to negative attitudes toward people with dementia. In cross-cultural exploratory study by Calia et al. [7] the American, Chinese and British lay public shared a fundamental understanding of dementia as a cognitive pathological condition. One of the theoretical constructs used to describe individualised illness representation is the Common-Sense Model of Self-Regulation of Health and Illness [8,9], which comprises some characteristics of the disease, like beliefs concerning: timeline, consequences, personal control, efficacy of treatment and causes of illness. The lay public perceived dementia as chronic illness with severe consequences and believed that it is uncontrollable, but to some extent it depends on treatment. Their opinions were that the main causes of dementia stem from risk factors, followed by psychological factors [10]. Parveen et al. [11] indicated that families and community perceive dementia in category of a biological basis for memory loss, nevertheless a number of misconceptions regarded the cause of dementia. Moreover, participants also made use of religion as a form of personal and treatment control. The review of Shinan-Altman and Werner [12] revealed that regardless of the population examined (lay public, family caregivers) dementia was mostly described as a chronic condition, presenting more cognitive than behavioural symptoms, and as being caused mainly by age, heredity and abnormal brain changes. Few studies have specifically explored illness representations in family carers of people with dementia. One of them was a case study comparing illness representation held by the person with dementia, the carer and the general practitioner [13]. The quantitative study by Roberts and Connell [14] showed misconceptions

and unrealistic beliefs of family members about the potential for dementia treatment. An exploratory study of family caregivers by Quinn et al. [15] has the descriptive character and it was meant to identify the extend of uncertainty about the cause, timeline, and controllability of dementia. The causes of dementia, according to family caregivers, included biological heredity, aging, and lifestyle factors. Quinn et al. [6] conducted the study in the large cohort of informal caregivers of individuals with dementia to explore dementia representation. They indicated that most caregivers believed that the person's with dementia condition was due to changes in the brain, and they felt the person's condition would get worse. They were split in their opinions as to whether the person with dementia could do anything to control the effects of his/her condition. Understanding caregivers' perception of dementia is important, given that illness representation can influence their response to care recipients [15,16].

Previous studies have found that older adults with dementia may be seen in a particularly negative light, which is reflected in social stigma [17,18,19,20,21,16]. The specific features of dementia process may lead to categorisation of a patient as "other" from individuals without memory problems and conduce to the loss of previous life status [22]. What is important, the diagnostic label of dementia alone may elicit stigma even if the dementia symptoms are not explicit [23,24]. Individuals with a dementia diagnosis, which serves as salient reminders of aging and mortality, may evoke death-related thoughts and death anxiety in other people (The Terror Management Theory) [4]. On the other hand, some studies including dementia community members and their carers showed also positive attitudes towards individuals with dementia. They revealed high levels of prosocial emotions, such as compassion, empathy and low levels of negative emotions like anger [25,18,26,27]. The stereotype content model by Cuddy and Fiske [28] indicates that social categorisation proceeds along the following orthogonal dimensions: competence and warmth. The Cuddy-Fiske model suggests that these two dimensions are relatively independent and provide a framework for understanding overall impressions of individuals or groups and affective reactions toward them. Several studies confirmed that college students perceive older adults as low in competence but high in warmth [29,30]. This model was applied in study conducted by Diekfuss et al.'s [31] on undergraduate students' perception of older persons with dementia, who, contrary to Fiske et al.'s [32] findings about elderly, were not rated as incompetent. According

to Diekfuss et al. [31] it is possible that attitudes about ageing and dementia are changing within these almost two decades, so the research should be continued.

Different combinations of stereotypic warmth and competence result in unique intergroup emotions [32]. The conceptualization of stigma includes emotional reactions as one important component besides labelling, stereotyping, cognitive separating, status loss and discrimination [33,5]. The common frames for dementia are depicted in association with negative emotions. Older persons with dementia were described as acting outside social norms, therefore they evoke emotional responses such as shock, anger, aggression, shame, indifference, and fear, which is the most common emotion associated with dementia [2]. Von dem Knesebeck et al. [5] indicated that between 25% and almost 50% of the population showed reactions indicating fear, which is strongly connected with a desire of social distance. A report by Alzheimer's Disease International [34] highlighted that about 80% of people are fearful of dementia and interacting with those with dementia. Guilty, pity and compassion were other feelings related to dementia [35,36]. Some previous research proved that attitudes toward individuals with dementia have also positive components. Werner and Davidson [37] found more positive emotional reactions addressed to people with dementia, including a desire to help, compassion, and concern than negative ones, such as rejection, anger, irritation, disgust, and consternation. Von dem Knesebeck et al. [5] revealed that the vast majority of their respondents expressed prosocial reactions, such as pity, sympathy and the need to help a person with dementia; they relatively rarely declared anger. It has been shown that meeting individuals with dementia can decrease stereotypic thinking in general public [38]. Cheng et al. [39] found that knowledge of a relative or friend with dementia had lowered stigmatizing attitude towards persons with dementia. Von dem Knesebeck et al. [5] confirmed that individuals who had contacts with a person having dementia or who had cared for a person with dementia tended to show less negative reactions than fear or anger, and more prosocial reactions.

In view of the predominant family care for persons with dementia recorded in Poland, it is important to identify social attitudes towards dementia itself and people struggling with it. Outlining this issue seems to be important both for family carers carrying out the complex tasks of long-term care for a relative in the dementia process and for people with no experience of caregiving. In the light of the above the aims of the study were formulated to assess: (1) the differences between carers for a family member with dementia and those with no experience in caring for a chronically ill person in terms of dementia representation, warmth and competence ratings

of persons with dementia, and feelings about them, (2) the influence of dementia representation and experience of caring on warmth, competence ratings, and feelings about persons with dementia.

We hypothesized differences in dementia perception held by carers for a family member with dementia and individuals with no experience in caring. In this study, we have chosen to focus on five components of dementia representations: timeline, consequences, control, illness coherence and causes. It is worth underlining that there has been little exploration of dementia representation both in family carers and in persons without caregiving experience [12]. Moreover, dementia is not a single, clearly defined disease entity and the mechanisms are not always obvious [6]. Previous research indicated that carers have basic knowledge about dementia, nevertheless, some of their beliefs are diverse and uncertain [15;6].

In terms of characteristics used to describe a person with dementia we evaluated the exploratory hypothesis that carers may differ in warmth and competence ratings from individuals with no experience in caregiving. An exploratory hypothesis about the differences between two tested groups was also formulated in reference to feelings evoked by persons with dementia. We expected that the direct contact with a person with dementia may modify attitudes toward individuals with dementia [5,39]. On the basis of a systematic review, in people which are not in direct contact with persons with dementia, feelings commonly associated with persons' dementia were fear, shame, compassion and guilt. Positive feelings were also present, though they were less common [2]. Carers of persons with dementia manifested less negative emotional reactions than positive [5]. However, there were no studies comparing warmth and competency ratings, and feelings evoked by persons with dementia between carers and individuals with no experience in caring.

The next assumption was the influence of dementia perception and caring on ratings for competence, warmth and feelings evoked by individuals with dementia. According to the scoping review by Shinan-Altman and Werner [12] it should be noted that research in the area of dementia and illness representation is mostly descriptive and, what seems to be important, only few studies examined factors associated with dementia representation, e.g. help-seeking, professional burnout, and sense of coherence. To date, no research has explicitly estimated the relationships between perceptions of dementia and attitudes towards persons with dementia in family carers and people without experience in caring. Exploring these relationships would provide a deeper insight into the understanding of the illness and persons with dementia. The beliefs about dementia may have relevant meaning for responses to persons with dementia

and increase readiness to support them [15,16].

2. Method

2.1. Participants

The research carried out was approved by the university's Ethics Committee for Research (Opinion No. 19/2019). The study covered a total of 57 participants including 27 family carers living in the same household with a relative with dementia (Cg) and 30 controls (C) who were not carers and in their close family there were no relatives with chronic illness demanding assisting. None of the participants had a history of neurological or psychiatric disorders. All participants received information regarding the scientific nature of the research and its anonymity, as well as the possibility to withdraw from the study at any stage. They gave written consent to take part in the research, which was carried out by psychologists in the form of one-to-one interviews. Despite efforts undertaken to provide a sense of anonymity and comfort to potential participants, some of the family carers refused to participate in the research, dropped out during the survey or did not respond to all question. There were no significant differences between Cg and C groups in age ($M_{Cg} = 54.89$, $SD_{Cg} = 12.20$; $M_C = 51.77$, $SD_C = 6.38$, $t = -1.229$, $p = .224$; $d = -.326$) and education level ($M_{Cg} = 13.78$, $SD_{Cg} = 2.58$; $M_C = 14.27$, $SD_C = 2.80$, $t = 0.683$, $p = .498$; $d = .18$). In the sample 81% of the carers and 75% of the controls were women. Total duration of care was $M = 6.6$ ($SD = 4.2$). All of the care recipients attended day care homes for a few hours a day participating in a programme of activities.

2.2. Measures

The Revised Illness Perception Questionnaire (IPQ-R) [40,41], conceptually based on the Common-Sense Model of Self-Regulation of Health and Illness [42,8], was administered to assess the perception of dementia. The items were modified to express participants' perception of dementia (e.g., *My illness is a serious condition* was replaced by *His/her illness is a serious condition*). The similar procedure was applied in previous studies [41,43]. The following factor subscales were used: Timeline Acute/Chronic, Timeline Cyclical, Consequences, Personal Control, Treatment Control, Illness Coherence. Participants also estimated the potential causes of dementia (stress/worry, heredity, pollution in the environment, poor medical care in the past, ageing, alcohol, smoking, accident/injury, personality). Respondents indicated the extent to which they agreed with a statement on a Likert scale (1 - strongly disagree, 6 - strongly agree). Subscales of modified version of IPQ-R showed consistent reliability (Cronbach's alpha ranging from 0.76 to 0.96) [41].

In order to assess the competence and warmth

of persons with dementia, and feelings about them, experimental tasks of our own design based on the study of Diekfuss et al. [31] were used. In the first task, the examined individuals indicated the extent to which they could attribute to the persons with dementia characteristics describing their competence in performing everyday tasks (efficient, capable, confident, independent) and characteristics concerning warmth in interpersonal relationships (friendly, well-intentioned, trustworthy, warm, kind, good-natured, sincere). In the second task, the participants determined the extent to which persons with dementia evoked in them the following feelings: positive (inspiration, fondness, admiration, pride and respect), negative (disgust, contempt, hatred, resentment, embarrassment, jealousy, frustration, anger) as well as empathy (sympathy, affection, good-will, tenderness, sensitivity), pity (compassion, mercy, understanding), fear (anxiety, worry). Response possibilities were on a Likert scale (1 - strongly disagree, 6 - strongly agree).

2.3. Statistical analysis

Data were analysed using the SPSS Statistics software (version 29). A parametric t test was used to investigate intergroup differences in age and education. The effect size for the t test (Cohen's d) was also calculated. Mixed-design ANOVAs were carried out to calculate the effects of group (between-subjects factor) and dimensions of the tasks (within-subject factor) on views about dementia, causes of dementia, competence, warmth, and feelings ratings. To identify the correlations between IPQ-R indices and competence and warmth ratings, and feelings about individuals with dementia, the Pearson (r) coefficient was applied. In order to determine whether caregiving uniquely contribute to the competence, warmth and feelings ratings above and beyond the perception of dementia, there were conducted several hierarchical regressions entering selected scales of IPQ-R at the first step (model 1), and Caregiving at the second step (model 2). To assess the multicollinearity in regression models a tolerance test (T) and Variance Inflation Test (VIF) were used. Statistical significance was set at .05 for all analyses.

3. Results

3.1. Dementia representation in family carers and those without experience in caring

The results obtained with mixed model ANOVA (Table 1) showed significant main effect of the dimensions of IPQ-R ($p < .001$). Pairwise comparisons with Bonferroni test showed that all participants rated dementia in dimensions of Timeline Acute/Chronic and Consequences significantly higher than Treatment Control, Personal Control, Timeline Cyclical and Illness Coherence ($p < .001$). Participants obtained also significantly lower scores in

Personal Control compared to Treatment Control ($p = .013$), Illness Coherence ($p = .026$), and Timeline Cyclical ($p < .001$). There was not significant main effect of group

and interaction between group and dimensions of IPQ-R. However, despite the lack of main effect of group, pairwise comparison revealed the significant difference in Illness

Table 1. Comparisons of IPQ-R indices, competence and warmth ratings and feelings evoked by persons with dementia in carers (Cg) and controls (C)

	Cg (<i>n</i> = 27) <i>M</i> (<i>SD</i>)	C (<i>n</i> = 30) <i>M</i> (<i>SD</i>)	Group effect		Type of task effect		Interaction effect	
			<i>F</i> (<i>p</i>)	η ²	<i>F</i> (<i>p</i>)	η ²	<i>F</i> (<i>p</i>)	η ²
Dementia representation (modified version of IPQ-R)								
Views about dementia								
Timeline Acute/Chronic	83.25(13.99)	82.13(14.92)	1.204 (.277)	.021	60.068 (<.001)	0.522	2.320 (.064)	.04
Timeline Cyclical	59.63(7.84)	61.17(8.17)						
Consequences	78.37(11.82)	77.33(11.70)						
Treatment Control	55.63(11.97)	58.77(12.18)						
Personal Control	50.04(15.13)	50.23(10.18)						
Illness Coherence	64.44(13.33)	53.33(14.26)						
Views about causes of dementia								
Stress/worry	3.37(.97)	3.23(1.10)	5.350 (.024)	.089	14.299 (<.001)	0.206	3.546 (.001)	.061
Heredity	3.33(1.24)	3.73(.87)						
Poor medical care	2.52(1.05)	2.67(1.09)						
Environment pollution	2.59(.84)	2.77(.90)						
Ageing	3.93(.96)	4.20(.71)						
Alcohol	3.67(.80)	3.93(.96)						
Smoking	2.56(1.15)	3.10(.84)						
Accident/injury	2.74(1.13)	3.57(.68)						
Personality	3.26(.86)	2.70(.95)						
Competence and warmth of individuals with dementia								
Competence ratings								
Efficient	2.54(1.10)	3.20(1.10)	3.030 (.087)	.053	10.199 (<.001)	.159	2,850 (.048)	.050
Capable	2.15(1.05)	2.93(1.08)						
Confident	2.85(1.38)	2.83(1.21)						
Independent	2.00(1.06)	2.23(1.10)						
Warmth ratings								
Friendly	3.96(1.08)	4.06(.87)	2.410 (.126)	.043	30.078 (<.001)	.358	1.665 (.161)	.030
Well-Intentioned	4.12(.71)	4.27(.78)						
Trustworthy	2.35(1.35)	2.97(1.00)						
Warm	4.00(.89)	4.03(.81)						
Kind	3.92(1.06)	4.01(.76)						
Good-Natured	3.73(1.08)	4.10(.92)						
Sincere	3.58(1.21)	4.20(.92)						
Feelings evoked by individuals with dementia								
Positive feelings	53.54(11.62)	50.23(10.45)	.097 (.757)	.002	66.491 (<.001)	.552	5.197 (.001)	.088
Negative feelings	36.19(11.26)	34.19(9.89)						
Pity	61.00(25.96)	73.73(14.84)						
Fear	66.04(19.59)	57.47(15.37)						
Empathy	70.00(9.92)	74.80(13.14)						

Coherence with higher scores in caregivers than controls ($p = .004$).

For views about causes of dementia main effects of group ($p < .024$) and the type of etiology factor ($p < .0001$) as well as the interaction effect of group and type of etiology factor ($p < .001$) were significant. Carers rated Alcohol ($p = .002$); Smoking ($p = .046$), and Accident/injury ($p = .001$) significantly lower than Controls. Nevertheless, they assessed Personality significantly higher than controls ($p = .024$). The Bonferroni post-hoc tests showed that profiles of potential causes of dementia are characteristic for each group. In the carers group only ageing ratings were significantly higher for: Poor medical care, Environment pollution, Alcohol, Smoking, and Accident/injury ($p < .001$). In controls Aging ratings were significantly higher for Stress/worry (for all: $p < .001$), Poor medical care ($p < .001$), Smoking ($p = .002$), and Accident/injury ($p = .045$). It was revealed that Heredity ratings were higher for Poor medical care ($p = .012$), Environment pollution ($p = .014$), and Personality ($p = .005$). Alcohol and Accident/injury were also rated higher than Personality ($p = .007$). Poor medical care ratings were significantly lower for Personality ($p < .001$), Alcohol ($p = .015$), and Accident/injury ($p = .034$). These two last factors were assessed higher than Environment pollution ($p = .048$, $p = .012$, respectively).

3.2. *Perceiving persons with dementia in terms of competencies related to daily functioning and warmth in social interaction*

According to competency ratings, there was a significant main effect of dimensions of competency ($p < .001$) and interaction effect between group and dimensions of competency ($p = .048$). The main effect of group was no significant (Table 1). Caregivers showed significantly lower ratings individuals with dementia in Efficient ($p = .029$) and Capable ($p = .008$) dimensions than Controls. Tested groups did not differ in the range of Confident ($p = .970$) and Independent dimensions ($p = .425$). Pairwise comparisons showed that Caregivers revealed significantly higher ratings in Confident than Capable ($p = .027$) and Independent ($p < .001$). Controls showed significantly lower ratings in Independent than Confident ($p = .011$), Capable ($p = .007$), and Efficient ($p < .001$).

The results obtained with mixed model ANOVA showed no significant main effect of group and interaction effect between group and dimensions of ratings for warmth characteristics of individuals with dementia (Table 1). However, there was a significant main effect of dimension of warmth with significantly lower ratings for trustworthy than for friendly, well-intentioned, warm, kind, good-nature and sincere ($p < .001$) independently on

caring.

3.3. *Assessment of feelings evoked by persons with dementia*

According to ratings of feelings evoked by persons with dementia there was not significant main effect of the group. However, a significant main effect for feelings dimensions and interaction effect were identified (Table 1). Carers obtained significantly lower scores than Controls only in Pity ($p = .026$); they did not differ in Positive feelings ($p = .268$), Negative feelings ($p = .477$), Fear ($p = .072$), Empathy ($p = .134$). Bonferroni post-hoc tests showed that Negative feelings had the lowest ratings than other dimensions in both groups ($p < .001$). Carers had significantly lower ratings in Positive feelings than in Fear ($p = .004$) and Empathy ($p < .001$). Controls rated Positive feelings lower than Pity and Empathy ($p < .001$) as well as Fear than Pity ($p = .004$) and Empathy ($p < .001$).

3.4. *The impact of dementia representation and experience of caring on competence, warmth and feelings ratings*

Regression models were built on the base on analysis of correlation coefficients between IPQ-R indices and competence, and warmth ratings, and feelings about individuals with dementia. The significant correlations between Timeline Acute/Chronic, Illness Consequences, Personal Control and Efficacy ($r = -.348$, $p = .009$; $r = -.438$, $p < .001$; $r = .319$, $p = .017$, respectively); Timeline Acute/Chronic, Illness Consequences and Independence ($r = -.407$, $p = .002$; $r = -.353$, $p = .008$, respectively); Personal Control and Confident ($r = .345$, $p = .009$); Timeline Acute/Chronic, Timeline Cyclical and Positive feelings ($r = -.349$, $p = .008$; $r = .285$, $p = .033$, respectively) were identified. Therefore these variables were included into the regression models. Other correlations did not reach the significant level ($p > .05$).

In order to determine whether caregiving distinctly contributed to competence, warmth and feelings ratings hierarchical regressions were performed, using Efficient, Independence, Confident or Positive feelings as criterion variables (Table 2). Mean values of VIF indices for all predictors in several models is lower than 2 and a tolerance test value (T) is higher than 0.2, which means that predictors are not strongly associated [44,45]. The results of analyses, using Efficient as a criterion, demonstrated that IPQ-R Timeline Acute/Chronic, Illness Consequences, and Personal Control were not significant predictors of Efficient ratings. After introducing Caregiving to the regression model these variables remained insignificant and Caregiving significantly accounted for approximately an additional 7.5% of variance. In the regression model with Independence as a criterion, IPQ-R Timeline Acute/Chronic but not Consequences was a significant predictor and remained when Caregiving was included. Nonetheless

Caregiving is not a significant predictor for Independent rating. Regarding the Confident rating, IPQ-R Personal Control was a significant predictor even after introducing Caregiving, which appeared insignificant. In the range of Positive feelings ratings, IPQ-R Timeline Acute/Chronic

but not Timeline Cyclical was a significant predictor, once Caregiving was included, both IPQ-R Timeline Acute/Chronic and Timeline Cyclical were significant predictors, but not Caregiving (Table 2).

Table 2. The impact of dementia representation and caregiving on competence, warmth and feelings ratings (the hierarchical regression model)

Model		B	SE	t	p	Inflation tests	
Outcome variable: Efficient						T	VIF
model 1	Timeline Acute/Chronic	-.193	.046	-1.328	.190	.706	1.417
	Consequences	-.261	.058	-1.455	.152	.465	2.149
	Personal Control	.131	.047	.840	.405	.614	1.629
	R ² _{kor} = .178, MSE = 1.032, F (3,52) = 4.980, p = .004						
model 2	Timeline Acute/Chronic	-.187	.044	-1.339	.187	.706	1.417
	Consequences	-.251	.055	-1.460	.150	.465	2.150
	Personal Control	.135	.045	.950	.370	.614	1.629
	Caregiving	.275	.266	2.339	.023	.998	1.002
R ² _{kor} = .243, MSE = .991, F (4,51) = 5.424, p = .001 ; R ² _{chg} = .075; F = 5.471; p = .023							
Outcome variable: Independent							
model 1	Timeline Acute/Chronic	-.306	.043	-2.135	.037	.738	1.355
	Consequences	-.197	.044	-1.369	.177	.738	1.355
	R ² _{kor} = 0.164, MSE = 0.987, F (2,53) = 6.387, p = 0.003						
model 2	Timeline Acute/Chronic	-.304	.043	-2.109	.040	.737	1.356
	Consequences	-.194	.044	-1.348	.184	.737	1.356
	Caregiving	.090	.266	.725	.471	.998	1.002
	R ² _{kor} = .156, MSE = .992, F (3,52) = 4.395, p = .008; R ² _{chg} = .008; F = .471, p = .471						
Outcome variable: Confident							
model 1	Personal Control	.345	.043	2.697	.009	-	-
	R ² _{kor} = 0.102, MSE = 1.209, F (1,54) = 7.272, p = 0.009						
model 2	Personal Control	.345	.043	2.672	.010	-	-
	Caregiving	-.008	.327	-.063	.950	-	-
	R ² _{kor} = .085, MSE = 1.220, F (2,53) = 3.571, p = .035; R ² _{chg} < .001; F = .004 p = .950						
Outcome variable: Positive feelings							
model 1	Timeline Acute/Chronic	-.319	.114	-2.547	.014	.985	1.015
	Timeline Cyclical	.246	.157	1.963	.055	.985	1.015
	R ² _{kor} = .150, MSE = 3.044, F (2,53) = 5.872, p = .005						
model 2	Timeline Acute/Chronic	-.324	.113	-2.612	.012	.984	1.016
	Timeline Cyclical	.263	.255	2.112	.040	.976	1.024
	Caregiving	-.181	.811	-1.463	.149	.990	1.010
	R ² _{kor} = .214, MSE = 3.012, F (3,52) = 4.712, p = .006; R ² _{chg} = .032; F = 2.140, p = .149						

T- a tolerance test value; VIF - Variance Inflation Test

4. Discussion

According to demographic changes and increasing number of older adults with dementia more and more lay community members will come in contact with older adults with cognitive deterioration. Therefore, the first aim explored in this study was to compare dementia representation, competences, as well as warmth ratings and feelings evoked by persons with dementia in family carers and those with no experience of caring.

The hypothesis about differences in dementia perception between the two tested groups was only partially confirmed. Perceptions of dementia were similar in many respects, regardless of caregiving experience. The prevailing view was that the disease was long-lasting and chronic, that it was severe, and that it had a significant impact on daily life. The possibility of controlling the disease through one's own actions was considered ineffective, while the impact of treatment on the course

of the disease was rated slightly higher. Nevertheless, it should be noted that caregivers revealed higher sense of illness coherence in the range of comprehensibility than individuals with no experience in caring. These findings are partially congruent with some previous studies, which show that dementia is perceived by lay public as chronic illness with serious consequences, not controllable and dependent to some degree on medical treatment [10,11]. In the studies of family carers some uncertainty and discrepancy about the timeline and especially about controllability of dementia were found despite their basic knowledge about this illness [14,15,6], and its progressive nature [6]. In the present study, greater diversity between the studied groups was found regarding causes of dementia. The previous studies revealed that a part of British lay public believed that dementia was an inevitable part of ageing [3] and a number of misconceptions about the cause of dementia were underlined [11]. Most caregivers believed that dementia was caused by changes in the brain [6]. The scoping review showed that regardless of the examined population, dementia was perceived as being caused mainly by age, heredity and abnormal brain changes [12]. The present study provides more detailed information about perceptions of potential dementia causes and their variety in tested groups. Compared to those with no caring experience, carers were less likely to attribute the causes of dementia to addictions (to alcohol or cigarettes) and to the consequences of injuries, whilst they were more likely to attribute the causes of dementia to personality traits. Each of the studied groups assigned different weights to individual potential aetiological factors in their perception of the causes. To the greatest extent, carers attributed the causes of dementia most strongly to the ageing process, as well as to heredity, stress and personality. In contrast, they attributed the causes to a lesser extent to addictions, past injuries, poor medical care or environmental pollution. Those without caring experience, in addition to ageing and heredity, emphasised alcohol addiction and past injuries. At the same time, they rated the significance of poor medical care, pollution or personality very low.

The next exploratory hypotheses in this study were based on the general previous findings, that the direct contact with a person with dementia may change attitudes toward individuals with cognitive deterioration [5]. We assumed that there were differences between family carers and individuals with no experience in caring as regard to ratings for warmth and competence of persons with dementia. Findings of the current study showed that generally both carers and non-carers rate daily functioning competencies of individuals with dementia poorly, nevertheless our study showed specificity of attitudes depending on people's direct experiences of

interacting with someone with dementia. Family carers rated the efficiency of people with dementia significantly lower than individuals without caregiving experience. However, both groups rated the independence and self-confidence of individuals with dementia similarly. Family carers perceived self-confidence as the relatively dominant aspect of individuals with dementia functioning, whilst capability and independence were rated by them much lower. It is worth noting that carers and those without caring experience may perceive the trait of self-confidence in different ways. Carers may interpret it as some certain behaviours that indicate a need for support, a craving for attention, resistance to the carer's actions – which often arises in carers' experiences as symptoms of deterioration worsen, when people with dementia attempt to maintain their sense of control and understanding of the reality around them, whilst their cognitive abilities prove insufficient. People with no caring experience, despite their belief that people with dementia retain a certain level of effectiveness and capability in carrying out daily tasks, rated their independence significantly lower, and this trait appeared to be most strongly emphasised in the assessments made by this group of people. In terms of traits revealed in social interactions, all respondents described people with dementia in rather positive terms, with the exception of the trait 'trustworthy', which was attributed to people with dementia to the least extent. The following traits were attributed to them to a similar extent: friendly, well-intentioned, warm, kind and good-natured. We also assumed differences in feelings evoked by people with dementia between family carers and those with no experience in caring. According to a systematic review, feelings commonly associated with dementia were fear, shame, compassion and guilt, however, some positive attitudes to dementia were also observed [2]. In the current study, regardless of the caregiving experience, the study participants identified negative emotions (including disgust, contempt, hatred, resentment, embarrassment, jealousy, frustration, anger) as the least likely to be evoked in them by people with dementia. In the emotional attitudes towards people with dementia, family carers exhibited significantly less pity encompassing compassion, mercy and understanding than those without caregiving experience. There is also a distinct difference in the distribution of specific emotional dimensions depending on experience of caring for a person with dementia. Positive emotions, which included inspiration, fondness, admiration, pride and respect, were rated by carers as significantly lower than fear (worry and anxiety) and empathy (sympathy, affection, good-will, tenderness, sensitivity). Those without caregiving experience reported higher levels of pity and empathy than positive emotions and fear. The obtained results are consistent

with previous findings pointing to less negative and more prosocial reactions as well as lower stigmatizing beliefs after contacts with people having dementia [39,5].

The second aim of the study was to evaluate the influence of the perception of dementia and experience in caring on warmth and competence ratings, and feelings about people with dementia. We assumed that perception of dementia and caregiving influenced attitudes toward individuals with dementia. The present study revealed that the caregiving explained how the efficiency of a person with dementia was rated, regardless of dementia perceptions. Everyday contact experiences relevantly contribute to perceiving persons with dementia as less efficient. We revealed that various aspects of dementia perceptions influenced attitudes towards people with dementia, what is congruent with previous research [12]. In our study, perception of dementia in terms of its chronic nature and possibility of personal control of the illness affected the ratings of some competencies of people with dementia. We also found that greater awareness of the chronic nature of the disease contributed to the perception of a person with dementia as more dependent. Moreover, perceiving dementia as a personally controlled illness impacted on attributing more confidence to persons with dementia. Finally, perception of the disease in terms of its repetitiveness, chronic and cyclical nature contributed to the explanation of why people with dementia evoked stronger positive emotions regardless of their experience in caregiving. Perceptions of personal control over one's illness deserve special attention as, according to systematic review [46], beliefs that treatment can help control symptoms were associated with greater engagement with services, treatment adherence and increase the use of adaptive coping strategies.

The current study has some limitations. Due to the size of the sample and exploratory nature of experimental procedure, the findings should be interpreted with caution. The sample of carers consisted predominately of female participants. This disproportion reflects tendencies in general populations, therefore the referential group of participants without caring experience was tailored.

5. Conclusions

1. Although all participants were aware of difficulties in dementia course control, carers represented stronger sense of illness coherence in the range of comprehensibility than persons with no experience in caring.
2. Common beliefs about causes of dementia involve ageing and heredity. However, lay public also consider alcohol abuse and past injuries as crucial factors in contrast to carers who underline personality traits as shaping process of dementia.
3. Poor efficiency is attributed to people with dementia mainly by individuals with caregiving experiences. They also highlight self-confidence as a dominant characteristic of individuals with dementia, which may reflect some problems in dementia such as limited insight into complexity of the situation context or expectation of need meeting.
4. In the emotional attitudes towards people with dementia empathy is generally articulated. Along with that the strong feelings of pity are evoked in individuals without experiences in caregiving. Caregivers mark out worry and anxiety as prevailing feelings encountered over the course of assisting people with dementia.
5. By virtue of the confirmed associations between various aspects of dementia perceptions and attitudes towards people with dementia further dissemination of knowledge about dementia among lay public members is needed.

Conflict of interest

The authors have declared no conflict of interest.

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