

Dementia-Related Knowledge, Experiences and Perceptions of Dementia among Adolescents in Slovenia

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ABSTRACT

Objectives: Without information about how adolescents perceive dementia, and what their dementia related experiences are, it is hard to raise awareness of dementia and positive attitudes towards people with dementia in adolescents.

Aim: To evaluate dementia-related knowledge with a focus on comparison between adolescents with and those without relatives with dementia and their perception and experiences of relatives with dementia to provide basic data for educating about knowledge of dementia and strengthening positive attitudes towards dementia.

Methods: 1128 students (aged 14 -19) from non-health related secondary schools in Slovenia completed the dementia-related knowledge survey. In subsample of 335 students with relatives with dementia we explored their experiences of dementia in relatives.

Results: Out of 20 questions and supplementary questions on dementia knowledge, participants were on average able to answer 71.5% correctly ($M = 14.30$; $SD = 2.56$). Respondents with relatives with dementia reported higher knowledge ($M = 14.67$; $SD = 2.44$, $p < 0.05$), boys reported lower levels of knowledge than girls ($p < 0.05$), and students of secondary technical and vocational school, and of general secondary schools (grammar-school) scored significantly higher on the knowledge questionnaire in comparison to students of lower vocational and secondary vocational schools ($p < 0.05$). We also identified that in subsample of 335 adolescents with a relative with dementia a sadness and fear prevail in their attitudes towards dementia (e.g. 55% of all responses).

Conclusions: Considering that adolescents are already forming negative attitudes and misconceptions of dementia, it is important that we raise awareness about dementia in this age.

Keywords

Dementia, Knowledge, Experiences, Adolescents, Slovenia.

the overall population, people with dementia will represent 3.40% in 2050 compared to 1.65% in 2018 [1].

Introduction

It becomes common to know someone with Alzheimer's disease and other forms of dementia because longer life expectancy is increasing the people with dementia [1,2]. Despite a minor decrease in population in Slovenia between 2025 and 2050, the overall numbers of people with dementia will almost double from 34,137 in 2018 to 65,892 in 2050 [1]. Similarly, as a percentage of

One of the earliest symptoms of dementia, especially in the most common form, which is Alzheimer's disease, is memory impairment [3]. Dementia is manifested by disturbances of many higher nervous activities, such as memory, thinking, orientation, recognition, comprehension, the ability to learn, and the ability to express verbally [4]. When these functions are disrupted, the deviations from normal social interactions and effect on established

personal relationships would be expected to affect the rules of normal social interaction and result in stigma [5]. The stigma of dementia is made more severe because dementia is generally a disease of old age. Older age is also stigmatised, and considered to be a time of increased vulnerability and dependence.

The World Health Organization (WHO) defines an adolescent as any person between ages 10 and 19 [6]. Adolescence is a formative period during which many life patterns are learned and established, and stigma towards persons with dementia may develop. However, quantitative studies identified that adolescents have gaps in dementia knowledge and some negative attitudes [5,7]. For this reason, information about adolescent's experience of dementia is important [7,8]. It is also unclear what adolescents' experiences of dementia are. Baker et al (2017) reported that 31.0% of Australian adolescents had never seen (or only seen in passing) someone with dementia, whilst 23.6% said they had a friend or family member with dementia [9]. Whilst in England, 23.4% of adolescents reported to know someone with dementia [7].

Understanding adolescents' experiences of dementia is important so that we can ensure that these experiences are framed in a manner that is positive.

Stigma towards mental illness including dementia develops at a young age and is maintained across the lifespan [5,10-14]. Stigma is a state of social disgrace, which marks an individual as discreditable or inferior in some way. When the illness carries social stigma, relatives of person with dementia can be stigmatized by implication how others view and relate to them [10-12]. Some of the key findings from the World Alzheimer Report 2012 (2012) include that societies including friends, relatives, and healthcare professionals do not have enough understanding about dementia, that 40 % of people with dementia report not being included in everyday life, and 24 % of them hide or conceal their diagnosis-citing stigma as the main reason [11]. Piot (2012) feels sure that Alzheimer's disease and other forms of dementia are particularly problematic, not only because they are increasing rapidly, but because the stigma is to some extent invisible [15]. It is a challenge for every educational system to develop of appropriate dementia awareness initiatives for adolescents [16,17]. In Slovenian research, Hlebec (2019) namely showed that youngsters can become carers in very early age and can care for their relatives with illness for years [18]. More effort is needed to embed initial dementia understanding in the school curriculum, which will improve awareness about dementia in an earlier age and will enhance dementia-friendly communities [7].

Due to a fact that the extent of Alzheimer's disease and other dementias will continue to grow and by 2050 it is expected the number of persons with dementia in Slovenia will reach nearly 70.000 [1]. This will increase the number of young people caring for one or even more of their close relatives, what will affect their educational pathways. In order to get an insight into what young people know about dementia we conducted a survey among youngsters in secondary education.

To our knowledge, little is known about Slovenian adolescent students' experiences and perception, and knowledge of dementia. In a single Slovenian study in small cohort of 70 adolescents (aged 13-19) authors found that 97 % of adolescents were aware of dementia, but were still likely to have misconceptions about the disease (e.g. about dementia risk reduction) [19]. In addition, most of adolescents (e.g. 70%) thought that forgetfulness is normal part of ageing, what is a negative perception of old age and calls for a need to raise the knowledge about dementia in this age group [19].

Moreover, the master narrative that people with dementia are "still" the same person they were prior to the onset of dementia, conflicts with the experiences of youngsters. Courser (2009) recognized the fact that adolescents did not feel their parent was the "same" person they were before their illness [14]. In consequence, they were not able to relate to and feel the same way towards them as they previously did was a cause of additional stress in what was already often an almost unbearable situation.

Understanding whether adolescents have gaps in their knowledge and their perceptions and experiences of relatives with dementia could provide focus for future educational programmes within Slovenia. This study aims to present descriptive data on the knowledge and attitudes of adolescent students toward dementia.

The study was conducted in cooperation with voluntary non-government Association Forget-me-not Šentjur (Spominčica Šentjur), which is an independent branch of the organization Spominčica – Alzheimer Slovenia. The Association's mission is to raise awareness and disseminate information to help relatives cope with the problems of the disease. In collaboration with reliable experts, it can also provide schools with knowledge and skills to include this important issue in the curricula.

Method

Research objective

The aim of the research was to obtain data on the knowledge of dementia among Slovenian non-health related students, and to recognize their experiences of dementia in relatives. In order to make the comparison as objective as possible, we excluded health care secondary school students from the sample, as they are more familiar with the facts about dementia than students from other secondary schools.

Research design

The study is based on the descriptive and causal non-experimental method. The research was conducted by the online questionnaire (1ka) which was available from 25 September 2019 to 2 December 2019. The participants were informed that the data would be used for research purposes only, and the main objective of the study was explained.

Sample

The basic sample was represented by students of Slovenian non-health related secondary schools from all twelve Slovenian

statistical regions [20,21]. The final sample consisted of 1128 respondents (62.3% of those who responded to the survey invitation) who completed the survey accordingly.

Most respondents were from general secondary schools (695 or 61.6%) and the least students from secondary technical and vocational schools (79 or 7.0%). From secondary lower vocational schools there were 201 students (17.8%) and from secondary schools with vocational education 140 (12.4%) students. The sample included more girls (68.3%) than boys (30.9%), more students from rural areas (65.5%) than from urban areas (33.2%) and they ranged in age from 14 to 19, the average age was 16 years.

Fifty secondary schools from all twelve Slovenian statistical regions were invited to participate. We (Felc Z.) first contacted the principal of each secondary school over the phone, explained the project and obtained his/her agreement for acceptance and distribution of the links to online questionnaires. After agreement, the online questionnaires were distributed to students from the secretariat of each school. Based on the data on the region and type of secondary school we can conclude that students from at least 20 secondary schools responded. The exact number cannot be determined, as the questionnaire did not include questions on the name of the school due to anonymity.

Instruments

The data was collected using a questionnaire that was prepared by Celdran et al. (2012) and adopted it to our circumstances [22]. The questionnaire consisted of three parts: the first part with twenty claims regarding dementia with true/false responses, the second part on experiencing changes due to dementia in relatives and the last part on basic demographic data (e.g., gender, age, place of residence, type of secondary school, the region in which the school is located, connection with a relative with dementia). With the first part we were looking for the knowledge about dementia, and the second part was constructed to identify students' attitudes towards relatives with dementia. The construct validity of the instrument was confirmed by three independent experts in the field of health education, school counseling and family law.

Data Analysis

The results were presented in the form of frequencies and percentages, in the bivariate analysis we used only nonparametric tests (Mann-Whitney U test, Kruskal-Wallis test, hi-square test, Spearman rank correlation coefficient). When the assumptions for performing the hi-square test were not met, we used the Kullback 2I-test (Likelihood ratio) instead of the hi-square statistic. In the bivariate analysis, only valid answers were considered. The total variable knowledge of dementia that occurs in the analysis was compiled by summing up the individual correct answers (20 possible answers). The correct answer was evaluated with one point, the incorrect with zero points.

Results

Of the 1812 respondents who responded to survey invitation, the final sample comprised 1128 respondents (62.3%) who completed

the survey. The typical participant was female (68, 9%), from general secondary school, aged 16 years [14-19]. Almost one third of respondents (29,7%) reported knowing relative with dementia.

The results are presented in two sets. In the first set, we determined how many basic facts about dementia students know and whether there are differences in dementia-related knowledge according to those who have or do not have a relative with dementia. The second set referred to the attitude of students towards people with dementia, which is reflected in their experience of changes due to dementia in relatives.

Knowledge of dementia

Male and female students demonstrated their knowledge of dementia by answering the first set of closed questions, which can be seen from Table 1. On average students scored 14.30 points out of 20 possible, the dispersion of data is close to between 2 and 3 (SD = 2.56), so for so many points the values deviate from this estimate on average.

Table 1: Comparison of differences in knowledge about dementia by demographic variables.

Demographic variables		N	M	SD	MW U / KW	p value
Relative with dementia*	YES	335	14.67	2.44	116482.500	0.002
	NO	789	14.14	2.60		
Gender*	Female	770	14.63	2.36	106979.000	0.000
	Male	348	13.63	2.82		
Residence	City	375	14.17	2.49	129917.000	0.086
	Countryside	739	14.40	2.58		
Type of school*	LVS	201	13.53	2.69	43.627	0.000
	SVS	140	13.63	2.33		
	STVS	79	14.73	2.63		
	GSS	695	14.64	2.46		

Note. * p < 0.05 = degree of comparison the difference between groups being statistically significant; N = number of respondents; M = arithmetic mean; SD = standard deviation; MW U / KW = Mann-Whitney test / Kruskal-Wallis test; LVS = Lower vocational school; SVS = Secondary vocational school; STVS = Secondary technical and vocational school; GSS = General secondary school

When asked where and from whom they heard about the term dementia, only 16.7% of respondents answered that from teachers.

Table 1 shows that the higher level of knowledge about dementia was statistically significant for students with a relative with dementia (M=14.67, SD=2.44), girls (M=14.63, SD=2.36), students in secondary technical and vocational school (M=14.73, SD=2.63) and in general secondary schools (M=14.64, SD=2.46). Neither permanent residence in the city or in the countryside affected scores on the dementia knowledge questionnaire (p>0.05).

Next, we in table 2 show that a set of twenty closed questions on knowledge (claims) regarding dementia was answered by 335 students (29.7%) with and 789 students (61.3 %) without relative with dementia. In subsample of 335 students with relatives with dementia among them grandparents predominated (67.4%).

Table 2 shows the percentages of incorrect responses to each of the twenty allegations of dementia. The question, to which the vast majority of all respondents (84.7%) answered incorrectly, concerned the claim that memory aggravation is normal with age, with only 15.3% answering correctly. Closely followed by questions on the claims that dementia appears as loss of speech, with only 23 % answering correctly on the claims that appears as a loss of planning, with only 35.9% answering correctly, and on the claim that dementia appears as an inappropriate behaviour, with only 41.9% answering correctly.

Table 2: Comparison of the incorrect answers in knowledge of dementia in respondents with or without relative with dementia.

Claims regarding dementia	Relative with dementia (N=335)	Relative without dementia (N=789)	Total (N=1128)	p value
It is disease of brain.	2.4%	2.7%	2.6%	0.791
It appears as memory loss.	0.3%	0.8%	1.1%	0.335
It manifests as a loss of orientation*.	40.0%	48.4%	46.2%	0.010
It manifests as hearing loss.	4.5%	4.7%	4.6 %	0.877
It appears as a loss of speech*.	72.5%	78.7%	77.0 %	0.025
It appears as a loss of planning.	62.4%	64.3%	64.1 %	0.551
It appears as a loss of mental ability.	45.4%	50.8%	49.6 %	0.095
It appears as a loss of recognition*.	23.0%	31.2%	29.4 %	0.005
It appears as an inappropriate behaviour*.	52.5%	60.1%	58.1 %	0.019
It is increasing after the age of 65*.	1.2%	5.3%	4.1 %	0.001
With age, memory aggravation is normal.	84.5%	85.0%	84.7 %	0.808
It is contagious.	3.0%	1.6%	1.9 %	0.147
Alzheimer's disease is most common cause of dementia*.	25.4%	31.7%	29.9 %	0.034
Person with dementia can live at home*.	13.7%	25.1%	21.7 %	0.000
Dementia risk is reduced through physical activity.	16.4%	14.6%	15.1 %	0.430
Dementia risk is reduced by alcohol drinking.	5.1%	4.2%	4.0%	0.507
An appropriate body weight reduces dementia risk.	34.3%	29.7%	30.9%	0.122
Smoking reduces the risk of dementia.	6.0%	4.1%	4.1 %	0.162
Dementia risk is reduced by eating healthy food.	12.5%	11.9%	12.1 %	0.769
The risk of dementia is reduced by reducing the use of computer games and social networks.	28.4%	30.9%	30.1 %	0.391

Note. * The difference between the groups is statistically significant at the characteristic level $p < 0.05$; N = number of respondents.

Participants were most successful in answering that dementia appears as memory loss (98.9%), that it isn't contagious (98.1%), that it is disease of brain (97.4%), and that it is increasing after the age of 65 (95.9%). In addition, participants were successful in answering that alcohol drinking and smoking are risk factors for development dementia, with 96% and 95.9% of participants

answering each question correctly, respectively. On the other hand, barely 69.1 % and 69.9% of respondents agreed that an appropriate body weight and reducing the use of computer games and social network reduce dementia risk, respectively.

Further, compared to respondents with relative with dementia, respondents without relative with dementia showed poorer knowledge of the facts that dementia manifests itself as loss of orientation, speech, recognition, inappropriate behaviour, that the number of people with dementia increases after age 65, that the most common cause of dementia is Alzheimer's disease, and in the belief that a person with dementia can live at home ($p < 0.05$).

Perceive and experiencing behavioral changes in relatives with dementia

In the second part, we presented students' perception and experiencing behavioral changes in relatives with dementia. 279 (83.3%) out of a total 335 students with a relative with dementia, answered an open-ended question about perceiving and experiencing change in a person with dementia. We obtained narrative answers from the respondents that had been summarised into twelve categories, presented in Table 3. Some of the respondents gave answers that fall into several categories, so a larger number of answers is possible for one respondent.

Table 3: Students perceiving and experiencing behavioral changes in relatives with dementia.

Perceiving and experiencing changes in relatives with dementia	Number of students who responded (N=279)	
	f	f %
It was hard and painful until we were educated about dementia and accept it.	42	15.7%
People with dementia need understanding, patience and help.	38	13.6%
It is awful because they don't remember past events.	50	17.9%
It is sad because they don't recognize their loved ones and mistake them for the deceased.	73	26.1%
It is difficult because they repeat the same thing over and over again.	30	10.8%
They live in their own world of illusions, and accusing you of injustice.	12	4.3%
It is painful because your grandparents don't recognize you anymore.	10	3.6%
Fear that your closest relatives with dementia will no longer recognize you.	5	1.8%
It has no effect on me.	54	19.4%
I don't know.	2	0.7%

Note. f = frequency distribution; f % = percentage of frequency distribution. N = the number of students who gave one or more answers.

To compare narrative results with other responses, we analyzed the frequency distributions by individual categories and found that they differ significantly in terms of positive (reduces stigma due to dementia) or negative attitude (increases stigma due to dementia) to symptoms in a relative with dementia. Table 3 shows that a sadness and fear prevail in their attitudes towards dementia in almost one third of the respondents with a relative with dementia (64.5% of all responses). A little over a tenth (13.6% of responses)

expressed an optimistic attitude towards people with dementia, believing that they need understanding, patience and help to be able to carry out activities in which they could still participate. A positive attitude was reflected in 15.7% of the responses in which respondents expressed the belief that experiencing changes in a relative due to dementia is easier and less painful when they are educated about dementia and accept it. Almost the fifth (19.4% of responses) indicate that they have neutral attitudes towards dementia.

Discussion

According to the findings obtained throughout the research, students with relative with dementia showed a better level of knowledge of the facts that dementia manifests itself as loss of orientation, speech, recognition, inappropriate behaviour, that the number of people with dementia increases after age 65, that the most common cause of dementia is Alzheimer's disease, and in the belief that a person with dementia can live at home ($p < 0.05$). This is in agreement with findings of Isaac, et al. Parveen, et al, and Baker, et al. that inclusion of the person living with dementia improve students' dementia knowledge and attitudes [7,16,23]. Scerri and Scerri also concluded in study with 280 Maltese nursing students that they had an adequate knowledge and showed positive attitudes towards Alzheimer's disease and dementia patients, and that previous care of dementia patients during their clinical placement was found to be associated with increased knowledge and positive attitudes [24].

In addition, the finding that female students have better knowledge of dementia is also consistent with other research, which showed that care work in the family is still predominantly performed by women what affects their knowledge about illnesses and conditions of persons receiving care [25,26].

Adopting a healthy lifestyle in adolescence can improve health in old age. The guidelines from the World Health Organization state that we can reduce the risk of developing dementia by regular physical activity, avoiding smoking and drinking harmful amounts of alcohol, maintaining a healthy weight, eating a balanced healthy diet and maintaining normal blood pressure, cholesterol and blood sugar [27]. When we compared the students according to whether they have a relative with dementia or not, there were no differences in knowledge of risk factors for dementia. In our research, we found that attention was paid to reducing the risk of dementia in 88.9% of all respondents. This finding is probably related to the fact that many schools are members of the Slovenian Network of Healthy Schools, which implement promotion programs as part of the educational process [28]. Health in the physical, mental, social and environmental health fields is taught for students, teachers and parents [28]. In spite of all that, the findings of our research showed gaps in knowledge of lifestyle-dependent risk factors for dementia. Still, only two thirds (69.1%) of all respondents recognized that an appropriate body weight reduces dementia risk. This finding of the research supports the Gurger's conclusion (2014) that the physician's role is to advocate for prevention and early treatment

of obesity because pharmacotherapy options for treatment of pediatric obesity are very limited. Therefore, establishing a comprehensive management program that emphasizes appropriate nutrition, exercise and behavioral modification is crucial [29].

One of the key messages of dementia education must be dementia is not a natural part of ageing. The worrying finding of our research is that 84.7% of all surveyed students believe that memory impairment with age is normal. Admittedly, a common problem in old age is poor memory, which does not hinder an individual's daily life. Brezovar (2017) emphasizes that it is necessary to separate healthy aging from dementia. In recent years, when we understand the background of dementia better, we know how to distinguish healthy aging from disease aging [30]. Only when independent functioning in everyday activities is significantly hindered and the problems worsen, we talk about dementia [3,4,30]. Therefore, if we accept forgetfulness, which is escalating, as something that is normal in old age, then we will deny the elderly timely treatment and therefore, of course, the necessary treatment of dementia [3].

Although students who had contact with relatives with dementia showed better knowledge of dementia ($p < 0.05$), but a minority expressed an optimistic and positive attitude towards people with dementia. Just over a tenth (13.6%) expressed the belief that people with dementia need understanding, patience and help to be able to carry out activities in which they could still participate, and an additional 15.7% felt that experiencing changes in a relative due to dementia was easier and less painful when get educated about dementia and accept it. However, the majority students who have a relative with dementia (64.5%) expressed fear and uneasiness towards people with dementia, which can increase the stigma due to dementia. Opposite, Fuh, et al (2005) reported findings of study in Taiwan with sample of 5,825 students (aged from 10 to 15) that most children, and adolescents had an overly optimistic attitude about dementia. In addition, the older Taiwanese students who had an individual with dementia were more likely to believe that dementia is preventable [31]. Most likely, the negative attitude is a combination of a lack of knowledge about the course of dementia and a lack of support for young people. This can lead to misunderstandings of the needs of people with dementia and is focusing on losses due to the disease, all deepening the stigma of dementia [23,32,33].

In our research, 16.7 % of respondents stated that they heard about dementia from teachers in school, which is consistent with the findings of a previous pilot study in Slovenian adolescents [19]. We have also received information from several school counseling services that some of the themes in relation to dementia are included into learning process but this is not taught systematically and depends on the awareness of individual teachers about the disease. Taking into consideration our findings that adolescents would have a higher tendency to experience embarrassment about dementia which can lead to the development of stigma, suggests the need of implementation of systematic, an inclusive and open dementia education in all secondary schools.

Here also an inclusive and open education is needed that is capable of incorporating experiences of caring families, young people, civil society organisations and public institutions. Young people can be excellent narrators of their own experiences of care. Peer education can also enable youngsters that do not speak about their home situations to open up and overcome fear of possible stigma.

Conclusion

This study highlights that whilst the knowledge of dementia among Slovenian non-health related secondary school students is solid, they had an overly negative attitude about dementia and higher tendency to experience embarrassment about this disease which can lead to the development of stigma. Furthermore, only minority of adolescents had been taught about dementia in school. In addition, the study did not include the dementia-related knowledge of teachers or perspective of people living with dementia. Importantly, the study has highlighted the need for dementia awareness education aimed at adolescents which should be co-designated with adolescents, teachers and people with dementia.

Further work is also required to overcome false beliefs about dementia held by adolescents that marked deterioration of memory with age is normal. Because of such a misconception among adolescents and other people, we will deny the elderly with dementia timely treatment.

We also recognised certain shortcomings of the research. The first shortcoming would be a sample that could include a larger number of participants from all Slovenian regions and would be more representative in certain areas (e.g., experiencing changes due to dementia in a relative). An additional shortcoming is that in the questionnaire all items in the dimension of knowledge of dementia are only positively or negatively evaluated. In the future, it would be useful to explore the components of knowledge and attitudes towards people with dementia among secondary school students with a health program. Additional information is also needed in relation to healthy life-style as prevention for the development of dementia.

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