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# Suggestions of Slovenian Students on Ways to Acquire Dementia-Related Knowledge

# Brina Felc<sup>1,2\*</sup>

<sup>1</sup>College of Nursing in Celje, Mariborska cesta 7, 3000 Celje, Slovenia.

<sup>2</sup>Association of Western Styrian Region for the help at Dementia "Forget me not" Šentjur, Svetinova 1, Šentjur 3230, Slovenia. \*Correspondence:

Brina Felc, College of Nursing in Celje, Mariborska cesta 7, 3000 Celje, Slovenia.

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## ABSTRACT

**Objectives:** Although the number of people with dementia is growing due to the aging population, knowledge of dementia among adolescents is unknown, as are their suggestions for how to acquire knowledge.

*Aim:* To determine the knowledge of dementia among students and to identify their suggestions on to acquire dementia-related knowledge.

**Methods:** An online cross-sectional study was conducted in order to determine the knowledge of dementia among students of non-medical high schools in Slovenia. The gender comparison of the knowledge and proposals for a way of educating were obtained.

**Results:** A total of 1128 students (770 girls and 348 boys) aged 14 -19 participated in this study. The results indicated that of 20 claims of dementia, participants were on average able to answer 71.5% correctly (M = 14.30; SD = 2.56), girls better than boy (p < 0.05), students with relative with dementia better than others (p < 0.05). Proposals for ways of future dementia education did not differ between the sexes (p > 0.05). Both, girls and boys in the same percentage indicated future priority learning methods namely: use of the Internet, learning in school lessons and from books and textbooks, learning from medical staff.

**Conclusions:** Organizers and providers of dementia education for adolescents should organize as much education as possible via the Internet. Further research on the most appropriate form of dementia education among high school students is recommended.

#### Keywords

Dementia-related knowledge, Acquiring, Students, Non-medical high schools, Slovenia.

### Introduction

The number of people with dementia is growing due to the aging population [1]. As young people are increasingly live at home with their parents and grandparents, the number of adolescents caring for grandparents with dementia can be expected to increase. Adolescents' lack of knowledge on the course of the disease leads to depersonalization of people with dementia, it encourages a negative attitude towards them and misunderstanding of their needs. With this in mind, adolescents need to be educated about dementia as much as possible, for which they need contact with person with dementia and access to appropriate literature [2-8]. To keep education contemporary, curricula need to reflect the ageing population. Grosvenor et al. (2017) realized this with the programme to enable healthcare students to learn with people with dementia and their carers—recognising that people with dementia have unique expertise derived from their experiences. Their personal narratives offer students a unique insight into the subjective experiences of dementia [5]. On the population of 99 students from introductory psychology classes at University of Massachusetts, Lundquist and Ready (2008) found out that if contact through intergenerational service learning can be made more intimate and close, then positive attitude change towards person with Alzheimer's disease may be most likely to occur [9]. Therefore, raising awareness of dementia with education in adolescents can be seen as an important method of reducing stigma, which undoubtedly leads people with dementia to social isolation and poorer quality of life [6].

The population of adolescents grow up in constant contact with digital media; so many experts believe that using the web can affect their way of learning about dementia [10-12]. According to Dadaczynski et al. (2021), the Internet and social media are important sources of health information, which proved to be the case during the COVID-19 pandemic [2]. However, there is a wealth of data on dementia on the net, so adolescents need the help of an educator, health professional or sociologist, who can guide them to the right information about health information including dementia [3,10]. Jain and Bickham (2014) also found that adolescents must be able to access, understand, analyze, and evaluate health information on the Internet and then apply this information to make appropriate health decisions [3]. However, the extent to which adolescents will benefit from using the Internet as a source for health information will be determined in great part by their level of media literacy and health literacy [3]. Knowledge of the symptoms at different developmental stages of dementia is important to help the adolescent understand the patient [13]. Challenges faced by adolescents fall into the area of functional literacy (e.g., not being able to spell a medical term needed in a search), critical literacy (e.g., not being able to differentiate accurate from inaccurate online dementia-related information), and, lastly, interactive literacy (e.g., translating online health information to appropriate health behaviors for reducing the risk of Alzheimer's disease) [9,12].

In educating adolescents about dementia, it is important, informing them about the modifiable risk factors of dementiaonset in adulthood which can be reduced with a healthy lifestyle at all stages of life, especially in adolescence [14]. Furthermore, they need to be informed that in addition to environmental risk factors, there are also risk factors associated with the use of digital media. The most common variable risk factors are thus: use of alcohol, tobacco use, obesity, intake of unhealthy diets, inadequate physical activity, addiction to Internet and different social media, online games, digital screens, and mobile devices [14-21].

When designing dementia-related education, it is necessary to take into account the level of knowledge of adolescents and their proposal of ways to acquire knowledge about dementia in the future. The aim of this study was therefore to investigate whether adolescents have gaps in knowledge about dementia and if they differ by gender, and what are their suggestions for future sources of dementia education.

# Method

# Participants

The participants of the 1KA online cross-sectional study were students in Slovenian secondary schools without medical program during autumn of 2019.

We used a questionnaire compiled on the basis of questionnaires used by Hwang et al. (2013) and Glynn et al. (2017) [22,23]. A structured online questionnaire was divided into three sections: the first part consisted of 20 dementia-related claims namely 14 claims on knowing the basic facts about dementia and 6 claims of modifiable risk factors of dementia, in the second part we wanted to find out the ways in which students want to acquire knowledge in the future, and in the last part we asked about basic demographic data. Each correct answer to the claim of dementia counted 1 point, and the incorrect one counted zero points.

## **Ethical Considerations**

The survey was conducted in accordance with the requirements of the Declaration of Helsinki. Permission for the study was granted by the head teachers of the schools involved in the study. All students were provided with an information sheet for themselves and their parents informing them of the purpose of the study, their right not to participate and to withdraw at any time, and assuring them that all questionnaires returned would be anonymous.

## Data analysis

Results were presented in the form of frequencies and percentages, in the bivariate analysis we used only nonparametric tests (Mann-Whitney U test, Kruskall Walis test, hi-square test, Spearman rank correlation coefficient). When the assumptions for performing the hi-square test were not met, we used the Kullback 2Î-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).

# Results

In the study there were 1128 students, of whom there were 348 males (31.7%) and 770 females (68.3%), less than a third of respondents (29.7%) reported having relative with dementia. The typical participant was 16-year-old (aged 14-19) and lived in a rural part of Slovenia (65.5%).

Out of 20 claims about dementia and variable risk factors for it, on average, students correctly identified 71.5% of the claims (M = 14.30; SD = 2.56). Boys showed poorer knowledge regarding ten claims of dementia compared to the girls (p<0.05).

Significant statistical differences in knowledge of dementia claims were shown between males and females in knowing half of the claims. Male students were less familiar with the claims that people with dementia have impaired manely: memory, orientation, speech, recognition and behavioral pattern, that dementia occurs in large numbers after age 65 and that Alzheimer's disease is the most frequent form of dementia (p<0.05). Additionally, male students were less aware than female students of the increased risk of dementia due to smoking, alcohol consumption and excessive use of digital media (p<0.05).

Respondents also made suggestions for future education about dementia. Their proposals were also presented separately by gender (Table 1). When asked openly about their proposals for the future way of educating about dementia, the respondents made several different proposals, which are grouped into 11 contentrelated categories. Some of them listed answers that fall into several categories, so a larger number of answers are possible for one respondent.

Preferred Sources of Information	Total (N=1128)		Boys (N=348)		Girls (N=770)	
	f	f %	f	f %	f	f %
Web pages	783	69.4%	247	71.0 %	536	69.6 %
School lessons, textbooks, books	405	35.9%	92	26.5 %	312	40.5 %
Medical staff	256	22.7%	55	15.8 %	199	25.8 %
Informal lectures, Forget-me-not associations	40	3.5%	7	2.0 %	32	4.2 %
Parents, other relatives	39	3.5%	10	2.9 %	29	3.8 %
People with dementia, their relatives	29	2.6%	8	2.3 %	21	2.7 %
Staff in the retairement home	27	2.4%	9	2.6 %	18	2.3 %
TV shows, radio, movies	24	2.1%	5	1.4 %	19	2.5 %
Psychologist, social worker	15	1.3%	7	2.0 %	8	1.0 %
Friends, adults	8	0.7%	2	0.6 %	6	0.8 %
I don't know	17	1.5%	10	2.9 %	6	0.8 %
No answer	68	6.0%	17	4.9 %	46	6.0 %

Table 1: Students suggestions for dementia-related education in the future.

The comparison of gender proportions did not show statistically significant differences in the results (p>0.05). N = Number of respondents; f = Frequency; f % = Frequency percentage.

Although boys showed a lower level of knowledge of dementia compared to girls, suggestions for future education on dementia did not differ between sexes (p>0.05). Both, girls and boys in the same percentage indicated future priority learning methods namely: use of the Internet, learning in school lessons and from books and textbooks, and learning by medical staff. More than two-thirds (69.4%) of students wrote they want to get information about dementia online, a good third (35.9%) of students wrote they want information from teachers, books and textbooks, and a good fifth (22.7%) of students wrote they want information from medical staff. The comparison of gender proportions did not show statistically significant differences in the suggestions for future dementia-related education (p > 0.05).

### Discussion

Our study found that out of 20 questions on dementia knowledge, Slovenian participants were on average able to answer more than two thirds correctly (71.5%), which is comparable to other studies [7,9,13]. Furthermore, Isaac et al. (2017) assessed dementia knowledge and attitudes of dementia in four-hundred and fifty adolescents, aged 15-18 years, from schools in Sussex (UK) [7]. Responses to the attitudes questionnaire showed that adolescent students had both positive and negative attitudes toward dementia, however out of 15 questions on dementia knowledge; participants were on average able to answer less than half correctly. The aim of study of Parveen et al. (2018) was to establish the dementia

education needs of 42 British adolescents aged 12 to 18 years who participated in eight focus group discussions [6]. Key themes to emerge from discussions included the importance of dementia awareness, topics of interest within dementia, preferred methods of learning, the inclusion of the person living with dementia and the use of social media. The findings of the study will enable the development of appropriate dementia awareness initiatives for adolescents and thus facilitate the sustainability of dementia friendly communities.

According to the gender of the respondents, knowledge of half of the total 20 claims about dementia is significantly worse in boys than in girls (p<0.05). More boys than girls are not adequately aware of half of the claims about dementia (p<0.05), namely that dementia means impeared: memory, orientation, recognition, behavioral pattern, and speech, that Alzheimer's disease is most frequent form of dementia, especially after age 65. The finding that female students have better knowledge of dementia is also consistent with other researches, 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 [24-26].

Additionally, it was found out in our performed study that significantly more boys than girls underestimate modifiable risk factors for developing dementia such as: smoking, alcohol drinking, and abuse of digital world (p<0.05). Compared to foreign authors, also Glynn et al. (2017) found out that Irish people over the age of 15 are poorly aware of the modifiable risk factors for the later development of dementia [23]. Namely, less than half (46%) of 1.217 participants beleived that there are measures in everyday life that reduce the risk of developing dementia.

### Alcohol drinking

Alcohol, which is readily available in societies throughout the WHO European Region, is one of the substances with addictive potential most commonly used by adolescents [27]. Alcohol use in adolescence can increase the probability of having mental health and neurocognitive problems in both the short and long terms [27,28]. Nagel et al. (2005) drew attention to the fact that alcohol abuse in adolescents is associated with reduction in the size of left hippocampus, which is responsible for memory and learning [17]. Risky and harmful drinking of alcohol also affects the students in Slovenia, although most Slovenian primary and secondary schools are members of the Slovenian Network of Healthy Schools, recommendations for healthy life-style are too often neglected, and students drink alcohol and smoke [19]. This is also evident from our research, as almost a tenth of adolescents (7.8%) believed that drinking alcohol reduces the risk of developing dementia. In Slovenia, in the period 2002–2018, the percentage of adolescents reporting weekly drinking decreased significantly between 13-year-olds and 15-year-olds in total and for both sexes, and the percentage of 11-year-old girls increased significantly. The percentage of adolescents who were drunk at least twice in their lifetime decreased significantly during this period in all age groups, in total and in both sexes [28].

#### Smoking

Children and adults mostly start smoking. This is also evident from our research, as 6,6% of male adolescents believed that smoking reduces the risk of developing dementia. Nicotine causes addiction. A young person who has started smoking can become addicted very quickly, after just a few days and a few smoked cigarettes, and long before starting regular smoking. Teenagers usually report signs of addiction when they smoke a few cigarettes a month. It is therefore wrong to think that only those adolescents who smoke every day are addicted. Sensitivity to nicotine is different in adolescents than in adults, as the adolescent's brain is particularly sensitive to nicotine addiction. Nicotine alters the structure and function of the brain by creating a long-term vulnerability to nicotine addiction as well as other psychoactive substances [28]. After the age of 25, we practically do not record the onset of smoking. Age at the beginning of smoking is an important indicator of smoking behavior and harmful consequences in adulthood [14,28]. The younger the individual is at the start of smoking, the greater the risk of developing certain smoking-related diseases. Rovio et al. (2017) concluded that ccumulative burden of cardiovascular risk factors (including smoking) from childhood/adolescence associate with worse midlife cognitive performance independent of adulthood exposure [18]. In the period 2002-2018, in Slovenia, according to data from the survey Health-Related Behavior in the School Period (HBSC), we have been recording a decrease in the prevalence of smoking among adolescents aged 11, 13 and 15 for a long time.

In Slovenia, one in eleven 15-year-olds (8.8%) and one in five a 17-year-old (19.8%) smoked tobacco at least once a day week, most of these every day. Trend (11, 13, 15 years): in the period 2002–2018 was the prevalence of weekly and daily smoking decreased between 13-year-olds and 15-year-olds in total and in both sexes, with the exception of daily smoking during 13-year-old boys [28,29]. With the new Restriction of the Use of Tobacco and Related Products Act from 2017, a number of favourable changes in terms of the reduction of tobacco and related products use among adolescents have been done, however the prevalence of tobacco and related products use among adolescents still remains high, therefore, new strategies to reduce smoking are emerging [29].

Children and young people are particularly vulnerable to the social and environmental impacts of smoking. Among the key factors for smoking are advertising and promotion of the tobacco industry. Other important factors influencing smoking among adolescents are the influence of peers who smoke, overestimating smoking among peers and adults, the number of important people in the life of individuals who smoke, parents' smoking and their attitude towards smoking, as well as poorer school performance, lower socio-economic status, certain personality traits, etc. Smoking among young people is also associated with an increased likelihood of using alcohol, marijuana and other illicit drugs [28].

Adopting a healthy lifestyle in adolescence can improve health, and reduce the risk of developing dementia in old age. The guidelines from the World Health Organization (2019) 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 [14].

Learning that comprehensively covers the facts about the risk of dementia could encourage young people of both sexes to take care of their health in order to stay healthy even in old age.

Although male adolescents reported, less knowledge of dementia and understanding risk factors for developing dementia than girls, most still appeared to be receptive to receiving more information. Especially in boys, it can also be an effective way to improve health literacy regarding dementia. Health literacy, associated with variable risk factors for developing dementia, enables an adolescent to make decisions that will reduce his or her risk of developing dementia in adulthood. Experts around the world agree that adolescents have a positive attitude towards real and objective health information and are very receptive to teaching about the variable risk factors for dementia that depend on lifestyle. This characteristic of adolescents should be used in their education about dementia together with their desire for sources or methods of education, which are evident from our research. That is why further discussion will focus on online education, school learning and the acquisition of knowledge about dementia from medical staff.

### Internet

Web-based education has changed the face of learning and provides flexible, accessible, and cost-effective platforms for the delivery of education to a wide audience, regardless of their setting or location. Modern pedagogues, psychologists and teachers pupils and students born in time internet, called internet, web or even net generation and point out that members of this generation start using the computer in kindergarten, most often at the age of five, then use it every day for an average of two hours, time spent behind the computer, but is extended over the years [4]. As indicated Jablonski et al. (2019), in dementia education about memory impairment pictorial comparisons can help such as e. g. "The brain is like a box full of Christmas decorations. The decorations from 1964 are at the very bottom, while the decorations from last year at sitting at the top. As the box shrinks, the decorations from last year fall out. Meanwhile, you can more easily reach into the box and pull out the decorations from 1964 because you have fewer layers to move aside. The brain is like the box. As brain cells die, newer memories "fall out" while older memories are more accessible. That is why your family member cannot remember if she ate breakfast, but can tell you about some event 40 years ago. This is also why long, drawn out explanations and sentences do not work. The brain does not have enough space to 'hold onto' the entire conversation" [10].

In our study, it turned out that boys showed the same desire as girls for further education on dementia, especially through websites. To slightly different conclusions came Bilić (2011) in study which included 286 students (58.7% females; 41.3% males), whose average age was 13.8 years, and who were enrolled in primary and secondary schools in Croatia. [4]. The boys preferred to learn via the Internet significantly more than did the girls, who were equally happy to learn from textbooks and the Internet. The aim of this study was to examine students' attitudes towards modern methods of learning via the Internet, as compared to traditional methods (books and textbooks), and to analyze the relationship between attitudes and perseverance, the need for knowledge, self-efficacy, and the characteristics of the students that might be influenced by situational factors. The results were consistent across type of school, place of residence, and school performance. However, differences were found according to gender. The boys preferred to learn via the Internet significantly more than did the girls, who were equally happy to learn from textbooks and the Internet. Pupils who generally use the Internet on a daily basis, and those who use it to search for information unrelated to school or to socialize in a virtual space, have a more positive attitude towards learning via the Internet. Moreover, students who prefer learning from books and textbooks showed a statistically significant greater persistence and a strong need for knowledge, as well as greater academic and emotional selfefficacy than did their peers who prefer learning via the Internet [4].

Unfortunately, the use of modern technology including Internet by adolescents can be excessive and lead to risks to their health including the risk of developing dementia in adulthood [20,21]. Anyway, abnormal, excessive, unnecessary use of Internet leads to addiction and can lead to the development of some lifestylerelated risk factors for development of dementia, such as physical inactivity, and unhealthy diets [14]. Parents, pediatricians, and teachers in particular should also be those who warn adolescents and their parents of the dangers of unrestricted use of digital media [20]. They could instruct adolescents how to avoid the negative effects of the Internet, namely: limit the use of digital technology; take time for quality sleep; treat yourself to a digital post; be a critical user of social media; remember you are the one in control; strive for a healthy lifestyle.

### School lessons, textbooks, books

Our research showed that a good third of students (35.9%) want to obtain information about dementia in school, and from textbooks and books. Therefore, it should be a challenge for every educational system to develop of appropriate dementia awareness initiatives for adolescents. Isaac et al. (2017) concluded that more effort is needed to embed initial dementia understanding in the school curriculum [7]. Farina (2017) reported that local dementia education initiatives exist in England schools but it is unclear what the wider uptake of such programmes are [30]. A self-created survey was sent to staff in a number of secondary schools (teaching ages 11-16) across Sussex, England. While the majority of schools expressed an interest in including some form of dementia education within their school in the future, only nine schools (15%) at the time of the survey had dementia education embedded within their curriculum. Using a RE-AIM framework, Smith et al. (2020) quantitatively evaluated the effects of an educational dementia program (with and without an intergenerational program) on dementia attitudes in the short and long-term, and qualitatively, which elements

of the program facilitated this change [31]. Eighty-one children  $(9.63 \pm 0.52 \text{ years}, 35 \text{ males})$  from three classes participated in an 8-week dementia education program and 52 also interacted with older adults through an intergenerational experience. Program reach was measured as the percentage of children who participated in the study. The Kids Insight into Dementia Survey (KIDS) was implemented to measure dementia knowledge and attitudes: efficacy and maintenance. Qualitative interviews with all participant groups informed both adoption and implementation. Cost-benefit analysis was used as a secondary outcome measure for efficacy. The program demonstrated strong levels of impact reaching 93% of school children across the three included classes. Efficacy was demonstrated by a positive change in children's dementia knowledge and attitudes immediately post program, which remained increased (as compared to baseline) 6- months post intervention; there were no differences between groups (those who interacted with older adults and those who did not). Interviews identified positive changes in children's empathy and improved community awareness. Barriers to adoption included the project scope, time constraints incurred by school terms and the management of children-to-adult ratios. The findings provided the first evidence that school-based dementia education improves knowledge of and attitudes toward people with dementia long-term. Authors demonstrated programs such as this could be successful in both primary school and wider community settings, with support from school and community partners key to the success [31].

If we take into account the successful dementia-related education of primary school students, as shown by Smith et al. (2020), Slovenian secondary schools could also provide education based on their experience. This means that one topic on dementia (45 min) would be addressed each week for 8 weeks in one school year. Topics would follow like this: week 1: what is dementia; week 2: communication and social interaction; week 3: environment; week 4: memories; week 5: cognitive reserve; week 6: sensory changes; week 7: role of families and care staff (questions and answers session with physician and brainstorm: how to make our environment dementia friendly?); week 8: prevention (lifestyle). For most of the lessons, other aids would be used such as activity booklet, videos, and intergenerational excursions from week 3 of the program.

# Medical staff

A good fifth (22.7%) of the students in our study expressed a desire to obtain information on dementia from medical staff. Physicians and nurses should explain to adolescents the importance of early diagnosis of dementia for treatment. And that adolescent, who are mostly grandchildren of people with dementia, play an important role in this. In addition, medical staff can explain to them some misconceptions about people with dementia that people with dementia can be considered as e.g. that individuals with dementia are "still people"; that it is "not the fault" of the person with dementia; that dementia is different and typically unpredictable for everyone. Medical staff can teach them about ways to relate to a person with dementia, and to appreciate "positives" within a relationship [24]. We also recognised certain shortcomings of the research. The first shortcoming would be a sample that could include a larger number of male adolescents from all Slovenian regions and would be more representative in certain areas (e.g., experiencing activities in relation to healthy life-style as prevention for the development of dementia). In addition, the study did not include the dementiarelated knowledge of teachers. 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 suggestions for dementia-related education among secondary school students with a health program.

### Conclusion

This study highlights that although male adolescents reported less knowledge and understanding of preventable risk factors for dementia than female adolescents, most still appeared to be receptive to receiving more information. Further information based on gender-specific educational interventions may be more appropriate and effective than traditional school approaches. Furthermore, the study has highlighted the need for dementiarelated education aimed at adolescents, which should be codesignated with adolescents, teachers and people with dementia.

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