

Adolescent Attitude Towards Behavioral and Psychological Changes Due to Dementia

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ABSTRACT

Objective: For adolescents who want to be part of a community that supports people with dementia, knowledge of dementia and a positive attitude towards behavioral and psychological changes in people with dementia are important.

Aim: Our aim was to evaluate adolescents' knowledge of dementia and attitudes towards behavioral and psychological changes in persons with dementia.

Methods: 1128 students of Slovenian non-medical secondary schools completed a series of questions that assessed their dementia knowledge and among them 335 those with a relative with dementia to further describe their attitude towards in a relative with dementia.

Results: Regarding the knowledge of dementia, students scored an average of 14.30 points (standard deviation = 2,56) out of a possible 20 points, while students with a relative with dementia demonstrated a higher level of knowledge ($M = 14.73$; standard deviation = 2.44; $p < 0.05$). Of the 335 respondents with a relative with dementia, 279 described their attitude towards their behavioral and psychological changes. Furthermore, it turned out that almost two-thirds (64.5 %) of students with a relative with dementia show a negative attitude towards them due to their behavioral and psychological changes due to dementia.

Conclusions: To make life easier for an adolescents with a relative with dementia, there should be regular formal and informal training sessions in which professionals from different disciplines should clearly describe the course of dementia, focusing on behavioral and psychological changes during the disease and how to easily deal with these changes.

Keywords

Dementia, Behavioral and psychological changes, Adolescent, Attitude, Slovenia.

Introduction

Dementia is a chronic and usually progressive degenerative syndrome. Alzheimer's disease most commonly causes it. According to the signs and symptoms of dementia and their severity, there are three stages: the early, the moderate, and the severe stage [1]. Since 2008, the voluntary Association of Western

Styrian Region for the help at Dementia "Forget me not" Šentjur (Spominčica Šentjur), which cooperates with the Slovenian association Spominčica - Alzheimer Slovenia, has been working in improving the quality of life of people with dementia and their relatives [2].

According to Kogoj [3], in a person with dementia, behavioral and psychological changes can occur at any stage, and often present greater problems than the decline in cognitive functions alone [3]. Almost all patients have at least one of the following symptoms

as the disease progresses: violent behavior, agitation, wandering, socially inappropriate behavior, sexually disinhibited behavior, eating disorders, depression, anxiety, apathy, insomnia, delusions, and hallucinations. Kogoj [3] described the changes as follows: "The consequences of these are different, but they usually increase the stress of relatives. Although it may seem easy to determine which disorder, it is, in reality it is not always the case, as patients' statements are often unreliable, more difficult to understand, and often we can only rely on observation. Just the first moment it may seem like an illusion, in fact it may be due to misidentification. What sounds like delusion may be confabulation. Patients' belief that they are not at home may be because they no longer recognize the home in which they live (agnosia), or remember only the home in which they lived as children (amnesia). To help identify which disorder it is, family tree can be a useful tool. Although sometimes certain behaviors seem to occur for no reason, we can determine the triggering factor with closer monitoring. There are often several causes for a particular behavior. Some behavioral and psychological symptoms can be predicted and prevented or interrupted by timely activity. By following all the rules of communication, with appropriate patient spatial and temporal arrangements we can reduce the occurrence of these problems. Pleasant experiences, engaging in activities that the patient is still able to do and that are interesting to him, and preventing loneliness also reduce the likelihood of inappropriate behaviour" [3].

These symptoms often cause the adolescent to have a negative perception of dementia and a negative attitude towards a relative with dementia. Since age is one of the dominant risk factors for dementia, the disease seems to be far away from younger people but closer to the older ones, Lokon et al. (2017) [4] researched if the understanding and attitudes towards dementia between these two age groups are different [4]. Results of a cross-sectional survey among 239 young people (aged from 15 to 30) and 62 older people (aged 60 or above) in Macao, China showed that elders had a higher score of dementia knowledge, but a lower score of dementia attitudes ($p < 0.001$) compared to the youths. Thus, the study implies that reducing and bridging the psychological distance of dementia would probably be an effective strategy to increase dementia awareness among young people, and intergenerational programs may be a good option to increase community acceptance and support for people with dementia [4]. Farina et al. (2020) [5] in a cohort of 901 adolescents (aged 13–18) from the South East of England explored the experiences and perceptions of dementia [5]. The adolescents within this study tended to have positive or neutral attitudes towards dementia, though there was evidence that a proportion of adolescents had misconceptions or held negative attitudes (e.g. 28.5% of adolescents disagreed with the statement 'In general, I have positive attitudes about people with dementia'). Considering that adolescents are already forming negative attitudes and misconceptions of dementia, they concluded that it is important that we raise awareness about dementia in this age group [5].

Isaac et al. (2017) [6] found in 359 students, aged 15–18 years, from schools in Sussex (UK) that out of 15 questions on dementia

knowledge, participants were on average able to answer less than half correctly ($M = 6.65$, standard deviation = 2.34) [6]. Responses to the attitudes questionnaire showed that adolescent students had both positive and negative attitudes toward dementia. They concluded that more efforts would be needed to include dementia education in the secondary school curriculum, which will improve dementia knowledge and attitudes towards people with dementia among adolescents [6].

Raising awareness in creating a dementia friendly generation is important because due to the aging population, it is very likely that adolescents will be caring for relatives with dementia in a few years. Proper information about adolescent dementia-related knowledge and perception of behavioral and psychological changes in a relative with dementia is an important part of creating strategies to develop students' interest in the subject. Therefore, the aim of the study was to evaluate adolescents' knowledge and attitude towards dementia.

Method

Research objective

The study aimed at investigating the level of knowledge about dementia among non-health related students in Slovenia. We were interested in the connection between the level of knowledge and the fact whether they have a relative with dementia and their attitudes towards dementia. 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 1128 high school students without a health program from all over Slovenia, who completed an anonymous online survey on dementia knowledge. 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. Within this sample, there were 335 students (29.7%) with a relative with dementia.

Instruments

The data was collected using a questionnaire that was prepared by Celdran et al. [7] and adopted it to Slovenian circumstances. The questionnaire consisted of the first part with twenty claims regarding dementia with true/false responses, of the second part on experiencing changes due to dementia in relatives and of the last part on basic demographic data (e.g., gender, age, residence,

type of secondary school, the region in which the school is located, and if they have 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 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). The correct answer was evaluated with one point, the incorrect with zero points.

Results

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 relatives with dementia, which is reflected in their experience of behavioral and psychological changes due to dementia.

Dementia-related knowledge

Of the 20 possible points on knowledge of the facts about dementia, respondents scored an average of 14.30 points (SD = 2.56), among them, respondents with a relative with dementia demonstrated the best knowledge (M = 14.67; SD = 2, 33; p < 0.05). Both, respondents with a relative with dementia and those without a relative with dementia demonstrated equally knowledge of the following claims relating to dementia (p > 0.05): it is disease of brain, it appears as memory loss, it manifests as hearing loss, it appears as a loss of planning, it appears as a loss of mental ability with age, memory aggravation is normal, it isn't contagious; and demonstrated equally solid knowledge of the claims relating to reduce risk of dementia: by physical activity, by avoiding tobacco, by avoiding smoking, by maintaining an appropriate body weight, by eating healthy food, by reducing the use of computer games and social networks (p > 0.05).

In seven of the 20 claims, students who have no relatives with dementia showed poorer knowledge of the claims compared to those who do, namely that dementia means loss of environmental orientation, speech, recognition, behavior, and that the number of people with dementia increases after age 65, that the most common form of dementia is Alzheimer's disease, and that person with dementia can live at home (p < 0.05).

Students' perception of behavioral and psychological changes in a relative with dementia

In the second part, we presented students' attitudes towards behavioral and psychological changes in relatives with dementia (Table 1). 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 ten categories, presented in Table 1. Some of the respondents gave answers that fall into several categories, so a larger number of answers is possible for one respondent.

Table 1: Students' attitudes towards behavioral and psychological changes in relatives with dementia.

Students' answers about 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	15.1%
People with dementia need understanding, patience and help.	38	13.6%
It is awful because they do not remember past events.	50	17.9%
It is sad because they do not recognize their loved ones and mistake them for the deceased.	73	26.1%
It is difficult because they repeat the same thing repeatedly.	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 do not 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 do not 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 1 shows that a sadness and fear prevail in their attitudes towards dementia in almost two thirds of the respondents with a relative with dementia (64.5% of all responses). This adolescent negative attitude was reflected in the following responses, which related to the relative's behavioral and mental changes as stated: "Horrible because they do not remember past events"; "Sad because they do not recognize their loved ones and replace them with those who have already died"; "Exhausting because they keep saying the same thing over and over again", "scary because they live in their own world of illusions" and "painful because they are unjustifiably accused".

A little over a tenth (13.6% of responses) expressed positive 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. Furthermore, positive attitude was reflected in 15.1% of the responses in which respondents expressed the belief that experiencing changes in a relative due

to dementia is easier and less painful when relatives are educated about dementia and accept it. Finally, almost the fifth (19.4% of responses) indicated that they have neutral attitudes towards dementia.

Discussion

The results of the research suggested some interesting results. One of the key messages for dementia education for adolescents must be dementia is not a natural part of ageing, and that it is necessary to separate healthy aging from dementia. The worrying finding of our research is namely that the vast majority (84.7%) of respondents recognized memory impairment with age as something normal that can prevent the recognition of dementia early enough. It is therefore very important to describe normal aging in dementia-related education for adolescents [8].

As another message is that students with relative with dementia showed a better level of knowledge of dementia-related claims. This is in agreement with findings of Isaac, et al. (2017), and Baker, et al. (2019) that inclusion of the person living with dementia improve students' dementia knowledge and attitudes [6,9].

However, the next key message remains that despite better knowledge ($p < 0.05$) of students with a relative with dementia, compared to students without a relative with dementia, barely a quarter (28.7%) of them still cultivate a predominantly positive attitude towards them. Of these, half felt that people with dementia need understanding, patience and help to be able to carry out activities in which they could still participate, and the other half felt that experiencing changes in a relative due to dementia was easier and less painful when get educated about dementia and accept it.

On the other hand, it is worrying that well over half (64.5%) of the respondents in our survey expressed a negative attitude towards behavioral, psychological, or both changes in a relative with dementia, which is consistent with the findings of Kogoj (2011) and Tible et al. (2017) [3,10]. Respondents' negative attitudes towards these changes were reflected in the answers, that the behavior of relatives with dementia is: "creepy because they don't remember past events"; "sad because they do not recognize their loved ones and replace them with those who have already died"; "exhausting because they repeat the same thing over and over again" and to live in their own world of illusions, these they are accusing unjustly".

These findings are in line with the beliefs that behavioral and psychological changes in dementia often present greater problems than decline in cognitive function itself [3]. Also in our research, it turned out that adolescents are the most difficult to experience delusions, that occur in different forms, different often. The most common are persecutory and pervasive delusions that occur in different forms, different often. In terms of frequency, delusions occur in the following order: they steal from them, this is not their home, these are not relatives [3,10]. Our respondents often cited these delusions, too. In such cases, adolescents can talk to

an agitated patient, reduce his loneliness and promote pleasant experiences such as walking the dog together, singing together, drawing together.

Recognizing such behavioral changes requires that adolescents be educated, attend counseling programs, and read literature [9-13]. In such a complex formal and non-formal education, the adolescent will gain not only theoretical and practical knowledge but also a good part of self-confidence, which will help him overcome the dilemmas due to behavioral and psychological changes in a relative with dementia.

This will help the adolescent to cope in situations where a relative with dementia repeat e.g.: You stole my money! Having dementia means giving up control over their own finances [3]. In this case, the adolescent can help relatives with dementia in one way such as "Oh no, is your money missing? I can see why you're upset. Don't worry, I'm going to help you look for it. Let's start by checking this drawer...«. Namely: Patients forget where they put various items or money and they therefore explain to themselves that strangers are coming to hide objects from them or have them even robbed. Avoid reasoning and logical explanations, and do not use reason to explain why it is not true or try to show proof that they are wrong. What often works better is to validate what they are saying and then, redirect to another activity or distract with something pleasant. Focus on validating the emotion behind their words. Let them know that you understand how they feel and that you want to help resolve the situation. Then, solve the problem, if possible, redirect them to another activity, or distract them with something they are interested in. Further, an adolescent can help them feel more in control by allowing them to have a wallet with a small amount of real money.

Most likely, the negative attitude of adolescents towards dementia is due to lack of knowledge about the course of dementia, so it does not lead to the promotion of activities in people with dementia, but to focus on losses due to dementia. If we take into account that a negative attitude towards people with dementia develops in adolescence, we must introduce elements of intergenerational dementia programs for adolescents [13]. Intergenerational dementia programs bring different generations together by organizing combined activities. Intergenerational socializing during non-formal education in the premises of the Spominčica voluntary association would have additional value. In such education on dementia, adolescents would in practice get to know a person with dementia in the initial stage accompanied by a relative. Adolescents could respectfully ask a person with dementia and their relative many things. In this way, adolescents would also learn to ask short, understandable and concise questions that are not too complicated for people with dementia. In such a complex formal and non-formal education, the adolescent will gain not only theoretical and practical knowledge but also a good part of self-confidence, which will help him overcome the dilemmas due to behavioral and psychological changes in a relative with dementia.

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., attitudes towards 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 also among secondary school students with a health program. Adolescents also need a clear additional information about memory function in healthy seniors.

Conclusion

As the proportion of people with dementia increases in today's long-lived society, one of the needs of adolescents is dementia education with elements of intergenerational education. We should also attract as many adolescents as possible to non-formal intergenerational forms of education and long-term participation in non-governmental voluntary organizations to help with dementia. In this way, adolescents would become acquainted with the actual symptoms of dementia and the behavioral and psychological changes due to dementia, making their coexistence with relatives with dementia easier.

Ethics approval and consent to participate

All procedures performed in study involving human participants were in accordance with the ethical standard of the school institutions and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Fully voluntary participation in completing the online survey for underage students was allowed by their parents or legal guardians after written consent, adult students agreed to participate themselves without any pressure.

References

1. <https://www.who.int/news-room/fact-sheets/detail/dementia>.

2. Ramovš J. Spominčica. *Kakovostna starost*. 2009; 12: 101-104.
3. Kogoj A. *Vedenjske in psihične spremembe pri demenci s študijskimi primeri*. El. knjiga. Celje: Visoka zdravstvena šola. 2011; 6-22.
4. Lokon E, Li Y, Parajuli J. Using art in an intergenerational program to improve students' attitudes toward people with dementia. *Gerontology & Geriatrics Education*. 2017; 38: 407-424.
5. Farina N, Laura J, Hughes LJ, et al. Adolescents' experiences and perceptions of dementia. *Aging & Mental Health*. 2020; 24: 1175-1181.
6. Isaac MGEKN, Isaac MM, Farina N, et al. Knowledge and attitudes towards dementia in adolescent students. *Journal of Mental Health*. 2017; 26: 419-425.
7. Celdran M, Triado C, Villar F. When Grandparents Have Dementia Effects on Their Grandchildren's Family Relationships. *Journal of Family Issues*. 2012; 33: 1218-1239.
8. Brezovar S. *Med zdravjem in demenco*. *Otrok in knjiga*. 2017; 44: 44-48.
9. Baker J, Jeon Y, Goodenough B, et al. What do children need to know about dementia? The perspectives of children and people with personal experience of dementia. *International Psychogeriatrics*. 2018; 30: 673-684.
10. Tible OP, Riese F, Savaskan E, et al. Best practice in the management of behavioural and psychological symptoms of dementia. *Ther Adv Neurol Disord*. 2017; 10: 297-309.
11. Fuh JL. Study of Behavioral and Psychological Symptoms of Dementia in Taiwan. *Acta Neurol Taiwan*. 2006; 15: 154-160.
12. Farina N, Hughes LJ, Jones E, et al. The effect of a dementia awareness class on changing dementia attitudes in adolescents. *BMC Geriatr*. 2020; 20: 188.
13. Gerritzena EV, Hullb MJ, Verbeek H, et al. Successful Elements of Intergenerational Dementia Programs A Scoping Review Research. *Journal of Intergenerational Relationships*. 2020; 18: 214-245.