

Understanding of Senile Dementia by Children and Adolescents: Why Grandma Can't Remember Me?

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Abstract-

Background: The present study sought to determine the knowledge and attitudes concerning senile dementia among children and adolescents in Taiwan with the intent of using the results in the design of an educational program about senile dementia for this population.

Methods: A 10-item questionnaire was distributed to all students aged 10 to 15 at 7 geographically selected public schools in Taiwan. The teachers in these schools and a group of 20 health professionals who were specialists in dementia were also invited to complete questionnaire for comparison.

Results: The majority of children, adolescents and teachers worried that their parents and grandparents might develop dementia in the future. Seven percent of all the student respondents felt that they would be embarrassed to invite classmates to their homes either because of actual demented family members living at home or if the hypothetical situation arose in which they actually had demented family members living at home. The younger students were more likely to have this feeling (χ^2 for linear trend=73.636, df=1, p=0.000).

Conclusion: Younger children were more likely to feel stigmatized by dementia in a family member which suggests that they may need more psychological support in order to effectively deal with dementia related issues. These results have important implications for the development of suitable educational programs about dementia in the curricula of primary and junior high schools.

Key Words: Aging, Cultural beliefs, Dementia, Illness concept, Children, Adolescent

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INTRODUCTION

The elderly population in Taiwan is rapidly expanding. It is estimated that by the year 2021, persons over the age of 65 will comprise 14% of all Taiwanese⁽¹⁾. Since the incidence of dementia increases with age, this

shift in demographics will carry an increase in extent of the burden of families and society in caring for people with dementia.

Dementia affects not only those who have it, but those who care about them. Family members typically watch with pain and sadness as the disease destroys

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their loved one's mind and personality. Many dementia victims move to live with their children because they no longer can take care of themselves. Does this disease cast a shadow over children and adolescents? Little is known about it. Previous studies have paid considerable attention to the impact of dementia on adult caregivers, while few studies have addressed the role of children and adolescents caregivers.

The purposes of this study were to assess the attitude towards dementia among children and adolescents and to investigate the relationship between selected demographic characteristics and these attitudes.

METHODS

A population-based questionnaire interview was conducted among 7 sampled public school students aged 10 to 15 from September 1998 to May 1999.

Sampling

In Taiwan, education is obligatory from age 7 to 15. In the Taiwan population more than 99% of children (age 7 to 12) and 90% teenagers (age 13 to 15) enter public schools; and the others attend private schools. Based on entirely on geographic considerations, a total of 7 schools were chosen from the northern (Kwan-Du, Taipei), central (Dou-Liu, Yun-Lin), southern (Nei-Pu, Pin-Dong) and eastern region (Yu-Li, Hwa-Lian) of Taiwan. This study was conducted with an adolescent migraine survey and the details were described elsewhere⁽²⁾.

Survey procedures

Letters describing the study objectives and methodology were first mailed to the school principals of the sampled schools for their approval to allow students to participate. A self-administered Attitude Toward Dementia Questionnaire was given to all of the students older than 10 and all of the teachers in these sampled schools. In addition, 20 health professionals from the different medical centers (14 neurologists, 4 psychiatrists and 2 psychologists) who were specialists in dementia were also asked to complete the questionnaire.

The survey consisted of 10 questions as shown in Table. The survey questions were divided into two categories: yes/no questions and responses to the questions with a four-point range of strongly agree to strongly disagree. We did not define dementia in the questionnaire.

Statistical methods

Descriptive statistics were used to analyze the attitude of subjects towards dementia. Chi-square tests were used to examine the association between the responses and demographic variables and to compare the responses among the different groups. Chi-square test for trend analysis was used to analyze the trend among different age groups. A p value of less than 0.01 was considered statistically significant.

RESULTS

Our target population consisted of 5825 students (2985 boys, 2840 girls) in 7 public schools. A total of 5515 questionnaires (2731 boys, 2784 girls) were returned with a response rate of 94.7%. Their ages ranged from 10 to 15 with a mean of 13.4 ± 1.4 . A significantly lower participation rate was found in boys (91.5% in boys vs. 98.0% in girls, $p < .001$). There were 566 teachers in the 7 schools and 282 (99 males and 183 females, mean age 40.8 ± 11.1 , range 23-64) teachers answered the questionnaire (response rate 49.8%). A total of 20 (18 males and 2 females) health professionals who specialized in dementia completed the questionnaire. The duration of the professional careers in these subjects ranged from 5 to 28 years, with a mean of 14.6 ± 6.0 . The responses of students, teachers and professionals to the questionnaire are shown in Table.

Having heard of dementia

The older students and girls had a significantly higher frequency of having heard of senile dementia (χ^2 for linear trend=19.9, $df=1$, $p < .001$; 95.0% girls vs. 91.8% boys, $\chi^2=23.1$, $df=1$, $p < .001$). Personal knowledge of a person with senile dementia was not related to age and gender (Chi-square test, $p > 0.05$).

Table. The percentage of responses to questions in students, teachers and professionals

Questions	Students N=5515	Teachers N=282	Professionals N=20
Yes response in Yes/No questions			
*Have you heard about senile dementia ?	93%	97%	100%
*Do you have dementia victims in your day to day surroundings ?	13%	45%	65%
*Is senile dementia a kind of psychosis ?	48%	28%	25%
*Is senile dementia hereditary ?	8%	14%	35%
Is senile dementia contagious ?	3%	1%	0%
Will you worry about your parents and grandparents getting senile dementia in the future ?	70%	70%	70%
% in 4-point agreement with statement			
*It is normal to get senile dementia when people are old.			
Strongly agree	4.0%	0.4%	0%
Somewhat agree	28.8%	27.9%	10%
Disagree	44.8%	39.2%	10%
Strongly disagree	22.4%	32.5%	80%
*Senile dementia is incurable.			
Strongly agree	6.8%	6.8%	10%
Somewhat agree	24.0%	37.6%	50%
Disagree	49.4%	44.9%	40%
Strongly disagree	19.9%	10.6%	0%
*Senile dementia is preventable.			
Strongly agree	44.9%	35.2%	0%
Somewhat agree	42.9%	61.4%	60%
Disagree	9.1%	2.7%	30%
Strongly disagree	4.0%	0.8%	10%
*I would feel embarrassed to invite classmates to my home if I had a family member with dementia.			
Strongly agree	2.0%	0%	0%
Somewhat agree	5.0%	1.9%	0%
Disagree	45%	29.7%	30%
Strongly disagree	48%	68.4%	70%

*means significant difference between these 3 groups by Chi-Square analysis.

Disease concept of dementia

The younger students and those who had an individual with senile dementia in their day to day environments were more likely to believe that it was normal to get dementia when people was old (χ^2 for linear trend=18.4 and 35.3, df=1, $p < .01$). The younger students and boys were more likely to harbor the misconception that senile dementia was contagious (χ^2 for linear trend=18.8, df=1, $p < .001$; boys 4.4% vs. girls 2.0%, $F=26$, $p < .001$). The younger students were more likely to believe that senile dementia was a kind of psychosis and that it was hereditary (χ^2 for linear trend=73.5 and 20.2, df=1, $p < .001$). The older students were more likely to believe that dementia is preventable (χ^2 for linear

trend=22.2, df=1, $p < .001$). Students who had or didn't have a demented patient in their environment did not differ in their beliefs as to whether dementia was preventable or incurable.

The teachers who had a demented patient in their environment worried more about family inheritance of senile dementia than teachers with no personal exposure to dementia (76.9% VS. 59.0%, $F=9.4$, df=1, $p=0.002$). These two groups of teachers did not differ significantly in their responses to the other questions.

Attitudes toward dementia

Boys and younger students would felt embarrassed to invite classmates to come to their home if they had

demented family members (boys 8.5% vs. girls 5.3%, $F=21.89$; $df=1$, $p<.001$; χ^2 for linear trend= 73.64 , $df=1$, $p<.001$). No association was found between having a dementia sufferer in their surroundings and feeling embarrassed in inviting classmates to come to their home because of the demented family member.

DISCUSSION

The respondents in the current study should constitute a good representative sample of all Taiwanese children and adolescents, since we randomly sampled 0.3% of all children aged 10-15 children in Taiwan. Our data showed that 45% teachers and 13% children and adolescents personally know someone with dementia. However, although most children, adolescents and schoolteachers were aware of individuals with senile dementia, their knowledge about senile dementia is meager and incorrect.

Ikels et al. reported that urban Chinese do not dread dementia as much as Americans⁽³⁾. They attribute this partially to the traditional Chinese belief that normal aging people frequently return to a childish state. In our survey in the present study, some children, adolescents, schoolteachers and even a few health professionals agreed that it is normal to get senile dementia when people are old. Currently, senile dementia is treated as a "brain disease" in medicine. The finding that older students tend to believe that it is not normal to develop dementia and that dementia is not a kind of psychosis suggests students understand dementia more as they grow up.

The questionnaire used in the present study was focused more on gross impression about dementia than on testing of knowledge about dementia. To our surprise, most children, adolescents and even the schoolteachers had an overly optimistic attitude about dementia. Most of them didn't consider dementia to be incurable and thought that it was a preventable condition. Health professionals had more realistic attitudes. This result partly reflected their expectation rather than their truly belief. Our previous community study in an urban region of Kinmen found that almost no dementia patients sought

medical help because they did not recognize the condition as being a disease or they thought that medical consultation would be useless⁽⁴⁾. From the Japanese-American study, they also found unrecognized dementia was common⁽⁵⁾. Accurate information about the diagnosis and prognosis appears to help families cope with and manage the problems more successfully⁽⁶⁾. So, public education is in need in our population.

Surprisingly, the results of this study indicate that personal experiences with senile dementia did not have a significant relationship to better understanding of this disease. Because instruction concerning this common disease is not included in the school curriculum for students in this age group, the media becomes their only widely available source of information. Extensive media reporting regarding positive progress in treating senile dementia in recent years may explain the over-estimated predictions about the effects of preventive measures and treatment among children and adolescents.

Knowing the degree of understanding and attitude of children and adolescents toward dementia is a necessary step in developing programs to reduce their fear of dementia symptoms. Many elderly Taiwanese live with their children and most demented patients in Taiwan are cared for at home⁽⁷⁾. Children's feelings toward the demented patient are very important. Although the low response rate in the teachers group might limit the generalization of our findings among the teacher group, our findings that younger children and boys would have a higher tendency to experience embarrassment about this disease suggests that need more psychological support and educational programs to help them to face this stressor should be designed and implemented.

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