

# Dementia as a Current Problem Due to Demographic Trends – Knowledge of Caregivers

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## Abstract

*Introduction:* Dementia is not a disease but a collection of symptoms resulting from damage to the brain. These symptoms can be caused by a number of conditions. It is generally assumed caregiver's better knowledge of the symptomatology and symptoms result in a better quality of care.

*Objective:* To assess the knowledge about the causes and symptoms of dementia in a selected sample of family members of seniors with dementia and in non-medical healthcare personnel caring for seniors with dementia at geriatric-psychiatric wards.

*Method:* A questionnaire-based survey applied to a selected group of family members and to non-medical workers (questionnaire by the Institut Universitaire de Gériatrie in Montréal).

*Results:* Younger age lay persons ( $p = 0.0012$ ) and relatives in a straight line of the elderly showed better knowledge of dementia ( $p = 0.0002$ ). The relatives' satisfaction with care did not correlate with their knowledge of the causes and symptoms of dementia ( $p = 0.5899$ ). The relatives' gender did not show a statistically significant correlation with knowledge ( $p = 0.937$ ). However, women showed better knowledge from the objective point of view. In the sample of non-medical professionals, education correlated with the level of proven knowledge of the causes and symptoms of dementia while respondents with university education demonstrated better knowledge ( $p = 0.0016$ ) as well as respondents with completed specialized education on dementia ( $p = 0.0003$ ). Family members of seniors with dementia did not give correct answers to questions on the pathophysiology and symptoms related to the progression of dementia. Non-medical healthcare personnel did not have sufficient knowledge of the general aspects of dementia and some behavioural and psychological symptoms of dementia.

*Conclusion:* The analysis of the family members' and non-medical healthcare personnel's knowledge about dementia proved statistically significant differences. The knowledge demonstrated by the family members of patients with dementia differs depending on the age and relation to the patient. The level of knowledge demonstrated by non-medical healthcare personnel caring for patients with dementia differs by gender, their achieved level of education and specialized education.

**Keywords:** care, dementia, family, non-medical personnel, psychiatry

## Introduction

Dementia is the most frequent mental disorder in old age. It develops gradually. The first emerging symptoms only indicate deteriorated mental functions, often generally connected with the senior age. However, it represents a serious condition for the patient, his family and, due to the demographic changes and population ageing, for the whole society. Dementia is a silent epidemic of the 21st century. This is due to the fact that every third person must expect some form of dementia after the age of 80 in their life (Haškovcová, 2012, p. 32). Statistical data give evidence

that the population of the European Union, the Czech Republic included, is ageing. The 2015 Annual Report on Dementia Status, published by the Czech Alzheimer Society, states that around 152.7 thousand persons suffer from dementia and two thirds of the patients are women. This means that the number of patients has grown by 50 thousand in the recent ten years. According to expert estimates, due to the social development and continuous prolongation of life expectancy, dementia might skyrocket up to 383 thousand persons by the half of this century (Mátl & Mátlová, 2016, p. 49). Dementia is being monitored not only in the Czech Republic but also in other developed countries where seniors are becoming an increasingly significant social group. For instance, an epidemiological survey on the Western-European population, assessing the occurrence of dementia in the course of 20-30 years, involving five various studies in Sweden, the Netherlands, England and Spain, informed that only Spain marked a decrease in dementia occurrence, concretely in men (Yu-Tzu et al., 2015, p. 116). More precise data on dementia prevalence in hospitalized persons are missing (Timmons et al., 2015) but it is certain that the quality of life of persons with dementia and their close persons is affected (Castro-Monteiro, et al., 2016). While assessing the impacts of dementia on seniors' life, the severity of the disease and the level of impairment of cognitive and other executive functions must be considered. The actual disease is not decisive for the quality of life; the most serious impact of the disease in higher age is the reduced self-sufficiency. Unfortunately, this often makes impossible the senior's and his relatives' efforts to stay in their natural social environment until the end of their life. The Czech Republic currently represents one of the oldest European populations by age, with a low proportion of infant population. Not only for the reasons stated above, it is indispensable to increase the public interest and awareness in seniors, to change the negative attitudes to age in the society and to endeavour to understand the current needs of seniors and their family members. This also involves the need for knowledge about dementia, especially in order to enable timely diagnosis, subsequent therapy and decision on provision of the corresponding care for people with dementia that are going to emerge due to the ageing population (Castro-Monteiro et al., 2016). The knowledge concerning dementia should become a priority for both professional and lay caregivers, i.e. family respecting the senior's wish to spend the "autumn of their life" in their natural environment. A support provided by family taking care of the senior should be a priority for the society.

## **Objective**

The objective of the present study is to assess the knowledge of the causes and symptoms of dementia in seniors in a selected group of family members of seniors with dementia, and in non-medical healthcare employees caring for seniors with dementia.

## **Methodology**

The tool for evaluating caretakers' knowledge was designed based on a questionnaire of the Institut Universitaire de Geriatrie in Montreal under the title "Dementia Knowledge Assessment Tool" (Robinson et al., 2014), applied in the translation of its full wording and supplemented by items focused on demographic data evaluation. The questionnaire included a total of 21 knowledge-related questions with possible answers: "I agree, disagree, don't know". The knowledge-related items were evaluated using a score according to the number of correct answers (all knowledge-related items were identical for both groups of respondents and the total score thus achieved values from 0 to 21 points, while average score values were subsequently tested in regards to demographic data). The subjective assessment of knowledge was based upon a self-assessment using a usual classification scale (1 = excellent to 5 =

insufficient knowledge). Answers were evaluated as correct or incorrect, “I don’t know” was considered a wrong answer. As described above, the knowledge-related explorative items were supplemented with items focused on identifying demographic data on the respondents. The data analysis was executed in IBM SPSS ver. 22 on significance level  $\alpha = 0.05$  (tests: Shapiro-Wilk Test, Levene’s and F-Test, Sheffé’s multiple comparisons method, Kruskal-Wallis Test and Brown-Forsythe Test). Between December 2015 and March 2016, a total of 75 questionnaire forms were distributed to healthcare employees, respecting the general personnel coverage of care at the relevant healthcare facility and 100 forms were provided to relatives of patients with dementia. To eliminate the possibility of respondents’ searching for replies, the questionnaires for professional caretakers were distributed in the course of work meetings and immediately retrieved. The relatives completed their questionnaires during visiting hours.

## Results

In total 93 questionnaires from relatives of seniors with dementia were analysed (93% return rate) and 75 (100% return rate) from non-medical healthcare personnel, working at Geriatric-Psychiatry Ward of the facility under observation. 28.0% of the relatives were males and 72.0% females. The average relatives’ age was 48 years. Most of the respondents (44.1%) stated son/daughter relation and 26.9% grandson/granddaughter, only 7.5% indicated husband/wife relation and 15.1% of the respondents indicated another relation (daughter-in-law, cousin, niece, aunt, great-granddaughter or son-in-law). A total of 57% of the seniors’ relatives were older than 45 years, with secondary level of education (44.1%) and sharing one household with the hospitalized senior (51.6%). Nevertheless, 57% of the relatives reported that after the hospitalization, the senior would be placed in a retirement home. Out of the 75 non-medical healthcare employees 21.3% were males and 78.7% females. By job position, 49.3% were general nurses, 10.7% were attendants, 32.0% medical orderlies and 8.0% specified “other” as their job position (ergo-therapists, physiotherapists). The average age of professional caretakers was 42 years. Most (45.3 %) respondents completed secondary-level education, with a school-leaving exam. Only 30.7% of the respondents had obtained specialized education in psychiatry. Their average length of practical experience in healthcare was 16 years and the average experience on a geriatric-psychiatry ward was 10 years. Most of the enrolled non-medical healthcare personnel (61.3%) did not share their household with an elderly person.

In the subjective evaluation of knowledge about dementia, the seniors’ relatives rated their knowledge mostly as good (53.8%); average grade = 3.0. In knowledge-related items, the relatives made mistakes mostly in questions related to dementia symptomatology and progression. They were, for instance, not aware of the fact that sudden confusion does not have to be a symptom of dementia (76.4%) or that swallowing disorders develop in late stages of dementia (58.1%). Also, they wrongly stated that it is important to always guide (correct) a person with dementia, when he/she is confused (71.0%). On the other hand, they proved good knowledge of behavioural symptoms and their compensation, as they correctly stated (84.9%) that a person with dementia must be supported in decision-making (e.g. on what clothes to wear) and also knew that people suffering from dementia may show atypical behaviours such as aggressive behaviour in usually moderate persons (87.1%). Most relatives (84.9%) also stated that if a person has a late stage of dementia, family members may help others (healthcare personnel) understand the needs of the given person (patient). The statistical testing of summary evaluation (score) of the knowledge verified that the knowledge of relatives differs depending on their age ( $p = 0.002$ ). Younger relatives proved to have better knowledge, which is also confirmed by the fact that relatives in son/daughter and grandson/granddaughter relation proved

better knowledge ( $p = 0.0002$ ). No difference between the knowledge of men and women was confirmed ( $p = 0.0782$ ) and there was no difference in knowledge attributable to education ( $p = 0.1759$ ). The relatives' degree of declared satisfaction with the care (services offered to the senior) did not correlate in a statistically significant manner with the level of relatives' knowledge about dementia ( $p = 0.5899$ ).

The subjective self-evaluation of knowledge by non-medical healthcare personnel equalled to the average grade of 2.5 while most respondents assessed their knowledge as good (41.3%) and very good (37.3%). The most frequent incorrect answer provided by “non-physicians” was due to a lack of awareness that at a later stage of dementia, the degree of pain cannot be identified (incorrect answer 61.3% and 14.7% “Don't know”). An alarming finding was the fact that most professional caretakers (68%) believed that if a person with dementia is desperate, they cannot be helped by talking to them about their feelings. A positive fact is that the healthcare personnel are aware that a change of environment has an impact on persons with dementia (e.g. opening and closing window blinds), as 74.7% stated. Same as lay caretakers, also a high percentage (80%) of healthcare personnel stated that if a person has a late stage of dementia, family members may help others (healthcare personnel) understand the needs of the given person (patient). We have found that the level of knowledge about dementia is independent on the age of non-medical healthcare employees ( $p = 0.8415$ ) but a difference between men and women was found ( $p = 0.0417$ ). Women had better knowledge. The worst knowledge was found in healthcare personnel with primary education ( $p = 0.0016$ ) and, contrariwise (vice versa), respondents with specialized education in psychiatry showed better knowledge ( $p = 0.000$ ); nevertheless, the length of experience on a geriatric-psychiatry ward did not correlate with the level of knowledge ( $p = 0.919$ ) of the healthcare personnel. As shown in Fig. 1 and Fig. 2, differences were found between objective (using knowledge scores obtained from the number of correct answers, see Methodology) and subjective assessment, both by relatives ( $p = 0.000062$ ) and non-medical healthcare employees ( $p = 0.004150$ ). Figure 3 shows the difference in objectively assessed knowledge (the sum of the knowledge scores) by the healthcare personnel and lay caregivers – seniors' relatives ( $p = 0.00608$ ).

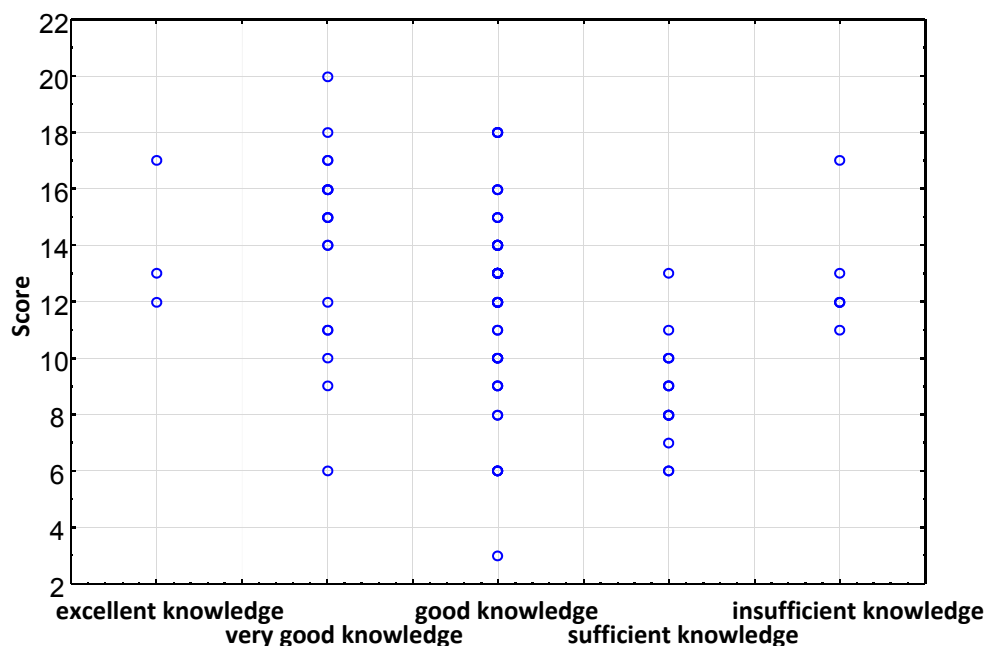


Fig. 1 Two-dimensional point diagram of total scores and subjectively assessed knowledge on dementia by seniors' family members

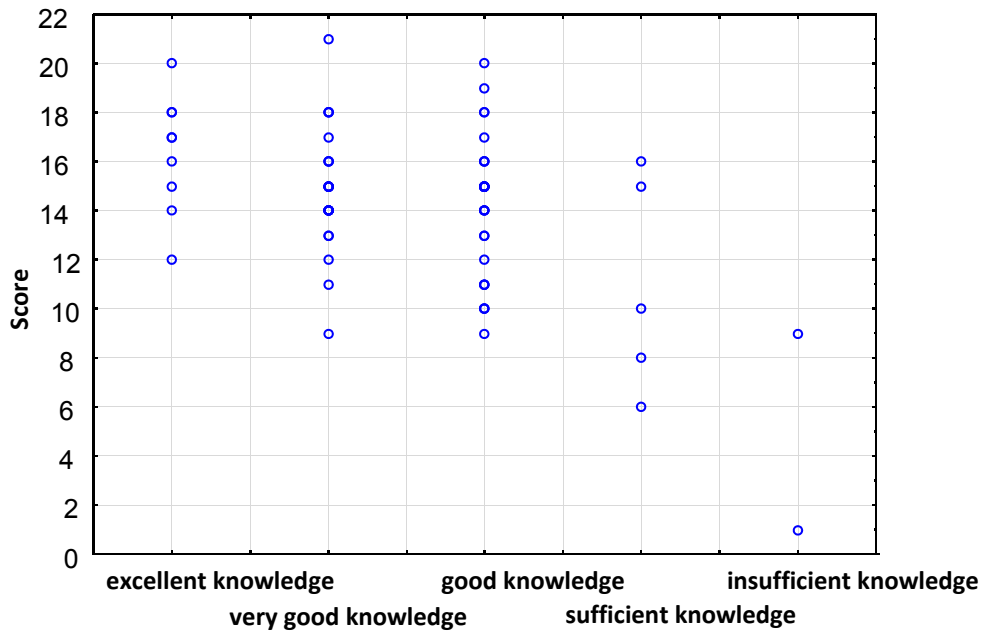


Fig. 2 Two-dimensional point diagram of total scores and subjectively assessed knowledge on dementia by non-medical healthcare personnel

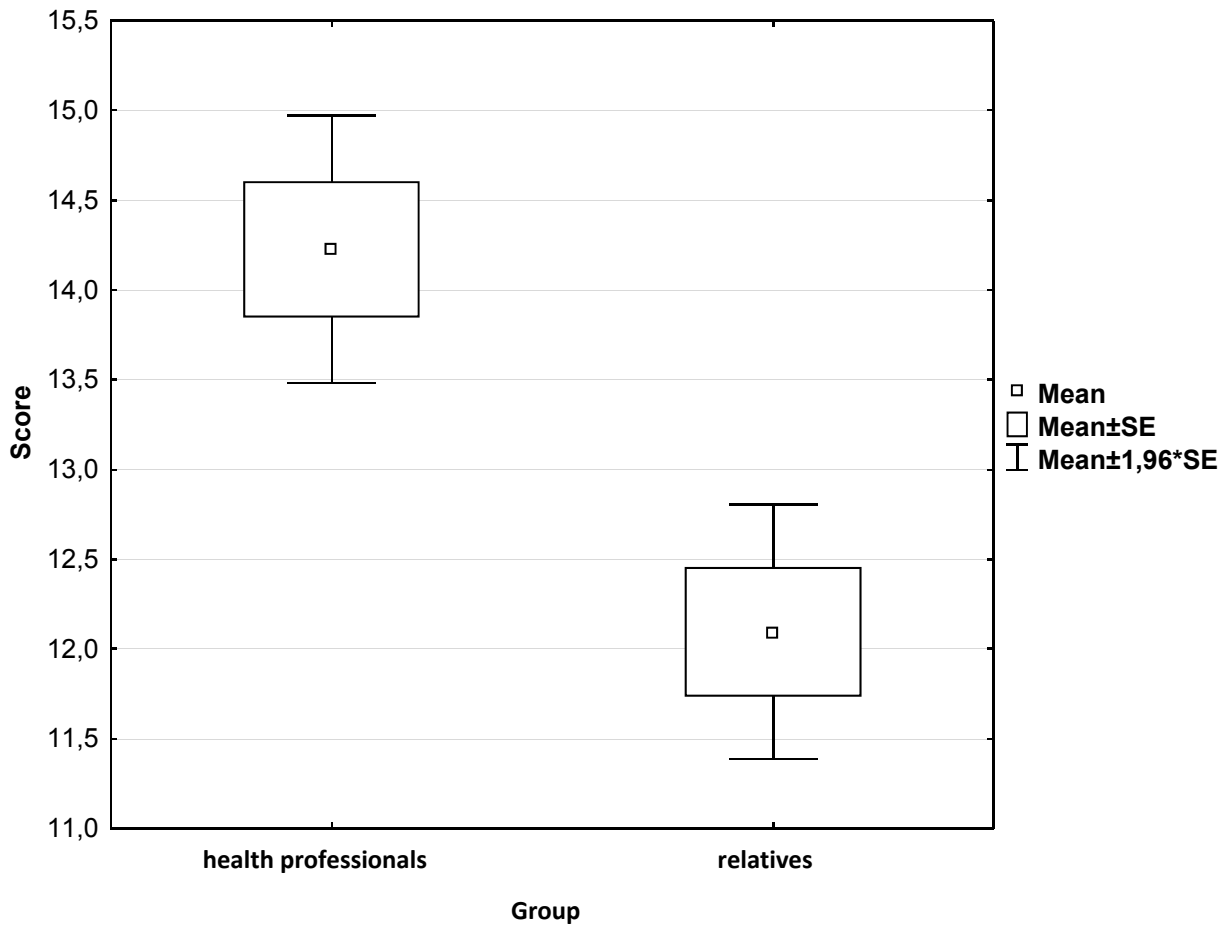


Fig. 3 Comparison of objectively assessed knowledge on dementia by healthcare personnel and relatives

## Discussion

The executed study deliberately compared the knowledge of dementia symptoms in a group of professional carers – non-medical healthcare personnel and in relatives of hospitalized patients with dementia. The discussion only covers those areas that have not been mentioned in the results or that can significantly affect the quality of care. The main objective of this study was to find out if and how the knowledge of both groups of respondents under consideration differed in the specific healthcare facility providing geriatric-psychiatric care, but mainly to identify the areas that must be addressed in order to improve the quality of collaboration and care for seniors with dementia. It is assumed that the level of knowledge significantly affects the quality of care. An interesting finding was that 67.7% of family members and 60.0% of non-medical healthcare personnel correctly agreed with the statement that “knowledge of the probable cause of dementia may help predict its progression”. In a study conducted by the Institut Universitaire de Gériatrie in Montréal, more than 85% of the family members and healthcare personnel replied correctly to the same statements (Robinson et al., 2014, p. 160). While here the knowledge of both groups did not differ, in case of incontinence, the situation was different. 54.8% of the family members of patients with dementia and 86.7% of non-medical healthcare personnel correctly disagreed with the statement that “incontinence always occurs in early stages of dementia”. A great span in the knowledge in the two groups is obvious here. The professional caretakers have better knowledge in regards to patients’ incontinence. The same was revealed by the Montreal study, where 40.6% of the family members and 49.5% of professional caretakers gave the correct answer (Robinson et al., 2014, p. 162). This is probably due to the fact that professionals encounter seniors in advanced stages of dementia more frequently and have more experience with them. Based on epidemiological studies, 10 to 20% of the population above 65 years of age are affected by urine incontinence. Women are affected by incontinence more frequently (1.5 to 2 times more frequently than men). The prevalence rises up to 80-90 years when one half of women and more than a third of men suffer from incontinence. Thus, based on expert estimates there are 170 to 200 thousand seniors affected by urine incontinence in the Czech Republic (Topinková, 2010, p. 18). 50.5 % of the family members of patients with dementia and 58.7 % of non-medical healthcare personnel correctly agreed with the statement that “dementia probably limits the length of life”. The results of the Montreal research suggest that around 50% of the family members and 40% of professional caretakers do not know that dementia is a life-limiting disease (Robinson et al., 2014, p. 162). 84.9% of the family members of patients with dementia and 80.0% of non-medical healthcare personnel caring for patients with dementia correctly agreed with the statement that “if a person suffers from a late stage of dementia, family members may help others understand the needs of such person”. We may assume that this finding is a good starting point for future cooperation. And, 80.6% of the family members and 84.0% of non-medical healthcare personnel correctly agreed with the statement “people with dementia may develop problems with visual perception”. Accordingly, in the study conducted by Institut Universitaire de Gériatrie in Montréal, more than 85% of the family members and healthcare personnel replied correctly to the same statements (Robinson et al., 2014, p. 160). In our survey, most participating relatives (67.7 %) were those whose senior hospitalized with dementia diagnosis fell within the age range of 75–89 years. Alarming was the finding that although 34.4% of the relatives reported that prior to hospitalization their senior lived autonomously and 51.6% shared the same household with them prior to hospitalization, the relatives planned to place more than a half (57%) of the patients in a retirement home after the hospitalization. The fact that family members tend to rely on placing the senior in social service facilities after

hospitalization was also confirmed by a study from the Kroměříž Psychiatric Hospital, monitoring the return of female senior patients to their home environment between 2003 and 2013. It was found that in 2003 70% and in 2013, only 63% of hospitalized female seniors returned to their home environment after hospitalization (Lužný, 2014a, p. 38). Although the life expectancy continues to grow and the prevalence of organic mental disorders will continue to grow in this regard, the number of healthcare personnel is decreasing, so there are relatively fewer means for satisfying the continuously growing demand for geriatric-psychiatric services (Lužný, 2014b, p. 140–141). A reform of psychiatric care should take these data into account while securing a high-quality and available psychiatric care for the ageing population (Lužný, 2014b, p. 140–141). A fundamental element of a purposeful cooperation between lay and professional caretakers is the knowledge of the possibilities and rightful demands on care, but the lay public has not always the chance to gain it. In a survey conducted at the Long-Term Care Hospital in Klokočov, focussing on identifying the needs of caretakers out of the family members of seniors with dementia, 96% of relatives stated that it was important for them to have basic information on what to do for the senior with dementia at home and 82% of the respondents replied that it was important to know about people who would help in case of need (Stolička, 2013, p. 161). To our question if they knew who to contact in case of a senior patient's mental problem, our respondents out of relatives mostly replied positively (65.6%) and 89.2% of the relatives replied that they were happy with the services and care provided. This may imply that the quality of geriatric-psychiatric care in the facility of concern is considered good.

## **Conclusion**

Dementia is the most frequent disorder in old age, the increasing incidence of which has a major impact on healthcare practice, nursing practice and private life. One of the fundamental prerequisites of an adequate care is the necessary knowledge, understanding and skills in the care for a person with dementia, both in their natural social environment and at healthcare and social care facilities. We found out that the knowledge of both lay and professional caretakers in the sample of concern showed significant differences. Family members of patients with dementia gave wrong answers to questions concerning the pathophysiology of the disease and symptoms related to the progression of dementia. Non-medical healthcare personnel working in the specific facility of concern (psychiatric hospital) had insufficient knowledge of the general aspects of dementia and of some behavioural and psychological symptoms of dementia. The results of the survey provide an impulse for improving the quality of care for seniors with dementia in a specific healthcare facility providing geriatric-psychiatric care.

## **Ethical aspects and conflict of interest**

Authors declare that they are not aware of any conflict of interest in regards to the study carried out. The study was approved by the Ethical Committee of the relevant healthcare services provider (psychiatric hospital), where the healthcare employees and the relatives of patients with dementia were inquired.

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