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## CURRENT PRACTICE IN CARING FOR PEOPLE WITH DEMENTIA

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### Abstract

**Introduction.** The increasing of the prevalence of dementia worldwide makes it a public health priority. This is due to the growing number of elderly populations around the world. The lack of research on dementia identified in Kazakhstan.

**Aim:** to study the current practice of care in primary healthcare (PHC) facilities for people with dementia in Almaty city.

**Materials and methods.** At the first stage, the number of registered cases with dementia in Almaty was analyzed. The data were obtained from the National Scientific Center for Health Development, Almaty branch. At the second stage, interviews were conducted with primary health care specialists on the provision of assistance to the target group. 12 PHC professionals involved in interviewing.

**Results.** From 2019 to 2023 the number of vascular dementia as well as Early or late onset Alzheimer's dementia is on the rise, whereas the Dementia in other diseases classified elsewhere decreased. The main barrier to providing care to people with dementia is related to the insufficient qualifications of primary care specialists, as well as the lack of screening for dementia among the adult population. There are no cognitive tests currently used for screening dementia in PHC, although they are effective in assessing it.

**Conclusion.** In Almaty, there is an increasing prevalence of dementia, which requires additional training for PHC specialists on early screening of the condition. Additionally, further research is needed in the future to revise the model of care for people with dementia at the PHC level and to raise public awareness.

**Keywords:** dementia, primary care, assistance, health policy.

### Резюме

## СУЩЕСТВУЮЩАЯ ПРАКТИКА УХОДА ЗА ЛЮДЬМИ С ДЕМЕНЦИЕЙ

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**Актуальность.** Рост распространенности деменции во всем мире делает ее приоритетной задачей общественного здравоохранения. Это связано с ростом числа пожилых людей во всем мире. В Казахстане недостаточно исследований по деменции.

**Цель исследования:** изучить текущую практику оказания медицинской помощи в учреждениях первичной медико-санитарной помощи (ПМСП) людям с деменцией в городе Алматы.

**Материалы и методы.** На первом этапе было проанализировано количество зарегистрированных случаев деменции в Алматы. Данные были получены из Алматинского филиала Национального научного центра развития здравоохранения. На втором этапе были проведены интервью со специалистами первичной медико-санитарной помощи по вопросам оказания помощи целевой группе. В опросе приняли участие 12 специалистов ПМСП.

**Результаты.** С 2019 по 2023 год число случаев сосудистой деменции, а также ранней или поздней деменции Альцгеймера растет, в то время как число случаев деменции при других заболеваниях, классифицированных в других рубриках, уменьшилось. Основным препятствием для оказания медицинской помощи людям с деменцией является недостаточная квалификация специалистов первичной медико-санитарной помощи, а также отсутствие скрининга на деменцию среди взрослого населения. В ПМСП в настоящее время не используются когнитивные тесты для скрининга деменции, хотя они эффективны для её оценки."

**Выводы.** В Алматы наблюдается рост заболеваемости деменцией, что требует дополнительного обучения специалистов ПМСП по вопросам её раннего скрининга. Также в будущем необходимы дополнительные исследования для пересмотра модели оказания помощи людям с деменцией на уровне ПМСП и повышения осведомленности населения

**Ключевые слова:** деменция, ПМСП, помощь, политика здравоохранения.

Түйіндеме

## ДЕМЕНЦИЯСЫ БАР АДАМДАРҒА КҮТІМ ЖАСАУДЫҢ ҚОЛДАНЫСТАҒЫ ТӘЖІРИБЕСІ

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**Кіріспе.** Дүние жүзінде деменцияның таралуының артуы оны денсаулық сақтаудың басымдығына айналдырады. Бұл бүкіл әлемдегі егде жастағы адамдар санының өсуіне байланысты. Қазақстанда деменция бойынша зерттеулер жеткіліксіз.

**Зерттеудің мақсаты:** Алматы қаласында деменциясы бар адамдарға алғашқы медициналық-санитарлық көмек (МСАК) мекемелерінде медициналық көмек көрсетудің ағымдағы тәжірибесін зерделеу.

**Материалдар мен әдістері.** Бірінші кезеңде Алматыда тіркелген деменция жағдайларының саны талданды. Деректер денсаулық сақтауды дамытудың Ұлттық ғылыми орталығының Алматы филиалынан алынды. Екінші кезеңде нысаналы топқа көмек көрсету мәселелері бойынша алғашқы медициналық-санитарлық көмек мамандарымен сұхбат жүргізілді. Сауалнамаға МСАК-тың 12 маманы қатысты.

**Нәтижесі.** 2019 жылдан 2023 жылға дейін тамырлы деменция, сондай-ақ ерте немесе кеш Альцгеймер деменциясы жағдайларының саны артып келеді, ал басқа рубрикаларда жіктелген басқа аурулардағы деменция жағдайларының саны азайды. Деменциясы бар адамдарға медициналық көмек көрсетудің негізгі кедергісі-алғашқы медициналық-санитарлық көмек мамандарының біліктілігінің жеткіліксіздігі, сондай-ақ ересектер арасында деменция скринингінің болмауы. Деменцияны анықтауға арналған когнитивті сынақтар жоқ, бірақ олар деменцияны бағалауда тиімді.

**Қорытынды.** Алматыда, деменциямен сырқаттанушылықтың өсуі байқалады, бұл МСАК мамандарының оның ерте скринингі мәселелері бойынша қосымша білім алуды талап етеді. Сондай-ақ, болашақта МСАК деңгейінде деменциямен ауыратын адамдарға көмек көрсету моделін қайта қарау және халықтың хабардарлығын арттыру үшін қосымша зерттеулер қажет.

**Түйінді сөздер:** деменция, МСАК, көмек, денсаулық сақтау саясаты.

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**Introduction**

Dementia has become a public health priority in recent years [6]. The Diagnostic and Statistical Manual of Mental Disorders-5 criteria redefined dementia as a major neurocognitive disorder characterized by significant decline or loss of the in at least one domains of cognition, including executive function, complex attention, learning, memory or other cognition which can also be influenced to social or occupational function [8].

A systematic review found that among people aged 50 years and over, the cumulative prevalence of dementia from all causes was 697 per 10,000 people [5]. Other authors note a likely increase in people with dementia from 57.4 to 152.8 million cases from 2019 to 2050. Dementia is more common in women compared to men, where the ratio was 1.69 [9]. Alzheimer's was most common in women over 60 years of age 1.9 times compared to men, while vascular disease was 1.8 times higher in men [5]. It has been determined that about 67% of people with dementia live in middle- or low-income countries [1]. A study of dementia in the Southeast Asia [10] showed that dementia in people under 65 years of age was 28.5%, especially Alzheimer's type [15]. People over 65 years of age have more cognitive impairment associated with vascular disease. The increase in dementia is associated with an increase in people's life expectancy and population. In Europe the prevalence of Alzheimer's disease was 5.05% in which women had higher rate 7.13% in comparison to men 3.31% [10].

Depending on the manifestation of dementia, its type can be determined, in particular in the early stages of its manifestation. Zoe Arvanitakis [3] provides clinical and pathological characteristics that allow differentiation of individual causes of dementia. Diagnosis of dementia is based on a survey or medical history, as well as questionnaires to identify cognitive impairment. For example, the Mini-Cog and Mini-Mental State Examination (MMSE) have been the most widely studied cognitive screening tools, and the Abbreviated Mental Test Score (AMTS) achieves high sensitivity and specificity [7] in the shortest time possible in primary care settings. In addition, neuroimaging of the brain is carried out to identify any structural changes in the brain [3] as well as identification of the clinically validated biomarkers (amyloid and tau pathology). Successful treatment of people with dementia depends on the training of a multidisciplinary team and the reduction of psychotropic medications and person-centred treatment [14]. Also, to improve care for people with dementia, Primary Care Memory Clinics in Canada and the Gnosall Memory Clinic in the UK. These models emphasize

integrated care approaches that combine medical, psychological, and social support services [4].

Therefore, the **aim** of our research is to study the current practice of care in primary healthcare facilities for people with dementia in Almaty city.

**Materials and methods**

This study was conducted in two stages. In the first stage, data were collected retrospectively, while in the second stage, a prospective study was carried out.

At the first stage, the number of registered cases with dementia in Almaty was analyzed. The data were obtained from the National Scientific Center for Health Development, Almaty branch from 2019 to 2023 years the types of dementia were categorized as follows: Early-onset Alzheimer's disease dementia; Dementia in late-onset Alzheimer's disease; Dementia in Alzheimer's disease, atypical or mixed type; Dementia in Alzheimer's disease, unspecified; Vascular dementia; Dementia in other diseases classified elsewhere; and Dementia, unspecified. Based on five years of data, a forecast of the prevalence of dementia until 2026 in Almaty was made. To predict the number of cases of dementia, the linear regression method was used according to the formula:

$$y=a+b*x$$

(where: y – dependent variable; x – independent variable; a and b are regression coefficients).

To calculate regression coefficients, the following formulas are used:

$$b = \frac{n \sum xy - \sum x \sum y}{n \sum x^2 - (\sum x)^2}$$

$$a = \frac{\sum y - b \sum x}{n}$$

At the second stage, a qualitative study was conducted to preliminarily examine the current practice of providing care to people with dementia. This method was chosen to more accurately identify the challenges within primary health care (PHC), which will help inform future, more in-depth studies on the topic and guide the development of recommendations for improving care practices for this patient group in the studied PHC.

The interview involved a PHC managers, who are typically responsible for business processes in PHC (2 people), as well as a general practitioner (3), a nurses (3), a

neurologist (1), a psychiatrist (1), and a psychologist (2), who could offer insights into working with families of patients with an established dementia diagnosis. In total, interviews were conducted with 12 participants.

The interviews were conducted in person at a PHC facility in Almaty, in either Russian or Kazakh, depending on the respondents' preferences. The duration of each interview ranged from 20 to 30 minutes. The interview questions included:

- What is the current practice of caring for people with dementia, and what barriers exist?
- Who is involved in the care of people with dementia?
- What steps should be taken in primary care to improve the care of people with dementia?

All interview data were initially transcribed briefly on paper, and a summary of each question was then entered into a Word document in table format. This document was sent to participants via email or WhatsApp after obtaining their consent. Once the responses were confirmed, they were included in the analysis. In the next step, Dedoose

software was used to analyze the information. During the analysis, several key themes emerged, reflecting the respondents' experiences and perceptions. Each interview was coded using an inductive approach, which enabled the identification of recurring issues and unique cases that required special attention.

The study design was approved by the Local Committee on Bioethics, Kazakhstan (Protocol No. 4, 26 June 2024).

### Results

The findings show that per 100 000 population, the highest rate is vascular dementia, which increased from 137.55 to 164.55, and significantly further increases can be seen to 234.91 by 2026. In addition, the dementia in other diseases classified in other categories significantly decreased from 264.51 to 196.69, which may also tend to gradually decrease to 118.96 by 2026 per population. Dementia, unspecified grew from 0 to 9.81 per 100 000 population over the period given. Moreover, it is expected the increase of the Early or late onset Alzheimer's dementia to 7.03 and 9.76 per population in 2026 (table 1).

Table 1.

### Trends in dementia in Almaty city.

Type of dementia	2019	2020	2021	2022	2023	2024	2025	2026
Early onset Alzheimer's dementia	6,61	6,30	6,69	5,99	7,23	6,84	6,93	7,03
Late-onset Alzheimer's dementia	7,27	6,93	4,87	4,36	11,36	8,64	9,20	9,76
Alzheimer's dementia, atypical or mixed type	1,32	1,26	1,22	1,63	1,03			
Dementia due to Alzheimer's disease, unspecified	1,32	1,89	0,61	0,54	0,52			
Vascular dementia	137,55	132,36	148,48	164,55	199,81	203,57	219,24	234,91*
Dementia in other diseases classified elsewhere	264,51	240,77	222,72	196,69	183,81	160,05	139,51	118,96*
Dementia, unspecified	0,00	0,63	1,22	9,81	8,26	11,69	14,26	16,83*
p<0.05*								

#### Interview results

What is the practice of care people with dementia and what barriers exist?

The main barrier identified by PHC professional was the need for training.

GP "In my practice I have rarely been diagnosed people with dementia, although I have read about its increase. However, it seems to me that I would like to deepen my knowledge of helping people with dementia, in particular, I think I can prescribe medications and refer to specialists, but I'm not sure if I can give recommendations to relatives on how they should accept the diagnosis and provide assistance."

GP "A gerontological office has been opened in a nursing home financed by the local executive body, where screening of people living there is carried out based on cognitive tests"

PHC manager: "We have the ability to train GPs, but we have not received any requests from them regarding training on dementia issues. Also, we usually receive a list of continuing education topics from universities, but I don't remember there being a topic on dementia, I mean separate courses".

Psychiatrist "The reality is that not enough work is being done to screen for dementia in the elderly population. The barriers that may be encountered by relatives of a person with dementia were identified related to the preparation of guardianship documents etc."

Nurses "We do not have algorithms for providing assistance to people with dementia, such as actions for coronary heart disease. On this issue, I do more of the tasks that the GP gives me"

Also, all specialists note that assistance is provided within the framework of a clinical protocol, which is approved by the Joint Commission on the Quality of Medical Services of the Ministry of Health.

Who is involved in helping people with dementia?

GP "In general, psychiatrists are involved and treatment is based on a clinical protocol. There is a dementia center in Almaty, and a private clinic treats this category of patients. Also, in the center of psychiatry in Almaty there is a gerontological department, where people with dementia receive the necessary inpatient treatment".

GP "There is no special model that specifies who should participate in dementia care. The GP refers patient with dementia to a narrow specialist as neurologist or

psychiatrics, and if necessary, GP can get involved in the treatment.”

Neurologist “depending on the type of dementia, we consider further treatment tactics. However, within the framework of ICD 10 it refers to a mental illness, treatment is mainly carried out by psychiatrists”.

What steps need to be taken at the primary care level to improve care for people with dementia? - All participants agreed on the need for training of primary care specialists, as well as to consider the possibility of introducing screening for people with dementia and conducting large-scale public awareness efforts.

#### Discussion

Our results show an increase in dementia prevalence in Almaty, which aligns with the findings of Zh.A. Zholdasova's work, according to which the projected number of people with dementia could reach 150,000 by 2050 [17]. A systematic review shows that the number of people with dementia doubles every five years; however, our results show that the number of people with dementia identified in Almaty remains low, which may indicate insufficient timely detection. [5]. It appears that lack of awareness or awareness of dementia among primary care physicians may play an important role. In this work, all participants note the need for training of primary care specialists. Researches identified primary care physicians' knowledge of age associated with dementia, but the largest number of physicians were unable to determine the correct course of treatment [2] or lack of knowledge on cognitive assessment tools [11]. The authors note the need to organize training for both doctors and residents on dementia issues [2]. In the US, the authors note that Alzheimer's disease remains underdiagnosed and undertreated, which further impacts the social and clinical consequences for people with Alzheimer's disease and their families, including challenges in obtaining an accurate diagnosis [11]. Hospitals specializing in emergency care often see dementia patients as having a low priority, which can disrupt their normal functioning. It is important for hospitals to take into account the need to provide high-quality medical care to such patients, the desire for quick release, minimizing risks and limited budgetary resources. Additional research is needed to develop effective treatment methods for dementia patients in inpatient settings Health and education institutions must coordinate efforts and work together to improve the skills of health workers and create a positive attitude towards dementia patients [11].

Another study found three important areas for improving care for people with dementia: reconsidering the role of primary care practitioners in the health system, taking into account the important role they play over time in the lives of their patients and in society; create and better understand the experience of primary care providers in models of collaboration, integration with the hospital, and streamline training; reviewing the payment model for dementia care and providing more time for dementia visits [12]. In general, the organization of PHC in Kazakhstan allows for the provision of multidisciplinary care, and digitalization in healthcare can contribute to better integration with the hospital. However, future research may be needed related the funding issue at PHC level, particularly in provision of long-term care. For example, ongoing cognitive support for

people with dementia may halt disease progression [16], but funding remains an unresolved issue.

Thus, to improve care for people with dementia, future steps should focus on developing training courses for primary care providers, reviewing funding to include cognitive skills training for people with dementia, and improving screening among the elderly population and strengthening public outreach efforts. Given the aging population, primary care managers should consider involving gerontologists to provide appropriate care and support to GPs [13].

#### Conclusion

As throughout the world, there is an increase in dementia in Almaty, which tends to increase in the future. It is necessary to organize training for primary care specialists to gain an in-depth understanding of screening issues and support patients and family members on dementia issues. Also, in the future, additional research is needed to revise the model of care for people with dementia at the primary care level and improve awareness among the population.

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