

Oleksandra Khudoba

PhD in Public Administration,

Postdoctoral student of the Regional Management and Local Self-Government
Department of Lviv Regional Institute for Public Administration of the National
Academy for Public Administration under the President of Ukraine

ORCID: <https://orcid.org/0000-0001-6944-2163>

**Leadership in policy response to dementia:
lessons learned from the international experience**

The article reveals the role of leadership in policy response to the spread of dementia. Comprehensive information from dementia studies is generalized and analyzed to generate evidence-based policy. It is underscore that excessive interpretation of results or careless analysis of key factors may overestimate the findings that can effect policy planning in not the best way, especially for countries with low economic development and limited resources, are explained. It is emphasized that excessive attention to the dementia epidemic can lead to misleading policy planning and can have unforeseen negative consequences for the health system. The need of Ukraine to learn from international experience is revealed.

Key words: *leadership, healthcare policy, dementia, multisectoral collaboration, effectiveness of governance*

Statement of the Problem: Population around the world is facing a huge variety of challenges. Poverty, corruption, military conflicts, migration, new diseases and natural disasters are just a few things (phenomena) which prevent many people from quality basic services provided to them. The need for the development of additional types of services is also due to the increasing aging of the population and hence the

increasing in the number of people living with dementia. Meanwhile, the absence of dementia policy in the developing countries leaves without services not only people living with dementia, but their families or caregivers. Given these challenges, the integration of dementia programs into the complex healthcare system as well as social welfare system is not an easy task for any country. This is especially difficult for countries with limited resources, low levels of population awareness concerning dementia, and high levels of stigma and ageism.

To meet the goals given an ever-changing and complex situation with healthcare, the interdependence of many aspects, scientists emphasize the need to develop leadership that could help to change actions and succeed in both development of dementia programs and their implementation.

The purpose of this study is to explore the meaning and importance of leadership at all levels of decision-making process based on the experience of the countries with dementia policy to help Ukraine in the development of its own comprehensive response to dementia.

Paper main body. It has been proven that leadership can bring about positive changes, but the question remains how to give impetus to the process of stimulating and supporting leadership development, which can play a crucial role in promoting the dementia agenda [29].

In formulating a comprehensive policy response to dementia WHO points out three central elements: leadership, governance and multi-sectoral collaboration [13]. Therefore, the concepts of "leadership" and "governance" are not identical, but they are complementary and indivisible in most cases [27].

There are many examples of individual leaders in the history of dementia policy-shaping that have transformed general thinking into new radical ideas, facilitated the transition to new knowledge or the pursuit of innovation [6]. On the one hand, there is a need to know who these leaders are and what skills they are required to have, specifically to form and implement the dementia policy [23]. Due to the

multidimensional nature of dementia, on the other hand, it is not enough to have individual traits alone, although they are useful and even necessary in creating good leaders, since leadership development depends on the willingness of the environment to perceive change, the political will and support at different levels, as well as on teamwork [11].

Each stakeholder has a unique role to play - knowledge generation, decision making, advocacy, service development and raising awareness of dementia, which generally ensures the integrity of the process [10]. And in each of these areas leadership is important and contributes to the best success in policymaking and initiatives. Therefore, it is important to understand the role of each stakeholder that is considered as a leader, the mutual influence of the participants and to determine their priority, as is it important to understand how to create a supportive environment for the development of leadership aiming to addresses the needs of the population [5].

The past two decades have seen a sharp increase in civil society activity and citizens' involvement in shaping the national and global response to the spread of dementia. Such involvement ranges from discussions of policy vision to advocating the development of the necessary services based on human rights. The private sector is also actively involved [1]. Moreover, the academic environment is beginning to assert its role as a catalyst for necessary social change, in addition to being a producer of knowledge. But leadership examples indicate that while the initial impetus for health interventions can be obtained from any of a variety of actors, the impetus for successful, scalable and sustainable health interventions can only be created by the government [22]. Government as such needs to be actively involved in bringing together many different groups to ensure the comprehensiveness of the process [8].

Since many developing countries are focused on achieving positive shifts in dementia issues, their attention is drawn to international experience, that is, to those countries that have been able to make dementia one of their national priorities or have made significant strides in this direction [15]. Leadership in developing countries must

be capable of acting in the face of uncertainty and untenable evidence. Therefore, the need to study international practices is driven by the need to be guided by knowledge from various sources to summarize evidence-based and substantiated facts [2]. In shaping the national response, the core potential of leadership is to make the best use of their internal resources and external partnerships, to transform the most relevant and easily applied knowledge into the most productive areas of action that can maximize the benefits of improving services for people living with dementia and their caregivers [9].

Until recently, dementia was associated with those diseases that could not be prevented and was considered as a natural part of the aging process. However, these statements did not take into account the role of risk factors and the impact of prevention programs in predicting the scale of dementia. Recent trends in the prevalence and incidence of dementia indicate a significant point in epidemiology and give grounds for cautious optimism [31]. Up to 30% of cases of dementia can be prevented due to exposure to risk factors and lifestyle [14]. Delaying dementia even for a few years in a small percentage of people would be a huge achievement and would increase the number of people who could avoid such kind of suffering [12]. Efforts to delay the manifestations of dementia, if successful, can be useful to adults of all ages and groups [25].

But some questions, for example, what major changes in society, education and health could be key to reducing the risk of dementia, have yet to be studied. Since dementia is a complex social disease, international cooperation that enhances the exchange of information on the course and aetiology of the disease is essential [24]. Therefore, analytical epidemiological approaches, in combination with transnational scientific research, can provide a unique opportunity to study neuropathology, which underlies the change in the occurrence of dementia in the general population [30].

Alzheimer's disease accounted for only 6 percent of all diagnosed cases of dementia in Ukraine in 2016. Of course these data are unreliable, as no screening is conducted in Ukraine for dementia in elderly patients who do not seek medical

assistance. One of the most difficult moments associated with dementia is a variety of behavioral disorders that require special care [27]. Unpredictable actions of patients with dementia frequently become the cause of accidents. This behavior leads to a heavy burden of caring process as well as to despair, depression, excessive fatigue and exhaustion, reduced productivity and quality of work of caregivers.

Little attention is paid to the systems and services in Ukraine that deliver healthcare for people living with dementia. The main majority of people living with dementia have stayed out of healthcare system's sight, have not been observed and hence have not received a proper diagnosis. Even when dementia is diagnosed, the care provided is too often fragmented (basically in mental hospitals), uncoordinated, and unresponsive to the needs of people living with dementia, their caregivers and families, and of inadequate quality, and coverage of core support services is low. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care.

There are some huge gaps in the Ukrainian system in this regard: diagnosis gap (when people with dementia are not diagnosed); treatment gap (when people with dementia, who received a diagnosis but not receiving healthcare); social gap (when people with dementia, who received a diagnosis but not receiving social care); palliative gap (when diagnosed people are limited in palliative care) and support gap (when families and caregivers are not covered of any social, educational or other kind of programs).

Taking into account all the above-mentioned facts, there is a high need to focus researches and receive evidence regarding the following directions:

1. Review of research evidence on the role of primary care within the dementia healthcare system. This should include evidence regarding the effectiveness of primary care services in the detection and diagnosis of dementia, and in the provision of continuing care; evidence on strategies and interventions to enhance the quality of care

provided by primary healthcare services; studies that compare aspects of the quality of care provided by non-specialist versus specialist services.

2. Review of the effectiveness of case management, wherever it is located within the health and social care system, with respect to outcomes for people with dementia and their caregivers, and evidence for improved efficiency of delivery of health and social care. Care coordination, through case management, has been presented as a means of improving care and reducing costs. The Case Management Society of America describes case management as “a collaborative process of assessment, planning, facilitation and advocacy for options to meet an individual’s health need through communication and available resources to promote quality cost-effective outcomes”.

3. Review of hospitalization of people with dementia seeking to clarify the extent of and reasons for hospitalization, the associated harms, the excess healthcare costs, the effectiveness of approaches to avoid hospitalization, and reduce harm and improve outcomes for those who are admitted.

4. Review the latest evidence on palliative and end-of-life care for people with dementia.

As a results it could be possible to have a clear understanding and the mechanism in which way it is possible to minimize these gaps. Developing these ideas and receiving both evidence-based and practical advice for enhancing both state institutions’ and NGOs’ activities will lead to crucial affordable and achievable improvements in formation and implementation of Ukrainian healthcare policy.

The conceptual framework of the research includes two Priorities, such as Policy and Service delivery, and answering some simple questions: Who? What? Why? and How? While researching of the former Priority is focused on Governance and Population, the latter is focused on Individuals.

“The governance part” includes the reviewing of the state strategies, plans, legislation, guidelines, monitoring and cross-sectoral cooperation.

There are some cross-cutting thematic areas that are necessary to review concerning population in general: Dementia as public health priority; Dementia awareness and dementia friendliness; and last but not least, Dementia risk reduction.

The biggest part includes the reviewing both diagnosis, treatment, care and support for people living with dementia and support for dementia caregivers. A lot of efforts is need to be put in this part to:

- identify the optimal models of care and support for people with dementia and their caregivers in the community (e.g. collaborative care, integrated health and social care, case management) across the disease course;
- identify strategies to anticipate and deliver effective and cost-effective late life and end of life care for people with dementia, including advance care planning;
- determine the most effective interventions for educating, training and supporting formal and informal caregivers of people with dementia;
- develop and evaluate policies, investments and plans for increasing the capacity, knowledge, skills and interest of the health and social care workforce in the field of dementia;
- establish norms and standards for the highest quality of care in residential and nursing homes and approaches to assist families of people with dementia to determine the optimal time to consider placement.

It is also crucially important to understand how to integrate the most efficient and effective practices into the administrative decision-making process. So the proposed research project could include follow-up with policymakers and the assessment of the impact of the information on their decision-making process.

The healthcare system in general and primary healthcare in particular are important, to the maintenance of health and wellbeing, and the achievement of the best quality of life for people with dementia and their caregivers. However, there are many other problems with dementia healthcare systems has currently faced.

It is important and necessary to use information from dementia studies to generate evidence-based policy. But excessive interpretation of results or careless analysis of key factors may overestimate the findings that can effect policy planning in not the best way, especially for countries with low economic development and limited resources. Excessive attention to the dementia epidemic can lead to misleading policy planning and can have unforeseen negative consequences for the health system. That is why Ukraine needs to learn from international experience.

International cooperation can play an important role in responding to this challenge through research, but governments still play a key role. The government of each country defines its own approaches to research, development of partnerships to strengthen prevention, diagnosis, treatment and care. Thus, the role of the national government and involving senior managers such as ministers, prime ministers or politicians in awareness raising is crucial. Top management can satisfy their ambitions by way of determining the strategy and the plan, which facilitates effective implementation and ensure that stakeholders fulfil their promises. Government participation can also contribute to the development of a cross-sectoral approach and interdependent work between different ministries and departments. It is very important that the highest officials personally act and participate in the development and implementation of the Dementia National Plan to recognize this problem as one of the national priorities [19].

One more advantage of state support is that it accelerates the diagnosis of diseases that are difficult to diagnose, including dementia, through management, coordination, standardization and research. There are successful examples of collaboration between different organizations in Europe on managing risk factors, such as HATICE [20], DIVA [21], FINGER [16] and MAPT [26]. These studies have shown the importance of a solid foundation for sharing experiences and data that, from their point of view, helped to increase funding for prevention programs. However, different countries have their own specifics of the disease and, based on data, they indicate a

reduction in the risk in successive generations, depending on their effects on health and lifestyle. In some countries, the current cohort of people over the age of 65 is cognitively healthier than their predecessors with greater resistance, due to reduced risk factors for dementia or increased exposure to protective factors [12].

Political responses to dementia require not only consideration of care issues, but also integration with general public health issues and interventions to reduce the impact of other non-communicable diseases. Seven [4] or nine [7] potentially modified risk factors at different stages of life were associated with cognitive disorders, including diabetes, depression, smoking, physical inactivity, moderate hypertension, middle aged obesity and low levels of education and it is predicted that approximately one-third of all Alzheimer's cases are associated with these factors. Reducing these risk factors by 10% -25% may prevent over 3 million worldwide cases of Alzheimer's disease [3]. In addition, the relative reduction in the prevalence of these risk factors by 10% every decade can reduce the prevalence of dementia in the world by 2050 by 8.3% [17].

Policy planning should be balanced between primary, secondary and tertiary prevention. Each of them has its place, but primary prevention has the greatest impact on the reduction of late dementia and disability. It follows that a pure dementia oriented policy can be problematic for effective prevention [32]. Since care for people with dementia remains a primary care problem [18], an integrated model of assistance is needed to build capacity to meet the needs of an aging population. Integration into health care and social assistance enables managers to make sure that people's needs can be better predicted. The integration of the health care system and social assistance may result in reduction of inadequate use of hospital services and the reduction of high-value services at the secondary and tertiary levels, as well as increased awareness and reduction of stigma in community.

Conclusion: Discussions about leadership in the sphere of dementia are focused mainly on experiences in high-income countries, while little information is available on the experience of developing countries. Studying international experience provides an

opportunity for the developing countries to rethink their own leadership experience, to enrich it with proven international practice tools, as well as to develop the ability to analyse situations related to leadership challenges, apply persuasion methods, make team decisions, and communicate effectively.

Lesson learned from this experience indicates the need to create platforms that provide tools for leadership development, bringing all stakeholders together to promote ideas in both national and global contexts. Globally, there are separate platforms for civil society debate, academic conferences, and the private sector. However, there are very few platforms where diverse groups of actors plan concerted action to overcome obstacles in the context of dementia, actively engaging and supporting developing countries. This should encourage more multidisciplinary research, quality leadership input to support families, especially in low- and middle-income countries.

There are numerous actors that in one way or another influence the formation and implementation of the dementia policy. They are academic and research institutions, civil society organizations, the private sector, patient groups, citizens' representatives, as well as international players, such as donors, development partners, and charitable foundations. Therefore, it would be appropriate to focus more on examining how leadership in each of these groups complements or competes with other groups, how priorities are set, and which leadership development models are most suitable for countries where dementia is not yet on the agenda.

References:

1. A Dementia Strategy for Canada: together we aspire. URL : <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>
2. All Party Parliamentary Group on Dementia. (2014). Building on the National Dementia Strategy: Change, Progress and Priorities.
3. Barnes, D. E., & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *The Lancet Neurology*, 10(9), 819-828.

4. Birdi, R., Stephan, B. C. M., Robinson, L., & Davis, D. (2015). Can we influence the epidemiology of dementia? Perspectives from population-based studies. *Postgraduate medical journal*, 91(1081), 651-654.
5. Chunharas, S., & Davies, D. S. C. (2016). Leadership in health systems: a new agenda for interactive leadership. *Health Systems & Reform*, 2(3), 176-178.
6. Dementia (2015). The OECD Response. *Organization for Economic Cooperation and Development (OECD)*, Paris, France.
7. Frankish, H., & Horton, R. (2017). Prevention and management of dementia: a priority for public health. *The Lancet*, 390(10113), 2614-2615.
8. Frenk, J. (2010). The global health system: strengthening national health systems as the next step for global progress. *PLoS medicine*, 7(1), e1000089.
9. Goodchild, C. (2009). *Living Well with Dementia: The National Dementia Strategy: Joint Commissioning Framework for Dementia*. Department of Health.
10. Hafford-Letchfield, G. C. T. Leadership from the bottom up: Reinventing dementia care in residential and. *Perspectives on management and leadership in social work*, 143.
11. Leithwood, K. (2005). Understanding successful principal leadership: Progress on a broken front. *Journal of educational administration*, 43(6), 619-629.
12. Livingston, G., Sommerlad, A., Orgeta, V., Costafrada, S. G., Huntley, J., Ames, D., ... & Cooper, C. (2017). Dementia prevention, intervention, and care. *The Lancet*, 390(10113), 2673-2734.
13. Minister Daly launches mid-term review of National Dementia Strategy. URL : <https://www.gov.ie/en/press-release/d04336-minister-daly-launches-mid-term-review-of-national-dementia-strategy/?referrer=/blog/press-release/minister-daly-launches-mid-term-review-of-national-dementia-strategy/>
14. Mitchell, S., Ridley, S. H., Sancho, R. M., & Norton, M. (2016). The future of dementia risk reduction research: barriers and solutions. *Journal of Public Health*, 39(4), e275-e281.

15. Nakanishi, M., & Nakashima, T. (2014). Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health-and social-care systems?. *Alzheimer's & Dementia*, 10(4), 468-476.
16. Ngandu, T., Lehtisalo, J., Solomon, A., Levälähti, E., Ahtiluoto, S., Antikainen, R., ... & Lindström, J. (2015). A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive dec.
17. Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. (2014). Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *The Lancet Neurology*, 13(8), 788-794.
18. Parmar, J., Dobbs, B., McKay, R., Kirwan, C., Cooper, T., Marin, A., & Gupta, N. (2014). Diagnosis and management of dementia in primary care: exploratory study. *Canadian Family Physician*, 60(5), 457-465.
19. Pot, A. M., & Petrea, I. (2013). Improving dementia care worldwide. Ideas and advise on developing and implementing a national dementia plan.
20. Richard, E., Jongstra, S., Soininen, H., Brayne, C., van Charante, E. P. M., Meiller, Y., ... & Ngandu, T. (2016). Healthy Ageing Through Internet Counselling in the Elderly: the HATICE randomised controlled trial for the prevention of cardiovascular dise.
21. Richard, E., Van den Heuvel, E., van Charante, E. P. M., Achthoven, L., Vermeulen, M., Bindels, P. J., & Van Gool, W. A. (2009). Prevention of dementia by intensive vascular care (PreDIVA): a cluster-randomized trial in progress. *Alzheimer Disease & Assoc.*
22. Shah, H., Albanese, E., Duggan, C., Rudan, I., Langa, K. M., Carrillo, M. C., ... & Saxena, S. (2016). Research priorities to reduce the global burden of dementia by 2025. *The Lancet Neurology*, 15(12), 1285-1294.
23. Storey, J., & Holti, R. (2019). Innovating Healthcare: The Role of Political,

Managerial and Clinical Leadership.

24. Tang, Q., Song, P., & Xu, L. (2016). The Government's role in regulating, coordinating, and standardizing the response to Alzheimer's disease: Anticipated international cooperation in the area of intractable and rare diseases. *Intractable & rare diseases* .
25. Tom, S. E., Hubbard, R. A., Crane, P. K., Haneuse, S. J., Bowen, J., McCormick, W. C., ... & Larson, E. B. (2015). Characterization of dementia and Alzheimer's disease in an older population: updated incidence and life expectancy with and without dementia.
26. Vellas, B., Carrie, I., Gillette-Guyonnet, S., Touchon, J., Dantoine, T., Dartigues, J. F., ... & Bories, L. (2014). MAPT study: a multidomain approach for preventing Alzheimer's disease: design and baseline data. *The journal of prevention of Alzheimer's* .
27. World Health Organization. (2016). Open mindsets: participatory leadership for health.
28. World Health Organization. (2017). Global action plan on the public health response to dementia 2017–2025.
29. World Health Organization. (2018). Towards a dementia plan: a WHO guide.
30. Wu, Y. T., Beiser, A. S., Breteler, M. M., Fratiglioni, L., Helmer, C., Hendrie, H. C., ... & Matthews, F. E. (2017). The changing prevalence and incidence of dementia over time—current evidence. *Nature Reviews Neurology*, 13(6), 327.
31. Wu, Y. T., Fratiglioni, L., Matthews, F. E., Lobo, A., Breteler, M. M., Skoog, I., & Brayne, C. (2016). Dementia in western Europe: epidemiological evidence and implications for policy making. *The Lancet Neurology*, 15(1), 116-124.
32. Wu, Y. T., Matthews, F. E., & Brayne, C. (2014). Dementia: time trends and policy responses. *Maturitas*, 79(2), 191-195.