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STIGMA AS SOCIAL EXPOSOME: INTEGRATING SOCIOCULTURAL AND ENVIRONMENTAL DETERMINANTS OF DEMENTIA IN INDONESIA

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Abstract

Background: The prevalence of dementia in Indonesia continues to rise alongside the demographic transition, with estimated cases surging from 1.2 million in 2016 to a projected 4 million by 2050. The risk of this disease is not solely influenced by biological factors but is cumulative, resulting from the interaction of social and environmental factors throughout life course. Objective: This study aims to reconceptualize sociocultural stigma as an integral part of the exposome framework in understanding the determinants of dementia risk in Indonesia. Methods: This study employs a narrative review design by synthesizing relevant scientific literature and strategic report documents (published 2012–2024). The analysis focuses on three domains: the construction of dementia in Indonesia, the biological mechanisms of the exposome, and the reciprocal interaction between the two. Results: Findings indicate that stigma in Indonesia—manifested through perceptions of "normal senility," fear of impulsive behavior, and supernatural attributions—significantly hinders access to healthcare services. Meanwhile, the exposome concept explains how macro-environmental exposures and lifestyle interact with genetics to accelerate brain aging through inflammatory and epigenetic mechanisms. An integrative analysis confirms that stigma acts as a toxic "social exposome" that exacerbates biological risk through mechanisms of social isolation and chronic stress. Conclusion: Stigma and the exposome form a mutually reinforcing cycle that accelerates dementia progression. Therefore, national prevention strategies and policies must not be partial; a comprehensive approach targeting stigma reduction is required as a direct effort to break the chain of dementia risk exposome exposure.

Keywords: *Dementia, Stigma, Exposome, Social Determinants, Public Health.*

INTRODUCTION

Increased life expectancy in Indonesia has led to a growing elderly population, where approximately 11% of the population was aged 60 years or older in 2020, a figure projected to rise significantly in the coming decades. Alongside this demographic shift, the prevalence of cognitive impairment and dementia is also increasing. Based on estimates by Alzheimer's Disease International and other organizations, approximately 1.2 million people in Indonesia were living with dementia in 2016, and this number is predicted to rise to around 2 million by 2030 and up to 4 million by 2050. This fact indicates that dementia is becoming an urgent public health challenge in Indonesia1.

In response, the Government of Indonesia, through the Ministry of Health and relevant stakeholders, has launched various initiatives, one of which is the document "National Strategy for the Management of Alzheimer's and Other Dementias" as a national framework for the control and prevention of Alzheimer's and other dementias using a life-course approach. At the civil society organization level, Alzheimer's Indonesia (ALZI) has been active since 2013 in conducting campaigns, education, and providing support for people with dementia and their caregivers10.

Beyond these structural efforts, it is crucial to understand that social and environmental factors also determine how dementia emerges and impacts individuals. Stigma against dementia—manifested as the view that forgetfulness or "pikun" (senility) is a normal part of aging, or that people with dementia are impulsive or dangerous—creates barriers to early detection and access to care. Meanwhile, the concept of the exposome describes how the totality of environmental exposures throughout life (including social, behavioral, biological, and physical aspects) influences dementia risk through mechanisms such as inflammation, vascular dysfunction, and epigenetic changes. Thus, stigma is not merely a social phenomenon but part of the social exposome that amplifies dementia risk exposure6.

Therefore, integrating an understanding of stigma and the exposome is essential for designing effective dementia prevention and management interventions in Indonesia.

METHODOLOGY

Study Design This study utilizes a Narrative Review design to explore and synthesize literature regarding the relationship between dementia stigma and the exposome concept. This approach was selected for its ability to integrate evidence from various disciplines—health sociology (stigma) and environmental epidemiology (exposome)—to build a new conceptual framework for dementia management in Indonesia.

Search Strategy The literature search strategy was conducted through channels including Google Scholar, PubMed, and ScienceDirect, as well as a review of national policy documents and international organizational reports.

Data Synthesis Collected data were analyzed using a qualitative-thematic approach. Information was extracted based on three main themes: (1) The social construction and stigma of dementia in Indonesia, (2) The biological mechanisms of the exposome in dementia risk, and (3) The reciprocal interaction between stigma as part of the social exposome that exacerbates health outcomes.

RESULT AND DISCUSSION

Dementia stigma is a social construction arising from a combination of stereotypes, ignorance, and negative societal judgments toward individuals with dementia. In the Indonesian context, stigma develops through the perception that dementia symptoms are a normal part of aging, beliefs that persons with dementia are impulsive and dangerous, and the attribution of symptoms to spiritual factors. This stigma operates through mechanisms of

public stigma, self-stigma, and courtesy stigma. Consequences include delayed diagnosis, avoidance of healthcare services, psychological burden on families, and discrimination in healthcare delivery. Strong societal stigma, coupled with low dementia literacy and negative representation, complicates comprehensive early detection and management efforts4.

The 2019 World Alzheimer Report presents data showing that in Indonesia, 74.2% of general public respondents consider people with dementia to be impulsive and unpredictable, while 44.1% consider them dangerous—figures higher than in other countries such as India, Australia, and the Philippines. This negative perception indicates that public stigma is sufficiently strong to influence social behavior, such as maintaining distance, avoiding interaction, or treating people with dementia with excessive fear and caution3.

In addition to public stigma, the 2019 World Alzheimer Report also describes self-stigma, a condition where individuals with dementia or caregivers internalize negative societal views and begin to feel shame, guilt, or fear of disclosing their condition. Such stigma exacerbates social isolation, increases the risk of depression, and causes people with dementia and their families to delay diagnosis or be reluctant to seek medical help. In the Indonesian context, cultural misinterpretation regarding dementia symptoms as merely a normal aging process reinforces this stigma. The report indicates that over 90% of caregivers in Yogyakarta view memory loss symptoms as a part of natural aging, thereby hindering early identification processes and worsening the patient's condition because symptoms are normalized rather than recognized as signs of a manageable disease16.

Stigma toward families or caregivers (courtesy stigma) also appears distinctly, especially in societies with strong cultural norms. Families of dementia sufferers may experience feelings of shame, social pressure, and concern that the condition is viewed as a family disgrace or proof of their inability to care for elders. In some cultures, dementia symptoms are even linked to spiritual or supernatural causes, such as spirit possession, leading patients to be taken for traditional healing before receiving medical care13.

Stigma is also found among healthcare professionals. A study by Taufik et al. showed that 59% of nursing students still had high stigma toward mental disorders. Additionally, 40% of Indonesians perceive that doctors and nurses “ignore” persons with dementia or do not provide adequate attention. This lack of competence reinforces barriers to care and negatively impacts the patient’s experience16.

THE EXPOSOME CONCEPT AND ITS RELATION TO DEMENTIA

The exposome refers to the totality of environmental exposures experienced by an individual from conception to the end of life, encompassing physical, chemical, biological, social, and behavioral factors that interact with genetic factors over time. In literature, the exposome is described as the comprehensive “environmental exposures from conception onward,” which includes pollutants, nutrition, lifestyle, psychological stress, infections, as well as internal exposures such as inflammation and oxidative stress. This understanding asserts that the development of neurodegenerative diseases like dementia is not only influenced by genetic factors but is heavily dependent on the accumulation of environmental exposures throughout life5.

In the context of dementia, the concept of the Alzheimer’s Disease Exposome was developed to explain how environmental factors contribute significantly to the risk of Alzheimer’s disease and related dementias. Twin studies in Sweden indicate that up to half of the variation in dementia risk stems from environmental factors, while the remainder is genetic contribution. This Alzheimer’s exposome highlights that environmental factors such as pollution, traumatic brain injury, vascular disease, and systemic conditions like renal impairment and chronic inflammation interact with neurodegenerative biomarkers such as amyloid accumulation, pathological tau, and neurodegeneration7.

The dementia exposome consists of three main domains: (1) Macro-level Exogenous Exposome, which includes urbanization, air pollution, socioeconomic status, and education; (2) Individual Exogenous Exposome, such as lifestyle (high-fat and sugar diet, smoking, alcohol consumption), infections, physical activity, and toxin exposure; and (3) Endogenous Exposome, namely internal biological exposures such as systemic inflammation, hormones, microbiome, brain trauma, and body fat storage. These three domains interact with one another7.

Specific environmental exposures are proven to increase neurodegeneration risk. Chronic air pollution and industrial nanoparticle exposure can trigger brain inflammation, microglial activation, and reactive oxygen species production, contributing to amyloid plaque and Lewy body formation. Some studies show the presence of magnetite particles, heavy metals, and organochlorine pesticides in human and animal brains exposed to heavy pollution. Other factors such as sedentary lifestyle, obesity, hypertension, diabetes, chronic stress, and social isolation are also parts of the exposome that accelerate brain aging and increase vulnerability to dementia7.

Gene-Environment interaction (GxE) is a critical part of the exposome concept. For example, carriers of the Apolipoprotein E ε4 (APOE) allele are more susceptible to the negative effects of air pollution, high-fat diets, physical inactivity, and hypertension. This can accelerate amyloid accumulation, increase inflammation, and hasten cognitive decline. Furthermore, early-life environmental exposures, including low education and poverty, have been shown to accelerate dementia onset in certain populations7.

The Alzheimer's exposome framework emphasizes the need for a life-course approach, as exposures at every life stage—from prenatal, childhood, and midlife to old age—have a cumulative contribution to dementia risk. Long-term exposures such as pollution, chronic stress, uncontrolled chronic diseases, and social factors like isolation or poverty all influence each other through epigenetic mechanisms, inflammation, and vascular dysfunction. This also requires international collaboration, cross-population exposure measurement, and multi-omics approaches to understand how these combined exposures shape individual dementia risk8.

THE RELATIONSHIP BETWEEN STIGMA AND EXPOSOME AS A CAUSE OF DEMENTIA

Stigma and the exposome share a mutually reinforcing relationship in the context of dementia risk and progression. The exposome describes cumulative environmental exposures throughout life that affect brain aging through inflammation, oxidative stress, vascular dysfunction, and epigenetic changes. Meanwhile, stigma acts as part of the social exposome that influences how individuals and families respond to dementia symptoms. When stigma is strong, individuals tend to delay examination, avoid formal healthcare services, and maintain behaviors or environmental conditions that prolong physiological and social risk exposures to dementia. Thus, stigma exacerbates existing exposome effects7.

Stigma also contributes to the exposome through increased social isolation, psychological stress, and reduced social support, which are dementia risk factors according to the exposome framework. In the Indonesian context, the perception that people with dementia are dangerous, impulsive, or unpredictable causes many families to hide symptoms and restrict the sufferer's social activities. This prolonged social isolation impacts the increase of systemic inflammation and stress axis dysfunction, identified in exposome literature as biological mechanisms accelerating brain aging and increasing vulnerability to Alzheimer's disease. In other words, stigma creates a social environment that amplifies pathogenic biological processes already triggered by other exposomes like pollution, obesity, hypertension, or unhealthy lifestyles16.

Exposome studies show that the longer these risk factors remain uncontrolled, the greater their impact in accelerating cognitive decline through accumulated biological damage. In Indonesia, the belief that dementia is a natural part of aging causes more than 90% of caregivers not to seek medical help at early stages, allowing risk exposome conditions to persist without intervention. Thus, stigma and the exposome form a mutually reinforcing cycle, significantly accelerating dementia progression16.

The relationship between stigma and the exposome is also evident in the healthcare context. Stigma among healthcare professionals, such as the view that patients with dementia are difficult to handle or do not require special intervention, leads some professionals to provide minimal care. This potentially prolongs risk exposomes such as family stress, delayed comorbidity management, and the non-implementation of lifestyle modification interventions. Meanwhile, the exposome concept asserts that multifactorial interventions, chronic disease control, stress management, increased physical activity, and family education are crucial to slowing neurodegenerative processes. When stigma hinders intervention implementation, risk exposomes become more dominant and rapidly worsens cognitive conditions16.

Thus, stigma does not stand as an isolated social phenomenon but as part of the social exposome that amplifies other biological, behavioral, and environmental risk exposures. This understanding is vital for developing comprehensive interventions that target not only medical and lifestyle factors but also social perception change, dementia literacy improvement, and stigma reduction in society. An exposome-based approach recognizes that dementia prevention and management require cross-sectoral efforts, and reducing stigma is one intervention pathway that directly lowers exposome risk throughout life.

CONCLUSION

Conclusion The surge in dementia prevalence in Indonesia, projected to reach 4 million cases by 2050, is not merely a demographic consequence of population aging but the result of complex interactions between biological vulnerability and life-course environmental exposures. This review confirms that a biomedical approach alone is no longer adequate. Through the lens of the exposome, dementia is understood as the accumulated impact of physical, lifestyle, and social factors experienced by individuals from an early age.

A crucial finding of this review is the position of stigma not only as a social barrier but as a tangible biological determinant. Cultural stigma that views dementia as “normal senility” or links it to supernatural causes, as commonly found in Yogyakarta and other regions in Indonesia, constitutes a form of toxic social exposome16. A study conducted in Yogyakarta shows that over 90% of caregivers looking after older people with dementia consider memory impairment (senility) to be a normal part of the aging process. This belief results in a lack of awareness regarding early detection and treatment. Exposure to this stigma triggers a cascade of social isolation, chronic stress, and delayed medical access, which physiologically accelerates neurodegenerative processes through inflammatory and epigenetic mechanisms. Thus, stigma and other risk exposomes form a feedback loop (vicious cycle) that exacerbates the national disease burden.

Recommendations Based on this synthesis, dementia management in Indonesia requires a paradigm shift from curative treatment to life-course-based prevention. The following are recommended strategic steps:

1. Integration of Stigma into National Strategy: The revision of the National Strategy for Alzheimer’s Management needs to explicitly recognize “stigma reduction” as a key public health intervention, not merely a social campaign. Program success indicators must include the reduction of public stigma levels and increased early detection rates.

2. Deconstructing Cultural Myths through Targeted Education: Health campaigns must shift from general messages to messages targeting the deconstruction of specific myths (e.g., “Severe forgetfulness is not a normal part of aging”). This program must involve religious and community leaders to change the perception of dementia from a “spiritual disease” to a manageable medical condition.
3. Strengthening Primary Care Capacity: Public Health Centers (Puskesmas) and Elderly Integrated Health Posts (Posyandu Lansia) must be equipped with simple cognitive screening capabilities and family counseling. Healthcare workers need cultural competence training to avoid stigmatizing behaviors (such as ignoring elderly complaints) that reinforce reluctance to seek treatment.
4. Local Translational Research: Given the limited exposome data in Indonesia, longitudinal research mapping specific local risk factors (air pollution, local dietary patterns, social cohesion) is needed to design precision interventions suitable for the Indonesian demographic context.

In closing, the rising burden of dementia in Indonesia necessitates a paradigm shift from a singular biomedical focus to a comprehensive, life-course approach. By looking a the multidimensional causes of dementia in Indonesia through the lens of the social exposome, it is clear that efforts in mitigating the negative impact of dementia in every domain (biomedical, social, psychological) are warranted this requires involving family and community members, as well as fostering inter-sectoral collaboration to better manage the emerging public health challenge of dementia in the country. The explicit integration of stigma reduction as a core public health strategy is essential to break the mutually reinforcing cycle between stigma and other exposome-based risk factors, thereby ensuring timely detection and holistic support for those affected.

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