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PROMOTING ETHICAL GOVERNANCE: A COLLABORATIVE FRAMEWORK FOR END-OF-LIFE CARE POLICIES FOR THE ELDERLY IN CHINA

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Abstract: Delivering end-of-life care services to elderly patients, addressing their physical and psychological needs, enhancing their quality of life, and preserving their dignity represent not only advances in human civilization, but also crucial benchmarks for a country's social development and justice. Effective provision of end-of-life care services hinges on robust national policies, adequate investment, and a cohesive societal effort. Clearly defining the roles and interplay between the government and society is paramount. This study examines China's end-of-life care policies through an ethical lens, aiming to elucidate the nation's stance on national and societal duties and ethical dynamics in end-of-life care development. The research reveals that, ethically, China's end-of-life care services require enhancements in legislative empowerment, regulatory oversight, financial backing, and the functioning of social entities. The absence of government and societal functions, along with inadequate collaboration and synergy between the two sectors, has led to incomplete fulfillment of the diverse end-of-life needs of the elderly. Consequently, China's end-of-life care sector should strive for a transparent delineation of responsibilities between the government and society, as well as precise ethical positioning.

Keywords: end-of-life care, government, society, ethical relationships, well-being

Promoción de la gobernanza ética: un marco colaborativo para las políticas de cuidados al final de la vida de los ancianos en China

Resumen: La prestación de servicios de cuidados al final de la vida a pacientes de edad avanzada, la atención de sus necesidades físicas y psicológicas, la mejora de su calidad de vida y la preservación de su dignidad representan no sólo avances en la civilización humana, sino también puntos de referencia cruciales para el desarrollo social y la justicia de un país. La prestación eficaz de servicios de cuidados al final de la vida depende de políticas nacionales sólidas, una inversión adecuada y un esfuerzo social cohesivo. Es fundamental definir claramente los roles y la interacción entre el gobierno y la sociedad. Este estudio examina las políticas de cuidados al final de la vida de China desde una perspectiva ética, con el objetivo de dilucidar la postura de la nación sobre los deberes nacionales y sociales y la dinámica ética en el desarrollo de los cuidados al final de la vida. La investigación revela que, éticamente, los servicios de cuidados al final de la vida de China requieren mejoras en el empoderamiento legislativo, la supervisión regulatoria, el respaldo financiero y el funcionamiento de las entidades sociales. La ausencia de funciones gubernamentales y sociales, junto con una colaboración y sinergia inadecuadas entre los dos sectores, ha llevado a un cumplimiento incompleto de las diversas necesidades al final de la vida de los ancianos. En consecuencia, el sector de cuidados al final de la vida de China debe esforzarse por lograr una delimitación transparente de responsabilidades entre el gobierno y la sociedad, así como un posicionamiento ético preciso.

Palabras clave: cuidados al final de la vida, gobierno, sociedad, relaciones éticas, bienestar

Promovendo governança ética: Uma estrutura colaborativa para políticas de cuidados de fim da vida para idosos na China

Resumo: Prestar serviços de cuidados de fim da vida para pacientes idosos, abordando suas necessidades físicas e psicológicas, melhorando sua qualidade de vida e preservando sua dignidade, representa não somente avanços na civilização humana como também parâmetros cruciais para o desenvolvimento social e a justiça de um país. A oferta efetiva de serviços de cuidados de fim de vida depende de políticas nacionais robustas, investimento adequado e um esforço social coeso. Definir claramente os papéis e a interação entre o governo e a sociedade é fundamental. Esse estudo examina as políticas de cuidados de fim da vida da China através de lentes éticas, objetivando elucidar a posição da nação sobre os deveres nacionais e sociais e a dinâmica ética no desenvolvimento de cuidados de fim de vida. A pesquisa revela que, eticamente, os serviços de cuidados de fim de vida da China requerem melhorias no empoderamento legislativo, na supervisão regulatória, no apoio financeiro e na funcionamento de entidades sociais. A ausência de funções governamentais e sociais, juntamente com inadequada colaboração e sinergia entre esse dois setores, levou a uma satisfação incompleta das diversas necessidades de fim de vida de idosos. Consequentemente, o setor de cuidados de fim de vida da China deve esforçar-se por uma delimitação transparente de responsabilidades entre o governo e a sociedade, bem como por um posicionamento ético preciso.

Palavras chave: cuidado de fim de vida, governo, sociedade, relações éticas, bem-estar

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1. Introduction

As the aging population grows and societal risks multiply, a rising number of elderly individuals encounter terminal illnesses like cancer, often contending with isolation and impersonal medical interventions*(1).* The pursuit of rational and compassionate end-of-life care becomes imperative to preserve their quality of life and dignity, representing a hallmark of human civilization advancement and a pivotal gauge of a nation's social progress, justice, and cohesion.

Currently, China grapples with pressing issues such as an aging population and weakened family structures, particularly concerning the elderly's emphasis on quality end-of-life care, encompassing palliative and end-stage support. Certain developed nations, having advanced into aging societies, have amassed valuable insights into public awareness of end-of-life care, pertinent training, analgesic employment, and transparency in doctor-patient relationships, offering potential lessons for China. Effectively leveraging scarce resources to furnish exceptional and comforting end-of-life care for terminally ill elderly individuals, catering to their end-of-life requirements, safeguarding their rights, enhancing their quality of life, and upholding their dignity in death constitutes a responsibility not only incumbent upon the government, but also society at large. Accordingly, delineating the responsibilities and interplay between the government and society holds paramount importance for the wholesome progression of end-of-life care.

In the evolution of the end-of-life care movement abroad, it predominantly unfolded as a grassroots, incremental process instigated by civil organizations, with gradual and cautious state involvement. Nevertheless, challenges persist in defining government responsibilities, fostering organic social initiatives, and individual governance, resulting in the marginalization and neglect of end-of-life care services. This article endeavors to delve into the delineation of responsibilities and the interplay between the government and society in the advancement of end-of-life care, subsequently aiming to propose recommendations and strategies for the enhancement of end-of-life care in China.

1.1 Definition of key terms

1.1.1. End-of-life and end-of-life patients

From a medical perspective, the end-of-life signifies the culmination of a disease or accidental injury resulting in an irreversible progression toward clinical death*(2),* Dying represents an inevitable phase preceding the conclusion of human life, constituting a transitional period during which individuals inhabit the space between life and death. This transition embodies a gradual shift from a quantitative state to a qualitative one. End-of-life patients encompass individuals who are approaching the threshold of death but have not yet reached the clinical stage of demise, inclusive of elderly individuals, adults, and those who are not critically ill*(3).* In the context of this study, end-of-life patients primarily denote elderly individuals who no longer respond to curative treatments for their ailments, experiencing a continued deterioration with a relatively brief remaining survival period.

1.1.2. End-of-life care

End-of-life care, with its origins tracing back to the medieval era in Europe, initially served as a sanctuary where pilgrims, travelers, and soldiers could find respite and rejuvenation. Over time, it evolved into a specialized setting catering to individuals afflicted with incurable diseases on the verge of death*(4)*. The end-of-life care examined in this article pertains to delivering appropriate treatment, medical attention, and comprehensive physical and psychological support to patients with a life expectancy of six months or less, aiming to alleviate their physical discomfort and mental anguish. The objective is not to cure the illness or prolong lifespan, but rather to enhance the patient's quality of life, uphold their dignity, and facilitate a dignified passage in the final stages. The goals of end-of-life care encompass refraining from artificially abbreviating or intentionally extending the patient's life span, prioritizing compassionate care, honoring the patient's rights and dignity, and prioritizing the patient's quality of life.

1.2 Theoretical basis

1.2.1. Social welfare models

In 1958, Harold Wilensky and Charles Lebeaux introduced the influential dichotomy of social welfare, namely the Residual Model and Institutional Model, in their book "Industrial Society and Social Welfare: The Impact of Industrialization on the Supply and Organization of Welfare Services." The Residual Model underscores the role of the family and market, emphasizing their responsibility to furnish the necessary welfare for individuals*(5)*. According to this model, only when the family and market mechanisms falter in providing essential welfare benefits will the state and government assume corresponding responsibilities. Conversely, the Institutional Model highlights the role of the state and government, asserting that the state bears an inherent responsibility for fulfilling individuals' welfare needs. This model advocates the reliance on a comprehensive regulatory system led by the state and government to supply individuals with the requisite social welfare. Similarly, British scholar Richard Titmus proposed a comparable classification standard, contending that the Residual Model is an outcome of market failure, and the state only offers limited social welfare to its citizens*(6)*. He emphasized that the Institutional Model represents a social policy aimed at enhancing the welfare standards of the entire populace. Regardless of the categorization or analytical approach, Western social welfare theory and related discussions can offer a relatively sound analytical framework and research paradigm for the establishment and advancement of end-of-life care services in China.

1.2.2. Welfare pluralism

The theoretical essence of welfare pluralism centers on the idea that the delivery of social welfare and services involves multiple entities, thereby reducing the predominant role of the government and moving away from a singular provider model*(7:55)*. It also denotes a transformation from a landscape dominated by monopolistic organizations to one that is more diverse and competitive*(8: x. i)*. This theory underscores the involvement of non-profit organizations and other third sectors, aiming to regulate the management of these entities and guide them into the sphere of welfare services. By relaxing constraints on private participation in welfare provision, this approach seeks to bridge the divide between government agencies and individual needs*(9)*.

1.2.3. Theory of the relationship between government and society

The founder of modern civil society theory is Hegel. In his book "Elements of the Philosophy of Right" from 1821, he initially established the analytical framework of "state civil society"*(10)*. Building upon Hegel's work, Marx employed the dialectical relationship between the "economic foundation superstructure" to elucidate the progression of human society*(11)*. Furthermore, Tocqueville expounded on the significance of civil society for democratic politics*(12)*. Habermas further expanded on Hegel's civil society concept, positing the theory of the "state civil society public sphere" ternary structure and systematically exploring the primary function of the "public sphere," which is to establish legitimacy*(13)*. Additionally, the theory of the third sector, rooted in modern economics, employs "market failure" and "government failure" to advocate for the rationality of the existence of the third sector or civil society. These theories scrutinize the origins and functions of government, society, and their interrelationships from diverse perspectives*(14)*.

2. Current situation of end-of-life care for elderly people in China

Internationally, the demographic consisting of individuals aged 65 and above designates different stages of aging: the aging society, the aged society, and the superaged society, corresponding to proportions of 7%, 14%, and 20% of the total population, respectively. Currently, China's elderly population is undergoing rapid expansion. According to data released by the National Bureau of Statistics on January 17, 2024, as of the end of 2023, the number of elderly individuals in China had surged to 290 million, constituting 21.1% of the total population. Within this demographic, a significant portion comprises critically ill elderly individuals and patients with advanced end-stage diseases.

In China, there is a noticeable dearth of laws and regulations governing end-of-life care services, resulting in a lack of a unified management system for such services. The current landscape is characterized by fragmented departmental oversight, ambiguous centralized management, and multiple coexisting management structures. This ambiguity is underscored by unclear management and supervision responsibilities, as well as undefined tasks within these domains. Furthermore, the health department lacks a dedicated management organization, leading to an overall absence of centralized management for end-of-life care services, effectively creating a vacuum in this aspect. Consequently, the clarity regarding what and how to manage end-of-life care services remains uncertain, with responsibilities and tasks inadequately defined.

In China, a considerable number of individuals, including healthcare professionals, are not well-versed in the concept and provision of end-of-life care. When confronted with patient deaths, there is a tendency to adopt an attitude of avoidance and taboo surrounding this topic. Furthermore, there is a lack of systematic education on death within the entire educational system. As a result, the broader society lacks adequate awareness and understanding of the significance of end-of-life care.

According to the theory of market failure and government failure, public goods exhibit non-competitive and non-exclusive consumption characteristics, making their provision susceptible to free riding, resulting in market failure*(15)*. This underscores the view that public goods can only be effectively provided by the government. However, the actual provision of public goods by the government is not without limitations. The theory of government failure elucidates the requirement for non-governmental organizations as institutional entities outside the realms of the market and government*(16)*. It also illustrates the complementary relationship between government and non-governmental organizations in the supply of public goods.

In developed countries such as the UK and Germany, the end-of-life care movement has been a bottom-up and spontaneous initiative driven by the public, with the third sector playing a crucial role. However, in China, the third sector's involvement in the provision of end-of-life care services is limited, and its potential role remains underutilized.

Since the 1990s, several comprehensive hospitals in major Chinese cities have undertaken initiatives to establish end-of-life care wards, with some piloting such wards in oncology specialty hospitals. State-owned institutions comprise the majority of these endeavors, while non-profit and non-governmental institutions of a private non-enterprise nature represent a smaller proportion.

Meanwhile, community health service centers in China have generally not established end-of-life care departments and have yet to develop an organizational network for end-of-life care services within the community system. End-of-life care services have not been incorporated into the functions of community health services, resulting in an inability to adequately address the needs of elderly individuals requiring end-of-life care at home. In general, the current state of end-of-life care services struggles to meet the demands of patients in need, and the scale of these services falls significantly short of the theoretical quantity required.

The needs of terminally ill elderly individuals encompass life care, physical care, psychological support, emotional assistance, and spiritual comfort. Considering the diverse physiological, psychological, and mental conditions experienced by different types of end-of-life elderly individuals, it is crucial to address personalized needs and unique requirements. Presently, the provision of end-of-life care services in China predominantly centers on life care, physical support, pain management, and relief. However, there is a relative scarcity of services focused on emotional care, psychological support, spiritual comfort, and other aspects, resulting in low service quality. Consequently, these limitations hinder the effective fulfillment of certain elderly individuals' needs for high-level services, thereby affecting their quality of life and end-of-life experiences.

3. The relationship between the government and society in end-of-life care for elderly people in China

Building upon the reliance of non-profit organizations on the government, three interrelationships emerge through financial support and funding provision, with the third sector delivering services*(17).*

Completion: The government provides funding while the third sector delivers services.

Supplementary: The third sector is responsible for addressing needs that the government cannot meet independently.

Advocacy: In this capacity, the third sector acts as a representative of public interest, advocating for policy improvements by the government.

Welfare pluralism advocates for the privatization of welfare in response to the broader crisis facing the welfare state, necessitating a reduction in the government's direct provision of social welfare. On one hand, welfare pluralism underscores the idea that welfare services can be delivered by the public sector, for-profit organizations, non-profit organizations, families, and communities. It envisions the government's role evolving into that of a welfare services regulator, purchaser, manager, mediator of resources, and promoter of engagement by other sectors in service provision. On the other hand, it stresses the involvement of non-profit organizations in filling the void created by the government's retreat from the welfare domain, resisting the overexpansion of market forces, achieving the integration of welfare services, enhancing the efficiency of welfare provision, responding promptly to evolving welfare needs, and bolstering democratic participation through non-profit organizations.

In China's context, the historical underdevelopment of civil society represents a tangible and current national reality. The highly centralized political authority and unified economic and social regulations enforced during the planned economy era held logical and historical significance at that time. These measures equipped the new regime with the resources and capabilities needed to achieve national unity and to initiate modernization, particularly in terms of economic advancement. In an era characterized by an all-powerful government, political authority extended into various spheres and levels of society. This led to the disruption of previous social connections, with political power being utilized to reconstruct them. Social organizations with autonomous traditions also experienced disintegration and were assimilated into the system of political power. Consequently, civil organizations experienced rapid decline or vanished altogether, while grassroots autonomous organizations became integral components of the bureaucratic chain within the political system.

Following the reform and opening up, the highly centralized system began to loosen, with the central government not only decentralizing power to local governments but also to society and the market. Civil organizations started to emerge, and grassroots organizations began to move towards autonomy. However, the development of civil society has remained relatively slow and immature. An equal cooperative relationship between the government and society has yet to be established. Furthermore, while grassroots autonomous organizations have been established, there is still suspicion surrounding the public and autonomous nature of the community. Moreover, the number of civil society organizations remains relatively small, and their scope of activities is significantly constrained.

Specifically regarding end-of-life care services, on one hand, the lack and misalignment of government functions, along with inadequate investment and support, have impeded the development of end-of-life care. On the other hand, the weakness of civil society has hindered the cultivation and growth of end-of-life care hospitals and hospices in the private sector, let alone cooperation and participation among the government, market, and society. Consequently, this situation inherently poses significant obstacles to the healthy development of China's end-of-life care service industry.

Certainly, civil society organizations in China are currently working to build momentum for the advancement of end-of-life care. However, China's end-of-life care services lack adequate develop-

ment across various aspects including legislative empowerment, management and supervision systems, financial investment, conceptual frameworks, and social organizations. The simultaneous absence of government and social functions, coupled with insufficient cooperation and complementary interaction between the two, has resulted in a significant number of elderly individuals having unmet multi-level end-of-life needs. As a result, end-of-life care is predominantly provided by family members, and professional end-of-life care services remain lacking.

4. Conclusion

4.1 The government should lead the development of end-of-life care

Social welfare is considered a public good, or at least a quasi-public good, as it represents a domain where market mechanisms either fail outright or only partially operate. As such, it can only be effectively managed by the government. This characteristic holds significant importance in the construction and development of social welfare systems in China and other countries. The "government-led" approach essentially represents a middle ground between assuming responsibility and refraining from intervention. In this approach, the government adheres to the principle of "taking action" versus "inaction" in the realm of social welfare construction.

Social welfare systems are established by various countries to address inadequate living security resulting from market failures and to enhance people's quality of life, with the government serving as the primary custodian of the system. However, it is important to note that the government should not exert complete dominance in this field, much less wield excessive power. Instead, it should engage in moderate intervention in the sphere of social welfare, aiming to achieve mutual compensation or balance among the government, market, and society.

Considering the development process and trends in social welfare undertakings across different countries, the adjustment of government responsibilities tends to lead to the establishment of a government-led, socialized social welfare system. In this framework, the government does not solely assume all responsibilities for contributions and management. Instead, it serves as a guiding force, mobilizing various entities such as social organizations, communities, and individuals to provide welfare protection. This approach does not entail completely relinquishing the management of social welfare but rather represents an alternative way for the government to fulfill its responsibilities.

In the realm of end-of-life care services, the government's responsibilities should encompass the following points:

- Establishing regulatory frameworks and standards for end-of-life care services.
- Facilitating financial support and investment in end-of-life care facilities and programs.
- Collaborating with social organizations and communities to ensure comprehensive end-of-life care coverage.
- Promoting public awareness and education on the importance of end-of-life care.
- Providing oversight and evaluation of end-of-life care services to maintain quality and accessibility.

Firstly, in terms of legislation and institutional design, the Chinese legislative body should expeditiously enact the Law on End-of-Life Care Services to grant and establish the right to end-of-life care for individuals, including the elderly, at a legal level. Additionally, policies and regulations pertaining to end-of-life care should be drafted and implemented, accompanied by the formulation of comprehensive design and plans for end-of-life care systems. This proactive approach will create a legal framework that ensures the provision of end-of-life care services and promotes the rights of end-of-life patients.

Secondly, regarding financial support, it is essential to establish clear guidelines for the financing of end-of-life care services, encompassing contributions from central and local government departments as well as social insurance. The Chinese government should formalize and clarify its finan-

cial obligations for various end-of-life care initiatives, specifying the proportion and institutionalization of governmental financial responsibilities for end-of-life care contributions and compensation within medical insurance and related security projects. This approach will entail outlining the financial responsibilities of both central and local governments for end-of-life care, ensuring alignment between financial resources and administrative authorities. Additionally, social medical insurance programs should enhance compensation provisions for end-of-life care services, thereby enabling elderly individuals in need of such services to receive appropriate economic support. This multi-faceted approach will help address the financial aspects of providing comprehensive end-of-life care services.

Thirdly, in terms of management, it is important to designate the China Health Commission as the competent department for end-of-life care services. All levels of health departments should establish dedicated end-of-life care departments, clearly defining their responsibilities and tasks. Furthermore, improvements to the public finance system and local government performance evaluation system are essential. This includes formulating comprehensive end-of-life care development plans, promoting the implementation of various end-of-life care policies and regulations, and managing the reasonable allocation of relevant resources. These measures will aid in effectively the daily operation of end-of-life care services. By centralizing responsibility within the China Health Commission and establishing clear management at all levels, the management and delivery of end-of-life care can be streamlined and optimized.

Fourthly, it is crucial to implement effective supervision of various policies and regulations related to end-of-life care. This includes oversight to ensure the diligence of staff within relevant end-of-life care departments, as well as monitoring the appropriate utilization and normal operation of financial resources allocated for end-of-life care. Additionally, supervision should extend to verifying the legality of activities conducted by end-of-life care-related institutions and social groups. By rigorously overseeing these aspects, the government can uphold the integrity and quality of end-of-life care services, promoting accountability and compliance with established regulations and standards.

4.2 Actively cultivate civil society

Absolutely, building on the foundation of government leadership, a framework guided by "welfare pluralism" or "cooperationism" can be actively pursued. This involves fostering the development of civil society, promoting the establishment of non-profit and non-governmental organizations, and enhancing participation and cooperation between the market and society. Encouraging the involvement of social intermediary organizations in end-of-life care services and management is also essential.

Furthermore, a diversified approach to investment entities and multiple investment forms should be embraced to harness the collective initiative of the government, market, social organizations, families, and individuals to advance end-of-life care. This entails attracting private capital for investment in the establishment of end-of-life care institutions and private end-of-life care hospitals. Coordinating and collaborating in the development of various end-of-life care institutions through methods such as "private - public assistance" and "public - private" can unlock synergistic potential.

Moreover, the implementation of tax preferential policies to support the construction of end-of-life care service institutions, including end-of-life care hospitals, nursing homes, day care facilities, and community end-of-life care service centers, is crucial. These policies may include incentives related to land and housing use, service facilities, and reduction or exemption of corporate income tax for the establishment of elderly end-of-life care service institutions, as well as relaxation of registration conditions. By incorporating these strategies, a comprehensive and collaborative approach to advancing end-of-life care can be realized.

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