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CONSTRUCTION AND PRELIMINARY APPLICATION OF COST ESTIMATION TOOL FOR HOME-BASED PALLIATIVE CARE

Zhiheng Zhou*[1], Zeling Zhu[1], Weiliang Zhu[1], Tingjun Li[2], Lishu Lin[2] and Honglian Xie[1]

[1]Pingshan Hospital of Southern Medical University, Shenzhen, 518118 China.
[2]Shenzhen Futian Second People's Hospital, Shenzhen 518040, China.

***Corresponding Author: Zhiheng Zhou**

Pingshan Hospital of Southern Medical University, Shenzhen, 518118 China.

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ABSTRACT

Background: Home-based palliative care is an effective method for improving the quality of life for terminally ill patients, but it is still in its infancy in China, with limited reports on cost assessments. **Objective:** This study aimed to develop a cost assessment index system and evaluation tool for home-based palliative care applicable in China, conduct preliminary applications, understand the costs of home-based palliative care in Chinese cities, and provide scientific basis for government compensation, resource allocation, and service optimization. **Results:** Literature review, expert interviews, consultations, questionnaires, and field observations were used to establish a cost assessment index system for home palliative care, which includes two dimensions (primary indicators): healthcare team and medical costs, and home care and caregiver costs, with five secondary indicators and sixteen tertiary indicators. In Shenzhen, 50 patients receiving home palliative care between 2023 and 2024 and their families were selected as research subjects. The costs were evaluated through big data analysis and questionnaire surveys. The results showed that the total cost per patient for community palliative care was approximately 74,100 yuan, with home care and caregiver costs (58.3%) significantly higher than healthcare team and medical costs (32.1%). Additionally, family caregivers spent an average of 6.2 hours daily, equivalent to an implicit economic cost of 4,120 RMB yuan per month. **Conclusions:** This study is the first to develop a cost assessment index system and evaluation tool for home-based palliative care applicable in China, revealing that the implicit costs borne by families are significantly higher than professional service costs. The Chinese government should increase policy support, establish a tripartite cost-sharing mechanism involving the government, families, and society, optimize resource allocation, and enhance the effectiveness and efficiency of community palliative care.

KEYWORDS: Palliative care, Cost, Index system, Evaluation tool.

1. INTRODUCTION

With the aging of the Chinese population, the prevalence of chronic diseases in China is increasing, and the deaths of chronic diseases in the elderly account for 86.6% of the total deaths. Therefore, it is noteworthy to improve the terminal care of elderly patients with chronic diseases and improve the quality of life in the terminal stage. However, the latest global quality of death index in 2024 showed that Chinese mainland ranked 37th in 80 countries and regions worldwide, and the quality of death index of dying patients was still low.[1-3] Therefore, to vigorously develop and promote hospice care work, improve the quality of life of dying patients, and effectively carry out hospice care work has become one of the continuing work of health departments in China. Panning care refers to providing painful medical and nursing services for dying patients suffering from incurable diseases, improving the quality of life of patients, saving medical costs, and reflecting the progress of social civilization. It through doctors, nurses, volunteers, social workers, physiotherapists and psychologist team services, help dying patients and their families, in reducing the physical pain at the same time, more attention to the patients' inner feelings, let patients with dignity through the last journey of life. At present, the areas with relatively mature hospice care development are divided into two categories: ward hospice care and home hospice care. The development of home hospice care services enables dying patients to die safely in their familiar environment, which not only avoids useless treatment, but also gets the company of family. However, due to the differences in Chinese people's understanding of death, home hospice care work lags behind in China and is still in the initial stage of.[4-7] At present, scholars calculate the human cost and economic cost of hospice care, mainly focusing on the cost calculation of hospital hospice care and institutional hospice care, while the cost calculation of home hospice care is rarely reported. At present, China has no recognized cost measurement index system and

quantitative evaluation tool for home hospice care, nor is it clear about the specific cost-benefit of home hospice care, and the government lacks scientific basis for compensation for home hospice care.[8-10] These weaknesses are one of the bottlenecks in promoting home-based palliative care in China. It is of great practical significance to carry out the cost calculation research of home hospice care. Therefore, through a series of methods, the project team has constructed the calculation index system and evaluation tool for the cost of home-based palliative care, and conducted preliminary application in the community and family to quantitatively evaluate the actual labor cost and economic cost of home hospice care in Shenzhen.

1. METHODS

2.1 Construction of calculation index system and evaluation scale of home-based palliative care cost

2.1.1. Constructed a theoretical model of cost calculation of home hospice care by consulting relevant documents and documents at home and abroad, through the description and analysis of the content and cost of home hospice care services, the relationship between the content and cost of home-based palliative care services is logically clarified, the logical framework of hospice care cost calculation is described, and the theoretical model for calculating the cost of home palliative care has been proposed.

2.1.2. Constructing a cost estimation indicator system for home-based palliative care

① Referencing relevant Chinese documents on home-based palliative care and social information quantification, as well as descriptions and standardized value models related to "Healthy Shenzhen", organize relevant experts to use brainstorming, empirical analysis, and hierarchical analysis to list indicators. Then, classify the indicators and repeatedly discuss and screen the initial evaluation system framework and system (primary indicators, secondary indicators, and tertiary indicators). Through individual interviews and expert symposiums, invite domestic authoritative experts to deliberate and revise the initially established indicator system.

②The importance and feasibility of the evaluation index were evaluated by Delphi method and hierarchical analysis method: experts filled in the importance comparison matrix according to their own experience and experience, and calculate the weight distribution of each index.

Selection of consulting experts (15 people): the selected experts must meet the following two conditions: The first one was engaged in home hospice care and health economics research, with associate high title or master degree education, working in the professional field of not less than 5 years. The second one was interested in hospice care and health economics, have the time and energy to complete the consulting work. Consultation method: conduct expert consultation by mail or direct delivery.

The implementation of expert consultation: a total of two rounds of expert consultation, according to the conditions of experts to determine the list of experts, first through the telephone contact, after the consent of the experts to send or send the consultation materials, start the first round of expert consultation. After recovering the consultation feedback information, the positive coefficient of experts and the coordination degree of expert opinions are analyzed. When the coordination coefficient of expert opinion is close to 0.5 and is significant, the consultation ends. In order to determine the economic cost, labor cost index and weight of home hospice care, and to determine the relative weight of the technical difficulty and technical risk of home hospice care services (α).

③Designed the evaluated index as a questionnaire to further test the feasibility of the index and obtain the measured value of the index; questionnaire survey: designed the index after the expert consultation as a questionnaire, and tested the reliability and validity of the questionnaire through the pre-survey.

2.2 An empirical study on the quantitative calculation of the cost of home-based palliative care

2.2.1. For the big data analysis (1) Object: Patients and their families receiving home hospice care in the region from 2023 to 2024 were selected as the research subjects. (2) Data collection and calculation content:

(1) Economic cost: all costs recorded in the social health information system (including medication, testing, treatment, home care, etc.) during home hospice care. Statistics of all types of the average home-based palliative care costs.
(2) Medical and health labor cost: all medical services, rehabilitation care programs, psychological intervention projects, times, manpower required and time consuming.
(3) Standardization of labor cost: mark the quantity of labor cost according to the work difficulty and work risk of the service content.

2.2.2 Questionnaire survey method

To engaged in home hospice care services staff, patients caregivers as the survey object, according to the construction of home-based palliative care cost evaluation index system, the design questionnaire of different objects, including the home-based palliative care community medical staff labor cost questionnaire and the home-based palliative care patients cost and caregiver labor cost questionnaire, questionnaire survey. Questionnaire on labor Cost of Community Medical Staff in Home Hospice Care: including basic information of personnel, content of home hospice care provided by community medical staff, manpower consumption and time consuming (refer to the number of all types of medical staff required to complete the service project and the average time spent in operation). The average time

spent did not include the waiting time, that was, the time without medical personnel participating in the operation, and the technical difficulty and technical risks of the service. Questionnaire on home hospice care patient expenses and labor costs of caregivers: including basic information of personnel, content of providing home-based palliative care, manpower consumption and time consumption; medical expenses of patients during hospice care, expenses for purchase of related materials and services, satisfaction and suggestions for home-based palliative care.

2.2.3 Cost statistics of hospice care at home

According to the collected data and the results of on-site questionnaire survey, and the cost calculation index system and evaluation scale of home hospice care constructed in this project, the economic cost and labor cost of patients receiving home hospice care were evaluated, and the cost-effectiveness of different home-based palliative care models were analyzed.

3. RESULTS

3.1. Calculation index system of home-based palliative care cost

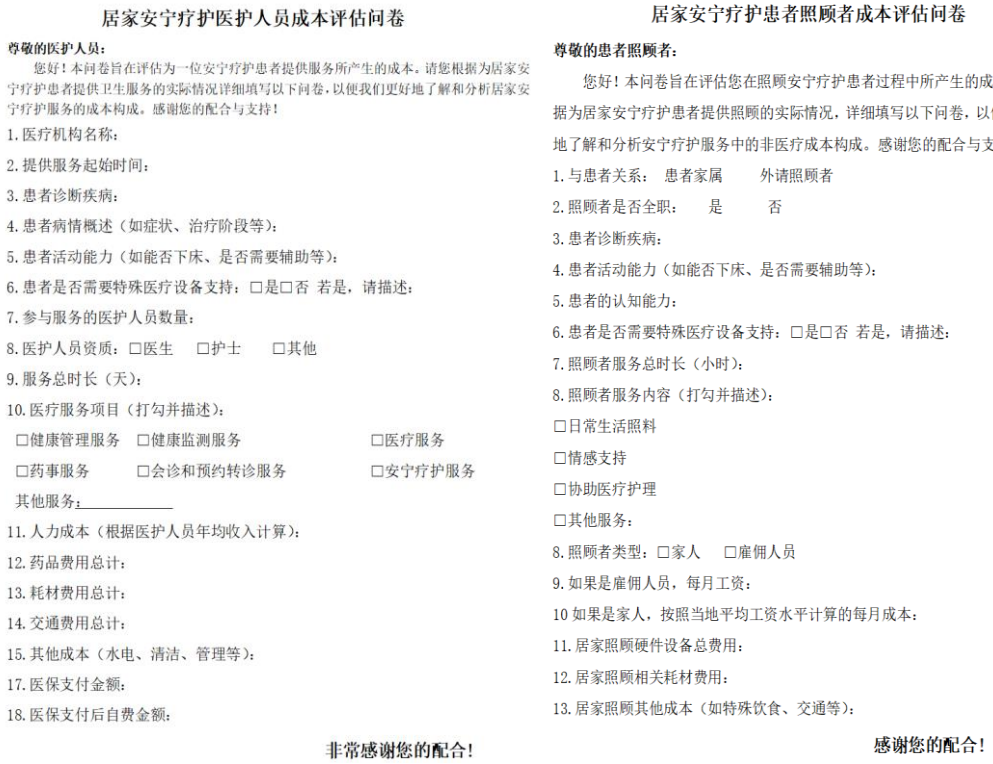
According to the requirements of cost calculation, the evaluation was conducted from the two dimensions of the health service team and its medical expenses cost and home care and caregiver cost. Through the literature research method, expert interview, expert consultation method, on-site observation method, the index system of home hospice care cost calculation index system was formulated. This system included 2 dimensions (health service team and its medical cost, home care and caregiver cost) and 5 second-level indicators (Medical requirement costs, medical team labor costs, care environment and equipment costs, drugs and consumables for care, and caregiver labor costs) and 16 three-level indicators were shown in Table 1.

Table 1: Calculation index system of home-based palliative care cost.

Level 1 indicators	Level 2 indicators	Level 3 indicators
Human cost and medical expenses cost of health service	Medical expenses	expenses for medicine Testing and health assessment fees medical expense Rehabilitation care mental intervention Nutritional intervention
	Human costs of the medical team	Doctor cost Nurse cost Other health-technical personnel costs Other social labor cost
Home-based caregiver costs	Home environment renovation and equipment costs	Environment configuration costs Home care equipment costs
	Cost of drugs and consumables for care	Self-purchased care drugs Expenses of self-purchased consumables
	Caregiver human costs	Human cost of patient family members Cost of external carers

3.2 Questionnaire for home-based palliative care cost calculation in Shenzhen

According to the cost calculation index system of home-based palliative care in Shenzhen, Combined with the actual needs, We have formulated the Labor Cost Questionnaire of Medical Staff in Community with home-based palliative care: including basic information of personnel, the content of home hospice care provided by community medical staff, manpower consumption and time consuming (referring to the number of all types of medical personnel required to complete the service project and the average time spent in operation), And questionnaire on patient costs and labor costs: including basic information of personnel, content of providing home hospice care, manpower consumption and time consuming, Medical expenses during hospice care, purchase of related materials and services, Satisfaction and suggestions for hospice care at home, See Figure 1A, B.



居家安宁疗护医护人员成本评估问卷

尊敬的医护人员：

您好！本问卷旨在评估为一位安宁疗护患者提供服务所产生的成本。请您根据为居家安宁疗护患者提供卫生服务的实际情况详细填写以下问卷，以便我们更好地了解和分析居家安宁疗护服务的成本构成。感谢您的配合与支持！

1. 医疗机构名称：
2. 提供服务起始时间：
3. 患者诊断疾病：
4. 患者病情概述（如症状、治疗阶段等）：
5. 患者活动能力（如能否下床、是否需要辅助等）：
6. 患者是否需要特殊医疗设备支持：□是□否 若是，请描述：
7. 参与服务的医护人员数量：
8. 医护人员资质：□医生 □护士 □其他
9. 服务总时长（天）：
10. 医疗服务项目（打勾并描述）：

□健康管理服务 □健康监测服务 □医疗服务

□药事服务 □会诊和预约转诊服务 □安宁疗护服务

其他服务：_____

11. 人力成本（根据医护人员年均收入计算）：
12. 药品费用总计：
13. 耗材费用总计：
14. 交通费用总计：
15. 其他成本（水电、清洁、管理等）：
17. 医保支付金额：
18. 医保支付后自费金额：

非常感谢您的配合！

居家安宁疗护患者照顾者成本评估问卷

尊敬的患者照顾者：

您好！本问卷旨在评估您在照顾安宁疗护患者过程中所产生的成本。请您根据为居家安宁疗护患者提供照顾的实际情况，详细填写以下问卷，以便我们更好地了解和分析安宁疗护服务中的非医疗成本构成。感谢您的配合与支持！

1. 与患者关系： 患者家属 外请照顾者
2. 照顾者是否全职： 是 否
3. 患者诊断疾病：
4. 患者活动能力（如能否下床、是否需要辅助等）：
5. 患者的认知能力：
6. 患者是否需要特殊医疗设备支持：□是□否 若是，请描述：
7. 照顾者服务总时长（小时）：
8. 照顾者服务内容（打勾并描述）：

□日常生活照料

□情感支持

□协助医疗护理

□其他服务：

8. 照顾者类型：□家人 □雇佣人员
9. 如果是雇佣人员，每月工资：
10 如果是家人，按照当地平均工资水平计算的每月成本：
11. 居家照顾硬件设备总费用：
12. 居家照顾相关耗材费用：
13. 居家照顾其他成本（如特殊饮食、交通等）：

感谢您的配合！

Figure 1: Questionnaire for cost calculation of home-based palliative care in Shenzhen.

(A. Cost assessment questionnaire for home-based palliative care medical staff and B. Cost assessment questionnaire of home-based palliative care patients).

3.3 Evaluation results of the cost of home-based palliative care

By assessing the cost of 50 patients with home-based palliative care, including medical staff, caregivers (patient family members or external caregivers), the cost assessment results are as follows:

3.3.1 Health service team and medical expenses costs

(1) Human cost of medical care: in the community hospice care service project, artificial assisted laxative (10 yuan), and the highest one was grade I nursing (500 yuan). We took the average value to calculate the labor cost, that was, (510) / 2=255 yuan. Considering the salary level of medical staff in Shenzhen, we estimated the labor cost of medical staff. Supposed a hospice care patient needs care for 6 months, 10 times of different levels per month, the total labor cost was 255 yuan / time ×10 times×6 months =15300 yuan.

(2) Total cost of drug treatment: including drug testing and health assessment fee, treatment fee, rehabilitation care, psychological intervention, nutritional intervention and other costs, about 6000 yuan.

(3) Total medical staff cost: 15,300 + 6,000 = 21,300 yuan

3.3.2 Cost of home care and caregivers

Care environment and equipment costs: 2000 yuan, care drugs and consumables costs: 1000 yuan, caregiver labor costs: estimated at 8000 yuan/month × 6 months =48000 yuan according to the average salary level in Shenzhen, other costs (such as special diet, transportation, etc.): we can estimate at 300 yuan/month × 6 months =1800 yuan.

To sum up, the cost of community palliative care for each patient was about 21,300 yuan for health service team and medical expenses + 52,800 yuan for home care and caregiver costs, with a total cost of 74,100 yuan.

4. DISCUSSION

In developed western countries and regions, home-based palliative care has seen good development and gained widespread social recognition. They have established a diversified service model primarily consisting of home-based palliative care, inpatient palliative care, and community palliative clinics. Home-based palliative care further embodies the characteristics of “a good end for patients and a proper farewell for families”.[11,12] Tailored to the needs of terminally ill patients, home-based palliative care provides medical services, pain relief, psychological counseling, family care guidance, and grief support according to the principles of graded management and appropriate services. It also offers spiritual, cultural, and emotional support, significantly enhancing the comfort of patients during their final days. In cities such as Shanghai, Tianjin, and Shenzhen in China, home-based palliative care programs have gradually been launched with satisfactory initial results.

In 2012 and 2014, Shanghai included "promoting the construction of hospice care institutions" in its municipal government's practical projects, focusing on building institutions and integrating home-based palliative care services at community health centers. This initiative has promoted the development of home-based palliative care services in multiple areas of Shanghai, establishing a work model where home-based palliative care is the core, improving referral mechanisms, and relying on the general practitioner teams and home hospital beds of community health centers to establish an integrated system comprising cancer lines, home hospital beds, palliative clinics, and institutional wards. Additionally, it utilizes home hospital beds, community home-based palliative beds, and institutional palliative beds to form a "triple-bed linkage" mechanism, providing continuous home-based palliative care services for terminally ill patients.

At present, Chinese scholars have made more studies on the service process and service mode of home hospice care, while there are few studies on the calculation of home hospice care cost, especially on the calculation of labor cost and economic cost. In this study, a series of methods were applied to construct the cost measurement index system and evaluation tool for home hospice care in China for the first time, and revealed that the hidden cost of family (58.3%) is significantly higher than the cost of professional services (32.1%). This finding is consistent with research trends in the global aging society: home hospice care by reducing hospice care spending (by 28-35% in the US study), while improving patient quality of life (e. g., 40% higher satisfaction with pain control). However, the particularity of Chinese family culture lies in the fact that the familial cultural tradition makes informal care the core pillar, but the chronic lack of economic compensation or social support for family caregivers at the policy level, leads to the excessive family burden or even the risk of "returning to poverty due to illness".[13-16]

The index system proposed in this study breaks through the traditional medical cost accounting framework, and includes the time cost, emotional labor and opportunity cost of family caregivers into the calculation scope. For example, estimates show that family caregivers spend an average of 6.2 hours per day, equivalent to a hidden economic cost of 4,120 yuan (local minimum wage), higher than similar studies in India (3.1 hours / day) and Latin American countries (4.5 hours / day). This assessment tool covers the multidimensional cost integration of health service team direct cost (drugs, medical labor) and the indirect cost of home care (e. g. loss of income, psychological depletion), and predicts the cost fluctuations of different disease stages (e. g. vs. organ failure in the end of cancer) through machine learning models. Compared with western developed countries, home-based palliative care in China presents the typical characteristics of "high family dependence and low professional compensation". For example, in the US, professional teams accounted for more than 45% of the costs (mainly relying on Medicare payments), while in this study, households had borne 58.3% of the costs, reflecting the absence of institutional support. The root of this difference lies in[17-21]: ① cultural factor: the family is regarded as "natural" care subject and suppresses the purchase intention of professional services; ② system defect: China has not yet established a national home care insurance system, the local pilot has limited coverage and low reimbursement ratio (e. g., Shenzhen only covers 30% -50% of drug costs).

The cost calculation results of this study provide three strategic support for improving the community hospice care system in China.① Resource allocation optimization: through the identification of high-cost services (such as 24-hour door-to-door care), guide the government to community nurse training and remote monitoring equipment procurement tilt resources[22,23]; ② fairness improvement: cost calculation reveals the urban and rural differences (rural family hidden cost is 22% higher than the city), through the transfer payment mechanism (refer to the Brazilian family health plan), can refer to the German "integrated home care" model (legislation clear multidisciplinary team cooperation and insurance sharing ratio), establish the government-family-society tripartite cost sharing mechanism. For economically developed areas (such as the Yangtze River Delta), the "commercial insurance + government subsidy" model (similar to the Medicare Advantage program) can be promoted in the United States; in less developed areas, community volunteer networks to reduce labor costs (such as the Indian community health workers model).③ Sustainable development path: establish the financing mechanism of "preventive palliative care", and integrate the management of some advanced chronic diseases into the basic public health service package (similar to the integrated model of cancer prevention and treatment in Japan).[24-30] ④ The results of this study also suggest that there is limited support for parent caregivers in China, and it is suggested that a national paid leave system for family caregivers (learn on Swedish experience).

Although this study has explored the construction and preliminary application of cost measurement tools for home-based palliative care, And get some meaningful results, However, there are still some deficiencies and limitations in this study: First, the sample representativeness of this study is limited: the data of this study are derived from community medical institutions and patients' families or caregivers in Shenzhen, It does not fully reflect the cost characteristics of the less developed central and western regions (e.g., rural families in Yunnan may bear a higher proportion of informal care); Secondly, lack of dynamic factors: unquantified the negative impact of long-term care on family relationships, In particular, the social costs caused by the health problems caused by the long-term care of the patients were not included in the statistics. Therefore,

in the future, we will combine mixed research methods to analyze the cost evolution rules of different stages of disease course, integrate health economics and sociology theory, and construct a prediction framework of "family-community-institution" collaborative cost.

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Conflict of Interest

The authors declare no conflict of interest.

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