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Systemic Design for Pediatric Palliative Care: Service Strategies for Butterfly Home in China

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Abstract

Pediatric palliative care in China is still in its early stages. As awareness grows and demand increases, welfare institutions face the pressure to improve both emotional care and service coordination. This study focuses on how systemic design can support this transition by offering better tools, stronger networks, and more sustainable service models.

This research explores how systemic design can improve pediatric palliative care within Chinese welfare institutions by addressing emotional, operational, and institutional challenges. Through a mixed-method approach—including field research, stakeholder interviews, case study analysis, and co-design workshops—the study identifies 29 opportunity points and narrows them down to 10 strategic interventions. These are embedded into a multi-layered system map that integrates emotional flow, trust networks, and task structures.

The interventions are grouped into 4 strategic directions: Emotional Support, Efficiency and Resilience, Communication and Fundraising, and Network Collaboration. Each strategy targets specific pain points, from caregiver burn-out to low public awareness. A case matrix and international benchmarking further inform localization strategies, ensuring cultural relevance and scalability.

Outcome analysis is conducted across three systemic levels: micro (individual), meso (organizational), and macro (societal) and categorized into 6 impact types: stress reduction, efficiency optimization, emotional wellbeing, cultural resonance, funding support, and system readiness. These classifications allow for a nuanced understanding of how design-led initiatives can generate both immediate and long-term change.

From a full analysis of system needs and stakeholder roles, I propose a practical roadmap, which prioritizes early wins (e.g., stress relief for staff), mid-term trials (e.g., intelligent task platforms), and long-term goals (e.g., multi-stakeholder governance). It also anticipates systemic transitions such as the platformization of services and the use of data for policy advocacy.

This thesis contributes to systemic design by demonstrating its capacity to not only improve service touchpoints but also influence institutional structures and governance. While grounded in a single site in Changsha, the strategies offer scalable insights for wider application. Ultimately, the study highlights the transformative potential of design in building compassionate, efficient, and resilient care ecosystems for the most vulnerable children.

Keywords: Systemic Design, Pediatric Palliative Care, Welfare Institutions

1. Introduction & Background

1.1 Social background: the increase in the number of critically ill children and insufficient service coverage

Palliative care refers to a nursing model that provides comprehensive physical, psychological, and social care to patients and their families when they are terminally ill and do not respond to curative medical treatment, so that they can obtain dignity and peace at the end of their lives, thereby improving the quality of death. Data show that cancer and critical illnesses are gradually becoming one of the main causes of death among children. Globally, more than 8 million children need to participate in pediatric palliative care (PPC) each year (NI X, 2022). In China, approximately 200,000 critically ill children die each year, among whom the number of children with cancer is increasing year by year. According to statistics, the number of new children in China from January 1, 2018 to December 31, 2020 is estimated to be 121,145 (CONNOR SR, 2017). Based on this, it is estimated that the number of new children each year is about 40,382. However, the proportion of these children who can receive palliative care is less than 20% (Liu Hui, 2021), which is far from meeting the actual demand.

The coverage of palliative care in my country is relatively limited, and its main resources are concentrated in large medical institutions in big cities. In the vast number of small and medium-sized cities and rural areas, families of sick children have very few opportunities to obtain such services. At the same time, palliative care services for children in the medical system have not yet been systematized. Compared with adults, the treatment and care needs of children are more complex, and the service gap is more obvious. Specifically, there is a clear imbalance in the acquisition of medical resources, treatment options and nursing support for families of sick children. This lack of service coverage not only directly affects the quality of life of sick children but also further increases the psychological and economic pressure on families. This lack of service coverage not only increases the pressure on families, but also exposes the weak links in the domestic palliative care system in terms of services for children. Although palliative care has become a hot topic in scientific research in recent years, research on children's palliative care in my country is still in its early stages, and there are still few related studies on sick children as research subjects.

1.2 Research background

1.2.1 Overview of hospice services

Palliative care refers to a nursing model that provides comprehensive physical, psychological, and social care to patients and their families when they are unresponsive to curative medical treatment, so that they can achieve dignity and peace at the end of their lives, thereby improving the quality of death (US National Library of Medicine, 2019) With the development of modern science and technology and the improvement of people's quality of life, higher and higher requirements are placed on the performance of engineering structures. Palliative care can be carried out throughout the entire process of patient treatment (Yang Yanlan, 2023). It aims to prevent and alleviate suffering through early identification and treatment of pain and other problems (whether physical, psychological, social or spiritual problems), thereby improving the quality of life of patients facing life-threatening diseases and their families (Xu Dan, 2022). Especially when terminally ill patients do not respond to curative medical treatment, a nursing model that provides comprehensive physical, psychological, and social care to patients and their families so that they can gain dignity and peace at the end of their lives, thereby improving the quality of death (US National Library of Medicine, 2019). According to the comprehensive health care model proposed by the World Health Organization, palliative care runs through the entire disease trajectory model. From this model, it can be seen that palliative care is centered on patients and families and runs through the entire process of the patient's disease: from early intervention at the time of diagnosis to palliative support during treatment, to bereavement care after the patient's death, emphasizing full companionship for patients and families.

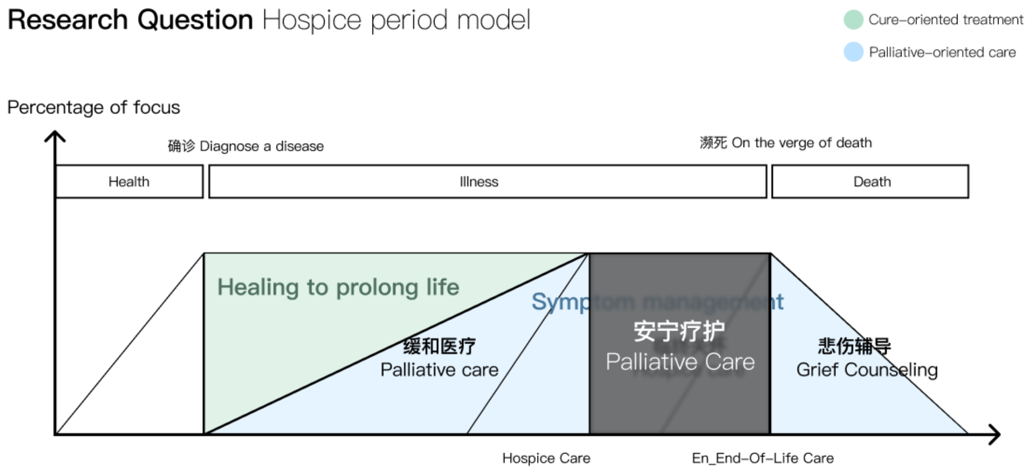

Figure 1.1 Hospice disease trajectory model (drawn by the author)

1.1.2 The number of critically ill children continues to grow

Data show that more than 8 million children around the world need to participate in children’s hospice care every year (Gao, 2021) and cancer has gradually become one of the main causes of death in children. Approximately 200,000 critically ill children die in China every year, and the number of children with cancer is increasing year by year (CONNOR SR, 2017). From January 1, 2018 to December 31, 2020, the number of new children with cancer in China is estimated to be 121,145 Example (Yang Yanlan, 2023), based on which it is estimated that there are approximately 40,382 new cases of children in China every year, but only no more than 20% of children receive hospice care (Liu Hui, 2021). Although hospice care has become a hot topic in scientific research in recent years, the research on children's hospice care in China is still in its preliminary stage (Yang Yanlan, 2023), and there are still few related studies using sick children as research subjects (Xu Dan, 2022).

1.1.3 The importance of children’s palliative care to families

In most families, children occupy an important position. Once a child suffers from a difficult-to-treat disease and develops into a terminal state, parents will be under great physical and mental pressure. Studies have shown that children with children are on the verge of death after birth, and the psychological stress of parents of children with children is as high as 90%. Moreover, the mother's sadness and guilt about the death of her child are difficult to let go of one year after the death of the child. Moreover, this kind of sadness It cannot be replaced by the birth of other children. In our country, the popularity of palliative care is far from enough. At present, hospitals rarely consider providing necessary services for relatives of dying patients (Xu Dan, 2022). Its importance and necessity have not been properly recognized, and it cannot satisfy patients and their families at the end of their lives. The need for caring work, so the palliative care of children is an indispensable and important topic in hospice care.

1.1.4 Children ’s hospice care is different from that of adults

Because the physical and mental development of children is significantly different from that of adults. Pediatric terminal patients are different from adult terminal patients in that they have special needs in the terminal stage such as different drug reactions, limited language expression, need for personalized care from parents, and inability to understand death (Zhao Fang, 2014). From the early stage, they were suddenly sent to the hospital and underwent a series of diagnostic and treatment operations as well as a series of physical reactions, which made them feel extremely fearful and extremely uncooperative with treatment. In the later stage, as the condition worsened and the people around them became sad, the children You will realize that you are about to die, and the whole person will suffer psychological pain. Children's palliative care is different from adults. In addition to taking care of children's physical, mental and spiritual aspects, it also includes support for families. Care for children begins when the disease is diagnosed and continues throughout the course of the disease (Ye Jianya, 2019).

1.1.5 The country attaches great importance to the development of palliative care-related fields

In 2016, the "Healthy China 2030" Planning Outline issued by the Central Committee of the Communist Party of China and the State Council mentioned "strengthening the construction of continuity medical institutions such as rehabilitation, geriatric diseases, long-term care, chronic disease management, and hospice care." Hospice care plays an important role in improving continuity. The important role of medical institutions (Xinhua News Agency, 2016). Palliative care can be used throughout the entire process of patient treatment, aiming to prevent and alleviate suffering through early identification and treatment of pain and other problems (whether physical, psychological, social or spiritual problems), thereby improving Quality of life of patients and their families facing life-threatening illness (DOWNING J, 2021).

1.3 Policy background: policy support and promotion of palliative care

In recent years, with the advancement of the Healthy China strategy, my country has gradually begun to incorporate palliative care into an important part of the national medical system and promote its development through a number of policies and pilot projects. With strong policy support, the coverage and social attention of palliative care have significantly increased, but the development of pediatric palliative care is still in its early stages and the system construction is not yet perfect. As early as 2004, the State Council issued the "Guiding Opinions on the Development of Urban Community Health Services", which first proposed to carry out palliative care in community health services. Since then, the country has further deepened its support for palliative care. For example, the "Healthy China 2030" Plan Outline issued in 2016 clearly stated that palliative care is an important part of continuous medical services and requires the strengthening of the construction of relevant medical institutions to meet the diverse needs of patients (Zhao Fang, 2014). In 2017, the "Guiding Opinions of the General Office of the State Council on Promoting the Construction and Development of Medical Alliances" proposed that in the process of improving medical service capabilities, the development and promotion of palliative care services should be strengthened. In the same year, the former National Health and Family Planning Commission (hereinafter referred to as the “NHFPC”) issued the “Notice on the Basic Standards and Management Specifications for Palliative Care Centers (Trial)” and the “Notice on the Practice Guidelines for Palliative Care (Trial)”, which clarified the beds, department settings and related management specifications of palliative care centers, and determined the specific service objects, teams and contents of palliative care practice· In 2020, the General Office of the National Health Commission issued another notice to determine the third batch of palliative care pilot provinces (cities) and pilot cities. In 2023, the General Office of the National Health Commission launched the third batch of palliative care pilot work (General Medicine Branch of Cross-Strait Medical and Health Exchange Association, 2021). The “Notice on Further Promoting the Development of Palliative Care” (National Health and Family Planning Commission [2023] No. 11) clearly requires “exploring the path of children’s palliative care services” and expanding the pilot to 185 cities (districts).

Based on the above policy guidelines, at the practical level, policy implementation and academic research are linked. Since 2017, my country has launched a pilot project for palliative care, with the first batch covering five provinces and cities, including Beijing, Shanghai, Jiangsu, and Zhejiang, and then gradually expanded to 71 cities and regions across the country. These pilot projects have achieved remarkable results in promoting medical institutions to provide palliative care services, accumulating practical experience, and enhancing public awareness of palliative care. As an important area of palliative care, pediatric palliative care has gradually received attention in policies and local practices in recent years. The "National Basic Public Health Service Standards" issued in 2018 emphasized that attention should be paid to health services for critically ill children (DOWNING J, 2021), and in 2021, the National Health Commission mentioned in the "Notice on Further Promoting the Pilot Work of Palliative Care" that pilot cities can appropriately explore pediatric palliative care service models based on regional needs. This policy provided a preliminary direction for local exploration of pediatric palliative care. Based on this policy, the pediatric palliative care team of Peking University People's Hospital integrated the resources of oncology, psychology and social work to establish a multidisciplinary collaboration model. The "Daisy House" project established by the Children's Hospital Affiliated to Fudan University and the Shanghai Juequn Culture and Education Foundation has accumulated services for critically ill children through multidisciplinary collaboration (MDT). The "Butterfly House" of Hunan Children's Hospital has become one of the few exemplary institutions in China that provides full-cycle care for critically ill children. 1.2 Research significance

1.4 Research Purpose, Significance and Value

1.4.1 Research motivations:

The origin of this research lies in my long-standing interest in vulnerable groups and my deep concern for the well-being of children in institutional care settings. My motivation to focus on pediatric palliative care stems from both personal value orientation and my hands-on experiences as a volunteer in various social welfare programs over the past few years. During my undergraduate and postgraduate studies, I actively participated in volunteer projects, including organizing companionship activities for children with severe illness, designing interaction kits for caregivers, and facilitating communication workshops between medical staffs and patients. These experiences offered me firsthand exposure to the emotional, psychological, and systemic gaps faced by children in palliative stages, especially those lacking family support. What struck me most was the fragmented nature of support, professional care often lacked emotional continuity, while volunteer services were temporary and poorly connected to institutional systems. In a welfare context where caregivers are overstretched, volunteers rotate frequently, and children are rarely able to express long-term preferences, the need for a systematic, human-centered care model became urgently clear to me. From these reflections grew my desire to explore how systemic design, as a discipline that bridges social complexity and design practice could contribute not only to reconfiguring service delivery, but also to reimagining institutional care ecosystems for children at the end of life. This thesis is thus a convergence of personal conviction, lived engagement, and academic pursuita response to a real-world dilemma through the lens of design.

1.4.2 Theoretical significance

(1) **Enrich theoretical research content in the field of children's palliative care.** Palliative care and hospice care are important developments in medical humanism, embodying the unity of the sanctity of life, quality of life and value of life. Pediatric palliative care is a relatively new field and there are still many understudied issues. Under the guidance of the theory of quality of life, by intervening in children's hospice care through service design methods, we can discover research gaps and explore specific service needs and problems in children's hospice care from the perspective of users and families. It can provide new perspectives and in-depth understanding of theoretical research content in this field, while filling gaps in the service design and user experience related fields of children's hospice care.

(2) Improve research methods or ideas in the field of children's hospice care. The service design method emphasizes actual operation and practice. It is based on the research foundation of social work, medical health, and psychology. By integrating product service system design methods in children’s hospice care, it uses service design thinking, methods and tools to explore the formation of psychological states. , quality of life, and life experience-focused service models and touch-point products, focusing on children and their families, hospice care institutions, and medical institutions , which can accumulate practical experience and cases and provide evidence for research on children’s hospice nursing theory. Base.

(3) Promote the development of public health service systems for children.

Through service design intervention, we can better understand the needs and usage of various resources in children's hospice care, help the public health service system better allocate and manage resources, and improve the efficiency and fairness of resource use. At the same time, children’s hospice care involves the cooperation of multiple departments and institutions, including medical institutions, community organizations, and volunteer groups. The service design method can promote cooperation and coordination among various departments and agencies, establish better collaboration mechanisms and communication channels, and improve the synergy of the entire public health service system.

1.4.3 Practical significance

(1) Improving perceptions and insights about children's hospice and end-of-life care.

Service design intervention in children's hospice care can break people's cultural taboos on the topic of death, convey the concept of "letting children leave the world with dignity and peace", and change the public's perception of children's hospice care so that they can understand and support it. Lift the shackles of medical care imposed by culture and empower children's hospice care institutions to provide professional, comprehensive assistance and guidance to terminally ill children and their families.

(2) Guide the service practice of children's hospice care and hospice care.

Starting from the perspective of product service system design, it provides a basis for other disciplines, such as social work, to intervene in end-of-life services for this type of group. Improving the quality of life and experience of pediatric patients at the end of life, empowering them to participate in decision-making and the care process, while enhancing overall well-being within the family.

(3) Promote public health policies that include children’s hospice care.

Through service design, a service strategy at the organizational structure level is proposed. For governments at all levels, attention should be paid to the development of hospice care and hospice care for children, and it should be included in the medical and health and children's medical service planning and public service systems, and the health committee should be clearly defined. Supervision, services and responsibilities of other competent departments, and an inter-department coordination working mechanism are formed to ensure the transfer and transition of children between institutions.

(4) Strengthen social advocacy for the extension of hospice care services.

Through the exploration of combining death education with hospice services, the period for groups who can enjoy this service is extended, so that more groups in need can enjoy timely care services early in life, and reduce the inevitable risk of chronic and non-malignant diseases. Predictability that causes the client to regret the impending death. Enhance social awareness and support for palliative care services, promote the participation of all sectors of society, advocate extending services to children, provide more comprehensive and detailed services, meet the needs of child patients and their families, and improve their lives and life quality and promote the development of life care.

1.5 Research Content

This research focuses on the systemic planning and strategic development of pediatric palliative care in China, especially for non-governmental organizations, charities, and collaborative networks managing limited resources under insufficient policy support. Using systemic and service design as methodological frameworks, the research aims to build a strategic roadmap for sustainable system evolution in pediatric palliative care. It investigates how to construct long-term development pathways by identifying feasible strategies grounded in the existing system, taking into account territorial specificities, stakeholder interests, and cultural resources.

For example, given the current limitations of charitable institutions, the research identifies context-based advantages such as “the developed doll-making industry in Changsha” and “existing gardening spaces within care institutions.” These become the foundation for short-term strategies such as customized therapeutic dolls and garden planting, which serve both emotional and social engagement functions.

Rather than optimizing care processes alone, this research emphasizes system integration—how to activate inter-institutional collaboration, trigger local resource flows, and promote policy alignment. Ultimately, it proposes strategic systemic solutions applicable to complex healthcare-social challenges, demonstrating the power of design to bridge service gaps and institutional limitations.

1.6 Exploratory Research Questions & Objectives

1.6.1 Research Questions (Exploratory)

This research is guided by the following exploratory questions:

- How can systemic design support the long-term development of pediatric palliative care in China, particularly in non-governmental or charitable settings?
- In resource-constrained environments, how can design help integrate scattered stakeholders and stimulate collaborative innovation across healthcare and social domains?

1.6.2 Research Objectives

- To explore the structural and contextual challenges facing pediatric palliative care institutions under the welfare system.
- To investigate potential system-based strategies that address service fragmentation, emotional needs, and resource scarcity.
- To develop a systemic roadmap to enhance the sustainability and collaboration of children's hospice care services through design-driven innovation.

1.7 Structure of the thesis

This paper is divided into nine chapters, each of which is logically progressive. Starting from the perspective of combining system design and service design, it gradually explores the strategic construction, spatial integration and social value of children's hospice centers embedded in welfare institutions. The overall structure reflects both the user-centered service design method path and the overall and autopoietic system perspective of system design.

Chapter 1: Introduction provides background and motivation for the study, clarifies the research question, objectives and methods, sets the scope of the paper, and explains the structure of the paper.
Chapter 2: Literature Review conducts a theoretical review, covering core concepts such as pediatric palliative care, systems thinking, and co-creation methods, and builds a theoretical foundation for the systems design method.
Chapter 3: Challenge Identification & Context Understanding combines field research, interviews and system mapping to identify key issues and conduct a four-stage challenge classification of B-D-A-T (Before–During–After–Territory) to prepare for the generation of opportunity points.

Chapter 4: Territorial and Stakeholder Analysis focuses on the resources and constraints in the embedded environment of welfare institutions, including spatial structure, policy environment, funding structure and user behavior journey, and sort out the key participants, material flow, information flow and capital flow in the system.

Chapter 5: Gigamap & System Mapping constructs system diagrams and problem visualization models to understand the organization's operating logic, resource flow paths, and system weaknesses as a whole, while introducing metasystem analysis to locate key problem nodes.

Chapter 6: Opportunities Identification & Assessment details the generation, classification and evaluation process of 29 opportunity points. Through a systematic scoring matrix, the 10 most strategic core strategies are screened out and classified into four strategic directions (A/B/C/D) to form a phased intervention roadmap.

Chapter 7: Design Scenarios and Proposals transforms core strategies into implementable design proposals and service mechanisms, builds spatial strategies, operational mechanisms and communication systems for children's palliative care services, covering modules such as information upgrades, emotional support and volunteer systems.

C*hapter 8: System Integration* discusses how strategies can be systematically embedded in the daily operations of the organization, demonstrates the integration path of strategies and material/information/relationship nodes in the system diagram, and forms a sustainable service ecosystem.

Chapter 9: Outcomes and Systemic Impacts evaluates the impact of design interventions at the Micro–Meso–Macro system levels and analyzes their long-term transformation potential in different dimensions such as social, psychological, and organizational. The structure of this paper ensures the presentation of the entire process from problem identification, resource sorting to strategy construction and system integration, demonstrating the role and value of design as a systematic tool in the construction of a pediatric palliative care ecology.

2. Literature Review and Case Analysis

2.1 Key Definition

1) Pediatric Palliative Care (PPC)

Pediatric palliative care is a comprehensive care field centered on children and their families, aiming to alleviate the physical symptoms, emotional stress, social impact and spiritual distress caused by serious or critical illnesses, and improve the quality of life of patients and families (Rosenberg & Wolfe, 2017; Goldman et al., 2012). It not only focuses on support at the end of life, but also emphasizes symptom control and psychosocial care at all stages of the disease (Rosenberg & Wolfe, 2017).

Pediatric Palliative Care (PPC) is defined by the World Health Organization (WHO) as the active holistic care of children with life-limiting or life-threatening conditions, integrating physical, emotional, social, and spiritual dimensions of well-being. Unlike adult palliative care, PPC emphasizes family-centered, developmentally appropriate interventions and often spans months to years due to the prolonged disease trajectories in children.

2) Total Pain / Total Care

Dame Cicely Saunders pointed out in her total pain theory that pain is a multidimensional, integrated experience that includes physical, psychological, social, and spiritual aspects (Clark, 2016; Saunders, 1964). This theory provides a systematic perspective for children's palliative care, requiring interdisciplinary teams (such as medical, social workers, and psychologists) to intervene collaboratively (Moody, 2022).

3) Anticipatory and Bereavement Grief Support

PPC emphasizes intervention in the family's early anticipatory grief and bereavement support after the death of a child. Schuelke et al. (2021) divides grief support into three categories: anticipatory grief, terminal grief, and post-death support, pointing out that holistic, multi-stage intervention has a significant impact on family recovery.

4) Integrated Care and Communication

Effective PPC services rely on collaboration and clear communication among interdisciplinary teams (Waldman & Wolfe, 2013). Literature indicates that integrating PPC with routine clinical care (integrated care model), especially in the treatment of pediatric cancer, can improve quality of life and family satisfaction without shortening survival time (Liben et al., 2002; Morell et al., 2019).

2.2 Research status of Pediatric Palliative Care

2.2.1 Research status in China

1) The current development status of children’s hospice care in China

The clinical practice of adult palliative care in my country continues to advance, and the second batch of national palliative care pilot projects was officially launched in 2019. However, the development of children's palliative care is very slow. Children's palliative care in my country exists sporadically in Beijing, Zhengzhou, Shanghai, Shenzhen and other places. Service resources are scarce and the treatment model is relatively simple. It is mainly palliative care beds attached to the hematology or oncology departments of some children's hospitals, such as Shanghai Children's Medical Center, Zhengzhou Third People's Hospital and others have launched children's palliative care projects to provide children with palliative care services.

2) design intervention in the field of hospice care

Currently, few researchers have applied service design thinking and tools to conduct systematic service innovation research on hospice care , and almost none are involved in the field of children's hospice care . The existing research on hospice services from the service perspective includes: Zhao Yang discusses hospice products and service design from the perspective of service design, which to a certain extent fills the gap in the design field of hospice care [17]. Li Xiaoli discussed the current hospice care model in the public service field and sought new development points from the public service field. From her professional perspective in social work, Zhang Lin analyzed the current situation of almost blank home hospice care services in my country, and constructed a social support network for home hospice care for patients with advanced cancer. Wu Qiong analyzed the needs of patients, families, and hospitals from the perspective of service design thinking, used service design methods to obtain and analyze service touch points, and based on this, innovatively proposed a hospice care App design plan [18].

2.2.2 Research status abroad

In terms of theoretical research, hospice care is relatively well developed in foreign countries. Hospice care for critically ill children was first proposed in 1970; in 1983, the International Hospice Care Organization for Children was established in the

United States. The "Guidelines for Hospice Care for Children in the United States" published by the American Academy of Pediatrics in 2013 proposed that "child-centered, family participation", "respect and cooperation", "high quality, openness, fairness" and "integration of clinical treatment" are the key to the care of children. The core concept of hospice care is to reduce the pain of children, improve the quality of life of children, and ensure that critically ill children and their families receive continuous care and attention are the goals of high-quality hospice care [4]. A team from the University of Pennsylvania, Johns Hopkins University, and the University of Missouri collaborated to publish the "Pediatric Hospice Care Guidelines" in 2022. The "Guidelines for Pediatric Hospice and Palliative Care" published by the American Academy of Pediatrics established four pillar principles: child-centeredness, family empowerment, interdisciplinary integration, and continuity of care [39]. This framework has been continuously verified and expanded in subsequent studies: Feudtner's team (2015) proposed a three-dimensional intervention model of "symptom control-psychological support-spiritual care" through a multicenter randomized controlled trial (RCT), which was confirmed to improve the total score of the quality of life scale of children and improve family decision-making satisfaction [33]; the Family Resilience Development Framework (FRDF) constructed by the European PALLIAKID Alliance (2020) improves the long-term adaptability of families through intervention measures such as grief counseling and legacy planning [40].

Knapp et al. [13] conducted a systematic review of the provision of children's palliative care. The results showed that 65.6% of countries around the world have no known children's palliative care service projects, 18.8% of countries provide basic palliative care services, and 9.9% of countries have no known palliative care services. Treatment services have become universal, and only 5.7% of countries have integrated palliative care services into the health care system. In the United States, almost every city has a hospice hospital with a dedicated area for dying children, and palliative care services are covered by national health insurance. Most countries in Europe also have relatively complete children's palliative care service systems [14][15][16].

2.2.3 Differences in Domestic and International PPC Development

International perspective: Europe and the United States often incorporate PPC into the medical system, set up specialist clinics and training systems, and emphasize multidisciplinary collaboration and institutionalized guarantees (Rosenberg & Wolfe, 2017; Waldman & Wolfe, 2013). Children's palliative care in China started late, mostly focusing on case pilots, lacking unified policies and medical insurance support, and lacking interdisciplinary professional talents (regional contrast in this study). What I found between these situations, they contained both differences and inspirations. International experience shows that PPC should cover the entire course of the disease, attach importance to communication and grief support; China needs to promote institutional construction, professional talent training and cultural embedding.

2.3 Practice status

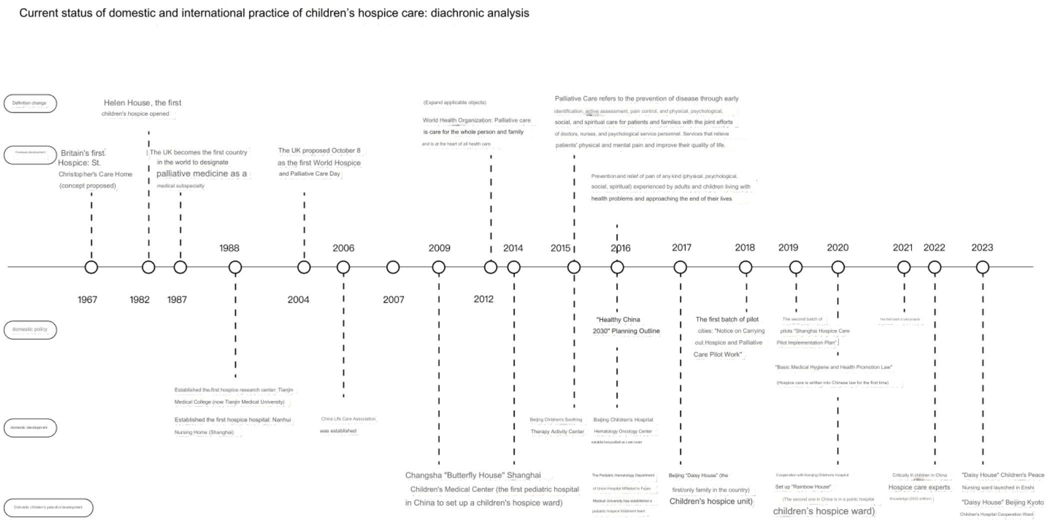

Figure 2 Diachronic analysis of the development of children's hospice care at home and abroad (drawn by the author)

2.3.1 Chinese practice status of Pediatric Palliative Car

Children's hospice care started late in my country. In 2009, China established the first children's hospice care home, marking the beginning of China's children's hospice care [19]. In 2009, the First Social Welfare Institute of Changsha City, Hunan

Province, and the British Charity Foundation jointly established China's first children's hospice care center, Butterfly House, to treat orphans with various congenital or refractory diseases. Lord. Shanghai Children's Medical Center established a palliative care team in 2012 to explore practical children's palliative care methods based on my country's actual conditions. It was the first pediatric hospital in mainland China to set up a children's palliative care ward. In 2015, with the help of charitable foundations, Beijing established a children's palliative care activity center. A palliative care team composed of professional medical staff, psychologists, volunteers, and social workers provided care for nearly a hundred children and families with hematological tumors. Provides hospice care, covering Beijing and Hebei and other surrounding areas. In 2016, the Hematology and Cancer Center of Beijing Children's Hospital established a children's palliative care team to provide holistic care for children with cancer, improve the quality of life, and pay attention to the healthy growth of children after recovery. In April 2016, the Pediatric Hematology Department of Union Hospital Affiliated to Fujian Medical University established a professional pediatric palliative care team and opened a ward classroom. In 2017, Beijing Children's Hospital and Beijing Songtang Hospital cooperated to establish the country's first and currently only family-style children's hospice care unit "Daisy House", aiming to allow dying children to die with dignity and peace [20] [21] .

2.3.2 Foreign practice status

The well-established systems and supervision mechanisms for children's hospice care services abroad, as well as the high level of attention and active support from the government and society for children's hospice care, have provided rich experience for the development of children's hospice care in China. Germany has promulgated the "Hospice Act", Japan has promulgated the "Cancer Control Act", and in the UK's larger hospices, about 70% of the funds come from the National Health Insurance... Strong legal and medical insurance support makes Pediatric hospice care has become the norm in society. Currently, more than 600 children's hospice care projects have been launched in more than 70 countries around the world, mainly providing hospice care for newborns and children with cancer [22]. Both Ireland and the UK have introduced corresponding policies to protect the rights of dying children and their families [23]. In the UK, New Zealand and other regions, hospitalization and home hospice care for children are basically free. Hospice care services in the United States have been included in the coverage of national health insurance. The Medical Act stipulates that children participating in Medicaid or the Children's Health Insurance Plan can also enjoy hospice care services.

Table 2.1 Comparison of Pediatric Palliative Care Policy Implementation in Selected Countries

Country	**Core Policy**	**Service Coverage**	**Out-of-Pocket Ratio**	**Key Innovations**
Germany	*Hospice and Palliative Care Act* (2015)	89%	≤10%	Tiered referral system / Mandatory physician training
Japan	*Basic Law for Cancer Control* (Amended 2016)	67%	≤15%	Standardization of home care wards / Support for religious rituals
UK	*Health and Social Care Act* (2012)	92%	0%	Community care packages / NHS dedicated funds
USA	*Children's Hospice and Palliative Care Act*	78%	5–20%	Concurrent care model / VR-based pain management

Some medical facilities in other countries provide hospice and hospice services for children with medical conditions. Japan's children's hospice was founded in 2012 by Yodogawa Christian Hospital. Professional doctors provide palliative care to terminally ill children through door-to-door services, organized activities, customized wards, etc., so that they can die as decently as possible. Cincinnati Children's Hospital provides the "StarShine Hospice Program " to pediatric patients and their families, which mainly provides three types of services: transitional palliative care, perinatal hospice care and bereavement care. Casa Sollievo Bimbi VIDAS is the first pediatric hospice in Milan and Lombardy and one of six in Italy. It provides support and care to children and young people with terminal, incurable illnesses whose social and environmental conditions do not allow for home care. At our facilities, young patients can rely on the help of a team specializing in pediatric palliative care and a warm and welcoming environment to allow them to spend their time in the hospital surrounded by their families.

Figure 1.2 Introduction to the hospice care plan of Cincinnati Children’s Hospital (https://youtu.be/FzjnammJYFQ)

2.4 Case study of children's palliative care services

2.4.1 Analysis of Typical Case Studies of Palliative Care Services for Children Abroad

The well-established system and supervision mechanism of palliative care services for children abroad, as well as the high attention and active support from the government and society to palliative care for children, provide rich experience for reference for the development of palliative care for children in my country.

1) Case 1: Rainbow Children’s Hospice in the UK
Rainbow Children’s Hospice is a UK institution that provides comprehensive palliative care for children and adolescents aged 0-25 years with serious or incurable diseases. Services include respite care, end-of-life companionship, family psychological support, grief counseling, etc., emphasizing "family atmosphere" and "personalized care". As a charity, it works closely with the NHS to provide patients and their families with integrated psychological counseling, emotional support and life adaptation plans [104]. For example, the NHS has designed a special grief counseling course to help family members gradually accept reality and rebuild their lives, which is an important part of the UK's children's end-of-life care system.

英国｜Rainbow Children’s Hospice

彩虹儿童安宁疗护中心

简介

Rainbow Children’s Hospice 是英国一家专门为0-25岁患有重症或不可治愈疾病的儿童与青少年提供全方位姑息照护的机构。服务包括喘息照护、生命末期陪伴、家庭心理支持、哀伤辅导等，强调“家庭式氛围”与“个性化关怀”。作为慈善机构，它与NHS合作密切，是英国儿童临终照护体系的重要组成部分。

背景

所在国家	位置	持续时间
英国	**莱斯特郡拉夫堡**	**1994年至今**

服务对象

患有限制生命或危及生命的疾病的儿童和青少年（0-25岁）及其家人

服务重点方向 Key Focus Areas

- 医学舒缓照护（疼痛管理、症状缓解）
- 心理与情绪支持（儿童与家属）
- 临终陪伴与美好告别（定制空间与仪式）
- 家属哀伤与丧亲支持
- 患儿愿望实现（如愿望清单计划）
- 兄弟姐妹支持
- 生命教育 / 死亡沟通
- 灵性照护（宗教、信仰、临终慰藉）

可用资源 Resources

- 慈善资金（主要来源）
- 医护与心理多学科团队
- 志愿者支持体系
- 公共传播与政策倡导渠道
- 医保或公共财政直接支付机制
- 数字技术工具（远程随访/平台）

服务提供模式 Service Model

- 独立儿童安宁疗护中心
- 医院/医疗系统合作（与NHS协作）
- 家庭式照护空间
- 居家探访与远程支持
- 临时喘息照护（仅短期寄住）
- 流动式服务（社区/上门团队）

家庭支持 Family & Cultural Care

- 家属共同居住与陪伴空间
- 多元文化与宗教包容性强
- 家属决策参与机制
- 丧亲期后续支持（超过6个月）
- 死亡文化/禁忌敏感沟通机制

服成效与影响 Key Outcomes

- 临终舒适度与尊严提升
- 家属心理恢复支持
- 社会认知度高、项目影响力强
- 服务模式复制与推广
- 制度层面政策倡导与变革推动

Figure 2.1 Case analysis of palliative care services at Rainbow Children’s Hospice in the UK (drawn by the author)

Rainbow Children’s Hospice is an independent palliative care center in Leicestershire, UK. Since 1994, it has provided services to children aged 0-25 years with serious or life-limited diseases and their families. As a charity, the center works closely with the UK's NHS, using a "family-style care space" to create a warm and respectful end-of-life environment. Services include symptom management, end-of-life companionship, emotional support for family members, grief counseling, etc., supplemented by temporary respite care, to provide families with a variety of support programs. Rainbow focuses on family participation and personalized design, helping families face the separation process more calmly by creating an intimate space and respecting cultural differences. The operation of the organization mainly relies on social donations and volunteer participation, and it has a strong influence in the UK's children's palliative care system. Its service focuses on the concept of "family as a care unit" and is a typical representative of the regional high-quality care model.

2) **Case 2: The Star Shine Program of Cincinnati Children's Hospital, USA**

The Star Shine Program, an emotional support program launched by Cincinnati Children's Hospital, USA, mainly provides three types of services: transitional palliative care, perinatal hospice care and bereavement care. Through psychological counseling courses and emotional support objects, it helps families of sick children better cope with emotional fluctuations.

美国 | Cincinnati Children Hospital

辛辛那提儿童医院 “星耀计划 “

简介

“星耀计划”是美国辛辛那提儿童医院创建的儿童姑息照护计划，专注于情感支持、临终陪伴与家庭系统性照护，服务贯穿患儿疾病全过程。通过设置心理课程、记忆盒、情感陪伴物等，帮助家庭正视死亡、逐步接受悲伤，被视为美国儿童姑息照护典范项目之一。

背景

所在国家	位置	持续时间
美国	**俄亥俄州辛辛那提**	**2000年至今**

服务对象

围产期至青少年阶段的重症、生命受限患儿及其家庭，部分为新生儿期诊断即介入

服务重点方向 Key Focus Areas

- 医学舒缓照护（疼痛管理、症状缓解）
- 心理与情绪支持（儿童与家属）
- 临终陪伴与美好告别（定制空间与仪式）
- 家属哀伤与丧亲支持
- 患儿愿望实现（如愿望清单计划）
- 兄弟姐妹支持
- 生命教育 / 死亡沟通
- 灵性照护（宗教、信仰、临终慰藉）

可用资源 Resources

- 慈善资金（主要来源）
- 医护与心理多学科团队
- 志愿者支持体系
- 公共传播与政策倡导渠道
- 医保或公共财政直接支付机制
- 数字技术工具（远程随访/平台）

服务提供模式 Service Model

- 独立儿童安宁疗护中心
- 医院/医疗系统合作（与NHS协作）
- 家庭式照护空间
- 居家探访与远程支持
- 临时喘息照护（仅短期寄住）
- 流动式服务（社区/上门团队）

家庭支持 Family & Cultural Care

- 家属共同居住与陪伴空间
- 多元文化与宗教包容性强
- 家属决策参与机制
- 丧亲期后续支持（超过6个月）
- 死亡文化/禁忌敏感沟通机制

服成效与影响 Key Outcomes

- 临终舒适度与尊严提升
- 家属心理恢复支持
- 社会认知度高、项目影响力强
- 服务模式复制与推广
- 制度层面政策倡导与变革推动

Figure 2.2 Case analysis of hospice care services at Cincinnati Children's Hospital (drawn by the author)

The Star Shine Program is a comprehensive children's palliative care program initiated by Cincinnati Children's Hospital, USA. The service covers children with severe or life-limiting conditions from the perinatal period to adolescence and their families. The program emphasizes full-course intervention and emotional support, with special attention to the psychological coping process of children and families. The service content covers pain and symptom management, individualized psychological counseling, emotional support objects (such as memory boxes), sibling companionship, wish fulfillment, and family support after bereavement. The project relies on the multidisciplinary collaborative team within the hospital (doctors, psychologists, social workers, etc.), and also extends some services through remote support and home follow-up. The "Star Project" is jointly supported by medical insurance and charitable funds. It has a relatively complete family participation mechanism and cultural adaptation strategy. It is a representative practice in the field of child palliative care in the United States. Its highly integrated emotional care and medical care system provides a demonstration value for exploring "whole-person care" worldwide.

3) Case 3: Children's hospice service at Yodogawa Christian Hospital in Japan
The Children's Hospice Hospital in Japan was established in 2012 by Yodogawa Christian Hospital. Through family-customized wards, psychological counseling and end-of-life companionship, palliative care is provided for terminally ill children, allowing them to leave as decently as possible.

日本 | 淀川基督教医院 儿童安宁疗护病房

简介

淀川基督教医院在2012年成立日本首个儿童临终关怀病房，以人文宗教背景为核心，结合医学照护与情感陪伴，提供“定制病房”、家庭参与和灵性照护。其关注患儿尊严、家庭情绪恢复，在日本乃至东亚地区具有先行性与文化引领作用。

背景

所在国家	位置	持续时间
日本	**大阪市 淀川区**	**2012年至今**

服务对象
患有晚期癌症、神经系统疾病或遗传病等不可治愈疾病的儿童及其家庭，临终期为主

服务重点方向 Key Focus Areas
- 医学舒缓照护（疼痛管理、症状缓解）
- 心理与情绪支持（儿童与家属）
- 临终陪伴与美好告别（定制空间与仪式）
- 家属哀伤与丧亲支持
- 患儿愿望实现（如愿望清单计划）
- 兄弟姐妹支持
- 生命教育 / 死亡沟通
- 灵性照护（宗教、信仰、临终慰藉）

可用资源 Resources
- 慈善资金
- 医护与心理多学科团队（包含牧师）
- 志愿者支持体系
- 公共传播与政策倡导渠道
- 医保或公共财政直接支付机制
- 数字技术工具（远程随访/平台）
- 医院资金

服务提供模式 Service Model
- 独立儿童安宁疗护中心
- 医院/医疗系统合作
- 家庭式照护空间（定制病房）
- 居家探访与远程支持
- 临时喘息照护（仅短期寄住）
- 流动式服务（社区/上门团队）

家庭支持 Family & Cultural Care
- 家属共同居住与陪伴空间
- 多元文化与宗教包容性强（尊重宗教文化）
- 家属决策参与机制
- 丧亲期后续支持（超过6个月）
- 死亡文化/禁忌敏感沟通机制

服成效与影响 Key Outcomes
- 临终舒适度与尊严提升
- 家属心理恢复支持
- 社会认知度高、项目影响力强
- 服务模式复制与推广
- 制度层面政策倡导与变革推动

Figure 2.3 Case analysis of children's palliative care services at Yodogawa Christian Hospital in Japan (drawn by the author)

In 2012, Yodogawa Christian Hospital established Japan's first children's palliative care ward in Osaka, integrating Western palliative medicine concepts with the understanding of "dignified death" in Japanese local culture. The ward features "family-customized space", allowing family members to live with the children and strengthen companionship and emotional support. This service is mainly aimed at children with incurable diseases such as advanced cancer and neurological diseases, and provides medical relief, psychological counseling, spiritual care and family emotional support at the end of life. The service is jointly promoted by a cross-professional team within the hospital (medical care, psychology, and pastoral care). The institution is backed by the Christian humanistic tradition, emphasizes the importance of spiritual care and last rites, and has a high degree of cultural sensitivity and depth of family participation. Although resources are relatively concentrated within the hospital, it has a pioneering significance in the field of palliative care in Japan and has promoted a change in the public's perception of children's hospice care.

2.4.2 Case analysis of domestic children's palliative care service practice

1) Case 1: Shanghai Children's Medical Center

Shanghai Children's Medical Center is one of the first tertiary hospitals in China to explore children's palliative care. It has a special palliative care ward, which mainly serves children with terminal tumors or blood diseases. It is the only pediatric hospital in China with a hospice ward. The center focuses on palliative care for patients in the hematology and oncology departments, providing services such as cancer pain control, psychological counseling and quality of life improvement. It is centered on the hospital-led model and emphasizes medical palliative care and partial psychological support. It is a typical case of domestic hospital-based children's palliative care.

中国｜上海儿童医学中心安宁疗护病房

简介

上海儿童医学中心是国内为数不多设有儿童安宁病房的三甲儿科医院。其服务模式以医院主导为核心，聚焦终末期患儿（如肿瘤、白血病），通过多学科参与实现疼痛控制、心理干预与尊严死亡，是国内医院型服务的重要探索样本。

背景

所在国家	位置	持续时间
中国	**上海**	**2010年代初至今**

服务对象

终末期肿瘤和血液病患儿（以住院患儿为主），以生命最后一段时间为主要服务窗口

服务重点方向 Key Focus Areas

- 医学舒缓照护（疼痛管理、症状缓解）
- 心理与情绪支持（儿童与家属）
- 临终陪伴与美好告别（定制空间与仪式）
- 家属哀伤与丧亲支持
- 患儿愿望实现（如愿望清单计划）
- 兄弟姐妹支持
- 生命教育 / 死亡沟通
- 灵性照护（宗教、信仰、临终慰藉）

可用资源 Resources

- 慈善资金
- 医护与心理多学科团队（包含牧师）
- 志愿者支持体系
- 公共传播与政策倡导渠道
- 医保或公共财政直接支付机制
- 数字技术工具（远程随访/平台）
- 医院资金

服务提供模式 Service Model

- 独立儿童安宁疗护中心
- 医院/医疗系统合作
- 家庭式照护空间（定制病房）
- 居家探访与远程支持
- 临时喘息照护（仅短期寄住）
- 流动式服务（社区/上门团队）

家庭支持 Family & Cultural Care

- 家属共同居住与陪伴空间
- 多元文化与宗教包容性强（尊重宗教文化）
- 家属决策参与机制
- 丧亲期后续支持（超过6个月）
- 死亡文化/禁忌敏感沟通机制

服成效与影响 Key Outcomes

- 临终舒适度与尊严提升
- 家属心理恢复支持
- 社会认知度高、项目影响力强
- 服务模式复制与推广
- 制度层面政策倡导与变革推动

Figure 2.4 Case analysis of children's palliative care services in Shanghai Children's Medical Center (drawn by the author)

The service focuses on pain control, symptom relief and emotional counseling, and the service window is mainly concentrated in the last period of the child's life. Led by doctors and nurses within the hospital, multidisciplinary collaboration is still being gradually improved. Family participation has a preliminary mechanism in some wards, but cultural communication still faces certain challenges. At present, most project funds come from the hospital itself or public welfare cooperation, and lack institutional guarantees. Although the service has not yet formed a complete system, the center is representative in the development of domestic hospital-based palliative care and has played a demonstration and guiding role.

2) Case 2: Butterfly House and Hunan Children's Hospital: "Fudie Xiaojia" Children's Palliative Care Ward

Butterfly House was founded in 2010 and is China's first palliative care project specifically for terminally ill orphans and severely disabled children. In 2022, it co-founded "Fudie Xiaojia" with Hunan Children's Hospital to accept terminally ill children with family backgrounds, strengthen medical support, and build a new model of medical + public welfare cooperation. The project is characterized by warmth, respect, and family-style care, and has public welfare and local adaptability.

中国｜蝴蝶之家 & 湖南省儿童医院“福蝶小家”

简介

蝴蝶之家创办于2010年，是中国第一个专为临终孤儿和重残儿童设立的安宁疗护项目。2022年，与湖南省儿童医院联合创立“福蝶小家”，接纳有家庭背景的终末期患儿，强化医疗支持。项目以温暖、尊重、家庭式照护为特点，具备公益性与本土适配性。

背景

所在国家	位置	持续时间
中国	**湖南省长沙市**	**蝴蝶之家2010年，福蝶小家2022年-至今**

服务对象
生命预期不足6个月的孤残儿童及患有重病的贫困患儿；多为0-12岁儿童

服务重点方向 Key Focus Areas

- 医学舒缓照护（疼痛管理、症状缓解）
- 心理与情绪支持（儿童与家属）
- 临终陪伴与美好告别
- 家属哀伤与丧亲支持
- 患儿愿望实现（如愿望清单计划）
- 兄弟姐妹支持
- 生命教育 / 死亡沟通
- 灵性照护（宗教、信仰、临终慰藉）

可用资源 Resources

- 慈善资金
- 医护与心理多学科团队
- 志愿者支持体系
- 公共传播与政策倡导渠道
- 医保或公共财政直接支付机制
- 数字技术工具（远程随访/平台）
- 医院资金

服务提供模式 Service Model

- 独立儿童安宁疗护中心
- 医院/医疗系统合作（医疗+公益机构合作）
- 家庭式照护空间（定制病房）
- 居家探访与远程支持
- 临时喘息照护（仅短期寄住）
- 流动式服务（社区/上门团队）

家庭支持 Family & Cultural Care

- 家属共同居住与陪伴空间
- 多元文化与宗教包容性强（尊重宗教文化）
- 家属决策参与机制
- 丧亲期后续支持（超过6个月）
- 死亡文化/禁忌敏感沟通机制

服成效与影响 Key Outcomes

- 临终舒适度与尊严提升
- 家属心理恢复支持
- 社会认知度高、项目影响力强
- 服务模式复制与推广
- 制度层面政策倡导与变革推动

Figure 2.5 Case analysis of "Fudie Xiaojia" Children's Palliative Care Ward (drawn by the author)

The service emphasizes family-style, non-medicalized companionship care, covering medical care, psychological support, spiritual comfort and "beautiful farewell" arrangements, and pays special attention to creating a warm environment and an atmosphere of respect for life. Service providers include nurses, social workers, and volunteers, while the hospital provides technical and medical support. The institution's funding relies on social donations and public welfare projects, and its operating mechanism is relatively stable but resources are tight. It has formed a unique exploration in local cultural adaptation and child care methods, and has the potential for replication and promotion.

2.5 Comparative analysis in China and abroad

2.5.1 Differences in cultural concepts

In the Asian cultural context, "death" is a highly taboo topic. Our society generally lacks life and death education for children, and takes a negative or evasive attitude towards the issue of children's death. Many parents and family members often avoid discussing topics about illness and death with children. Even when the child is about to die, they tend to avoid directly facing this topic by concealing or beautifying it [72]. This implicit way of expressing emotions often causes children to have a sense of mystery or even fear about death, and parents are also prone to strong emotional guilt after losing their children [57]. In addition, Asian parents' emotional fluctuations when facing their children's death are particularly significant. The tug-of-war between insisting on treatment and accepting reality often leads to a great psychological burden. This emotional complexity is relatively rare in Western culture [73]. In contrast, Western culture places more emphasis on facing death, incorporating death education into school and community courses, and helping children and families accept the reality of disease development earlier through open discussions [74]. For example, the American Association for the Advancement of the Patient's Association (AAP) guidelines require doctors to discuss end-of-life plans with children's families at the early stage of diagnosis to improve the consensus rate on treatment goals [77]. Studies have shown that concealment, avoidance, and beautification often increase fear and disappointment, and positive discussion and guidance are effective ways to reduce fear [76].

2.5.2 Differences in service models

In recent years, with the advancement of my country's palliative care pilot work, palliative care social work has also begun to explore localization. At present, relevant domestic practices are mainly based on the case intervention model, and the service scenarios are mainly nursing homes and specialized hospitals, while there is relatively little exploration of hospice care in large general hospitals.

Global hospice care can be divided into the initial stage, the organizational stage, the service stage and the integration stage. The development level of hospice care in China is currently in its infancy [25]. By reviewing relevant literature on children's hospice care at home and abroad in the past ten years, we sorted out the children's hospice care service models proposed by different scholars from different disciplines such as nursing, medicine, psychology, social work, etc. [26], see Table 1.

Table 1 Children's hospice care service model

Children's hospice care model	advantage	shortcoming	references
children's hospice	Palliative care, symptom management and end-of-life care provided by professionals 24 hours a day in an institutional setting	There is only one welfare institution in my country, and the professionalism of the team and the operation model are not up to international standards.	[9]
Family-centered hospice care for children	Mainly in hospitals, multiple teams work together to provide medical services, education and training, support services, and physical and psychological care for family members and children.	The medical space is limited and medical resources are occupied; the parents refuse to inform the patient of the fact that the child is dying.	[10]
Community-centered hospice care for children	Based on the cooperation between a community medical center, a hospital and a family, it is carried out at home, with social workers conducting full case management and community medical workers regularly visiting the home for follow-up visits.	Insufficient professional capacity and financial allocation for community medical care, as well as a lack of professional social workers	[11]
Continuing Pediatric Hospice Care	From the inpatient department to the clinic, to the home, and to the hospice center, we provide holistic care and continuous care, and the families of children are highly satisfied.	The society needs to have a higher understanding of children's hospice care, supporting medical resources and training for practitioners. There is still a gap.	[12]
PDS hospice care model	Focusing on reducing pain in children, integrating hospitals, communities and families with hospice care	Failure to fully consider social factors and my country's basic national conditions, resulting in poor operability	[13]
Palliative care for critically ill children	It is in line with the characteristics of critically ill and dying children and my country's national conditions, and has high scientificity, reliability and practicality.	This model has not yet established a complete assessment process and out-of-hospital referral channels for end-of-life children.	[14]
Neonatal Hospice Care	The decision is made jointly by the medical team and the patient's family, including whether to enter the hospice stage, who will provide the services, the content of care, the place of death and funeral arrangements, etc.	Due to the taboo on the death of children in traditional cultural customs, most parents will leave the end-of-life and follow-up arrangements to the hospital for disposal.	[15]
Remote hospice care	Use electronic devices to provide palliative care remotely, breaking through geographical space limitations	In the exploratory stage, there is no systematic operation process, and network construction and professional hospice training need to be promoted.	[16]

Note: PDS hospice care model: also known as "one, three, nine PDS model", specifically expressed as "one center, three directions, nine combinations" (one point, three subject, nine direction)

Table 2.2 Children’s hospice care service model (u Lili, 2021)

2.4.3 Differences in policy support

The well-established systems and supervision mechanisms for children's hospice care services abroad, as well as the high level of attention and active support from the government and society for children's hospice care, have provided rich experience for the development of children's hospice care in my country. Some countries have incorporated palliative care into the national medical and health care system. At the same time, in order to ensure the quality of palliative care services, many countries stipulate that personnel engaged in palliative care must receive professional training and obtain a palliative care qualification certificate before they can work, and at the same time attached great importance to and widely publicized children’s hospice care.

Children's palliative care has already started in China, but compared with foreign countries, there is a large gap in practical experience and theoretical research. Comparison is shown in Figure 3. At present, most of the palliative care services in our country are for cancer patients, mostly the elderly. Few people pay attention to the mental and physical support of children and their family members when they face the death of a child. China's children's hospice care needs to be further developed and improved, and China's children's hospice care still has a long way to go.

3. Research Methodology and Content

3.1 Research Process and Phases

Use service design methods to solve problems in specific scenarios of children's hospice care services. At the same time, combined with the practical experience of palliative care, we respond to this problem and provide solutions through product and service system design innovation. This research can be carried out in four stages: the research background and user research stage, the definition of research problem stage, after analysis stage, the product service system design stage, and the iterative testing and practice stage of the design plan.

3.1.1 Research background

At this stage, it is necessary to conduct background research on in-depth knowledge of children's hospice services to understand the issues and needs of specific scenarios. All experiences are the result of the interaction between people and their environment. Experience is not just a simple behavioral interaction based on environmental perception. The behavioral process and behavioral results must also be perceived and felt to form an emotional, meaningful and memorable experience [31]. Cognitive abilities, behavioral processes, and environmental factors may all affect the quality of experience [32]. At this stage, we will investigate the current situation, problems and development directions of children's hospice care, collect information through interviews, observations, review of relevant literature, case reports, interviews with stakeholders, etc. to understand their views and needs for children's hospice care. Provide a research basis for subsequent design.

1) Understand the main users (groups): sick children and their families

Observe the behaviors of sick children within the controllable and allowable range, record and observe what behaviors and emotions they have in their daily lives, and what needs they reflect. The main purpose of the research is to gain insight through facts into "how they understand death (carry out corresponding death education)", "how to make them better face this matter (how to help family communication)", "how do they identify and propose themselves needs (so that there are no regrets)”

2) Meet other key users: families with children

As minors without decision-making ability, children and family relatives play a decisive role in this process. By constructing a model of the demand factors of family stakeholders in different situations and the weighting factors of the final decision, we understand what considerations affect their decision-making on whether to stay in a children's hospice (decision-making between active treatment and delayed treatment) ", "How to choose the institution of your choice (what factors are more important, maybe external/internal to the family)", "What situations will make them feel morally guilty or regretful (help them eliminate psychological barriers and barriers)" decisions on key issues.

3) Understanding Key Stakeholders: Children’s Hospice

From the perspective of the organization, understand what support they can provide to different target users (including themselves). " The current operating model dilemma of the institution (how to operate better from the organizational level) ", " What kind of personnel composition is needed within a complete children's hospice care institution (which types of stakeholders can be satisfied to provide better services)" services) ", " How children's hospice care institutions cooperate with other external organizations such as medical institutions and funeral institutions (looking for new possible models) "

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3.1.2 Redefine the Systemic Problem

1） Problem Mapping and Core Stakeholder Needs

Based on preliminary research, field visits, and interviews, the project identifies multiple unmet needs within the pediatric palliative care system embedded in welfare institutions. These include the emotional isolation of children lacking family presence, information fragmentation across staff and volunteers, and difficulties in sustaining volunteer engagement. The initial mapping revealed three major systemic tensions:
- Emotional wellbeing without familial support
- Information and communication gaps within multidisciplinary teams
- Volunteer retention and systemic continuity

2） Research Focus and Questions Refinement

In response to the mapped challenges, the research refines its focus toward the strategic and systemic development of pediatric palliative care in institutional settings. Refined Research Question: How can short- and long-term systemic strategies be developed to enhance emotional well-being and operational continuity in welfare-based pediatric palliative care centers?

3） System Mapping and Strategic Evaluation Framework

To guide and evaluate systemic design strategies, this research develops a dual-layered evaluation framework composed of Systemic Enabler Dimensions and Strategic Comparative Dimensions. The former reflects essential principles of systemic design—such as autopoiesis, information loops, and integration—serving as structural criteria for system viability. The latter considers context-specific comparative indicators such as psychosocial value, innovation feasibility, and stakeholder coordination potential.

The indicator matrix is constructed based on insights from system mapping and stakeholder flows, and it informs both the mid-term selection of priority opportunities and the final strategic roadmap formulation. This framework replaces conventional user-centered or family-centered evaluation models with a multi-actor systemic logic tailored to institutionalized care environments. Emotional support, therefore, is not measured only through direct interpersonal care, but through the ecosystem's ability to sustain substitute relationships (e.g., peer care, volunteer scaffolding) and generate long-term systemic change.

3.2 Research methods

This study uses a combination of multiple methods to analyze and explore the information communication and emotional support needs in children's palliative care services, combining literature research, user research and design research to provide theoretical support and practical guidance for subsequent framework construction and design. The specific research methods are as follows:

3.2.1 Desktop Research

Analyze and discuss the development origin, conceptual connotation, and existing design intervention methods of children's hospice care services. Pay attention to the differences in experience between China and foreign countries in children's palliative care, and compare the current research and practice status. First of all, the service design perspective is focused on the families of children, and the existing service system is analyzed around the scenarios related to hospice care services. The research content is as follows: quantitative analysis is conducted based on the number of literature and regions, and the main research on children's hospice care worldwide is concluded. Countries and regions, main research content, research trends and research hotspots at each stage, and summarize the historical development of this field and select representative turning points and breakthrough points as representatives for analysis, to gain a preliminary understanding of China's children's hospice care.

i. Literature research

Literature research provides theoretical support for the demand analysis and service framework construction of this study, and also provides an academic basis for the adaptability of the design scheme. Through the systematic combing of relevant domestic and foreign literature, the core theories, development status and trends in the field of children's palliative care are studied, including the key elements of medical information communication, emotional support and psychological counseling. Focus on analyzing the theoretical basis and current practice of palliative care services for children at home and abroad, theories related to support, grief counseling, sustainable development of the institute and the characteristics of emotional expressions of death under the Chinese cultural background.

ii. Case study

By analyzing excellent practice cases in palliative care services at home and abroad, I study the specific models of medical teams in palliative care services under different cultural backgrounds. The case study content includes: investigating the mature palliative care service system for children in Europe and the United States; analyzing the existing palliative care practice cases for children in China and extracting successful service models and processes from the cases to provide reference for subsequent research.

3.2.2 **Field research**

Field research is the main method of this study. Through various channels, we can deeply understand the current situation and needs of children's palliative care services. The study will adopt the following five specific methods: field investigation, participatory observation, interview and questionnaire survey. The implementation process and purpose of each method will be introduced in detail below.

1. On-site inspection

Go to a hospice institution to conduct an on-site inspection of the service environment, model and quality, observe, record and analyze its operation methods, and understand the current main service content. This aims to directly observe and record the service environment, model, and quality of hospice institutions, so as to fully understand their operation mode and service content, and provide scenario support and basis for subsequent design through observation and interaction. Go to relevant institutions to observe the actual implementation of daily work, including the configuration of facilities and equipment, the working status of staff, and the daily activities of patients. At the same time, by analyzing the recorded data, we can further explore the advantages and disadvantages of these institutions in terms of service model and quality, and provide important first-hand information for research.

2. Participant observation

Participate in daily work with staff and volunteers in hospice institutions to gain an in-depth understanding of their work experience and management methods. Participatory observation: Gain a deeper understanding of the internal operations and culture of hospice institutions by personally integrating into their daily work. Participate in daily tasks with staff and volunteers, including patient care, family communication, and management activities within the institution. This method allows for a direct sense of the challenges and needs of staff in providing services, while also bringing more practical insights to the research and enhancing the authenticity and reliability of the data.

3. Case interviews

Conduct case interviews with hospice children or their families to understand their needs, pain points and experiences through gentler language and topics. Interview data will be used to establish a core needs model for service recipients and provide a basis for the service framework and touchpoint design. Through in-depth interviews with core stakeholders related to pediatric palliative care (including medical service providers, families of children with the disease, and social support networks), their needs, pain points, and expectations in the actual service process will be explored. User interviews will include the challenges faced by the medical team in information communication and emotional support, the emotional support needs of family members at different stages of the disease, and the role and function of social support networks. Expert interviews aim to obtain more comprehensive professional insights and practical experience through exchanges with experts in different roles in the field of pediatric palliative care.

4. Expert interviews

Interviews with experts in the field of children’s hospice care, including: doctors, nurses in medical institutions, social work department organizations in public hospitals, social workers, staff of hospice care institutions, volunteers from public welfare organizations, volunteers Organization leaders, philanthropic foundation leaders, and more, get their thoughts and recommendations on hospice care.

5. Questionnaire survey

Distribute questionnaires among volunteers or patient family groups (need to pay attention to the use of words) to understand the public group ’s understanding and attitude towards children’s hospice care. The results of the questionnaire survey will provide data support for the refinement of the toolkit content during the design process. The questionnaire survey will collect the public's cognition and attitude towards children's palliative care and understand the preferences of families of sick children for emotional support tools and services by distributing questionnaires among volunteers or patient family communities and quantitatively analyzing the questionnaire data. The questionnaire design will focus on the use of words to ensure the clarity and comprehensibility of the questions, thereby improving the response rate and data quality. The questionnaire design will focus on the following aspects: the priority of family needs for information, communication and emotional support at different stages of the disease, the specific preferences of family members for the content of the toolkit, and the acceptance and demand characteristics of emotional counseling methods for the grief stage.

3.2.3 Integration of research methods in medical scenarios

Interdisciplinary research methods present a unique value in the innovation of children's palliative care services. By comprehensively applying the research results of disciplines such as design, psychology, sociology and medicine, we explore the multidisciplinary cooperation model of emotional support services. Design Thinking systematically reconstructs the service touchpoints in medical scenarios through the five-stage model of "empathy-definition-concept-prototype-testing" [22]; uses relevant emotional theories in psychology to build an emotional support framework; uses sociological research methods to identify the roles and needs of sick children's families in the social support network and design a more adaptable service system. This user-centered methodology breaks through the limitations of "pathocentrism" in traditional medical research and puts sick children and their families at the core of service design.

The general theories and methodologies generated by general design research are not directly applicable to design practice. They provide frameworks and models for further research to develop knowledge and methodologies in specific fields applicable to actual design projects [23]. At the methodological integration level, this study constructs a research framework driven by three dimensions: psychological emotional theory supports Norman's three-level theory of emotional design (visceral level-behavioral level-reflective level), and establishes a hierarchical strategy for emotional support for the family of sick children[24], such as alleviating anxiety at the visceral level through sensory perception and strengthening the construction of meaning at the reflective level through interactive rituals. In sociological analysis, the "boundary object" theory [25] is used to design collaborative tools that connect medical staff, social workers, and volunteers to promote knowledge translation and consensus formation among heterogeneous actor networks; based on Latour's "translational sociology" framework [26], the interest network of subjects such as the family of sick children, medical staff, social workers, and volunteers is mapped to identify service breakpoints. In medical evidence-based practice, the expert consensus method of the WHO palliative care guidelines is used to convert clinical evidence into operational design principles. The application of specific methodologies needs to match the characteristics of the research stage:

In the demand insight stage, observation methods can be used to describe the behavior of the target research object, including: action observation method, hidden observation method, and flow observation method. The concealed observation method was used to record the non-verbal interaction patterns of families in the ward. The Cambridge University Medical Design Laboratory verified its effectiveness and can capture 83% of implicit needs [28]. Through the interview method, we can understand the user's point of view and gain insight into their core needs, including online and telephone interviews, as well as in-depth interviews, to help understand users and deconstruct decision-making dilemmas. Or user portrait method; in the solution co-creation stage, if group-based collective innovation is required, it can be achieved through organizing workshops and focus groups composed of stakeholders; in order to understand the user's behavior process and better empathize with the user, user journey maps, user portraits and other methods can be used. Participatory Design workshops are used to activate stakeholder collaborative innovation through role-playing and scenario prototyping. The Care4Carers toolkit developed by Eindhoven University of Technology in the Netherlands has confirmed that this method can improve user acceptance of service solutions [29]. Through the above-mentioned design-related user research and co-creation methods, we can help to gain a deep understanding of the current situation of the group and the research target scenario, and then help analyze the core issues.

3.2.4 Research methods in the field of design

The general theories and methodologies produced by general design research are not directly applicable to design practice; they provide frameworks and models for further research to develop domain-specific knowledge and methodologies applicable to actual design projects [33]. In the research on children's hospice care services, based on the basic research methods of medicine, nursing, psychology, social work and other disciplines, general research methods of design are added to adapt to actual projects.

Select appropriate design research methods based on the research goals and needs at different stages. To describe the behavior of the target research object, observation methods can be used, including: action observation method, covert observation method, moving line observation method, etc. [34]; communicating and conveying information through the interview method can help understand the user's perspective and help gain insights into their core needs. Including: online interviews, telephone interviews, etc. Or user profiling method; if you need to carry out group-based collective innovation, you can organize workshops and focus group cooperation methods composed of stakeholders; to understand the user's behavior process and better empathize with users, you can use Methods such as user journey maps and user portraits. Through the above design-related user research and co-creation methods, we can help to gain an in-depth understanding of the current situation of groups and research target scenarios, and then help analyze core issues.

3.3 Systemic and Service Design Methodologies

This research combines systemic design with service design methods to respond to the multi-layered challenges of pediatric palliative care within welfare institutions.

Systemic design provides the foundational structure to explore how institutions, policies, material flows, and stakeholder dynamics interrelate and evolve. Drawing upon the works of scholars such as Norberto Patrignani and Daniela Sangiorgi, the methods are inspired by the principles of autopoiesis, relational feedback, and circularity. Systemic design enables the strategic integration of interventions at macro, meso, and micro levels.

Service design, meanwhile, contributes tools and perspectives for mapping user journeys, stakeholder interactions, emotional experiences, and service touchpoints. Techniques such as persona profiling, experience mapping, co-creation workshops, and ecosystem visualizations are employed to ensure that design outcomes are grounded in real-world user needs and operational realities. The methodology integrates both service design's human-centered insights and systemic thinking’s focus on feedback loops, resource flows, and long-term adaptability.

Key principles include:

- **Autopoiesis**: the system's ability to self-regenerate through internal mechanisms
- **Integration over optimization**: favoring structural coherence over isolated improvement
- **Resource circularity**: enhancing value through material and immaterial flows
- **Participatory complexity management**: engaging multiple actors to co-define solutions in complex conditions

These principles guide each stage of the research—from mapping user journeys and institutional relations, to generating opportunities, benchmarking cases, and assembling a strategic roadmap. The approach ensures that interventions are not merely functional fixes, but transformative actions aligned with the evolution of a sustainable pediatric care ecosystem. The integration of the two ensures that both systemic transformations and user-centered improvements are addressed simultaneously. It allows the research to construct a strategic roadmap that not only optimizes care experiences but also builds long-term institutional resilience and sustainability.

4. Territorial and Stakeholder Analysis

4.1 Butterfly Home Introduction: Site structure and operation mechanism

Butterfly Home is the first pediatric palliative care charity organization in China dedicated to serving critically ill children. Located within the Changsha Welfare Institute, it provides comprehensive end-of-life services that integrate medical, emotional, and social support. Operating under a hybrid model, the center combines institutional administration, volunteer engagement, and donor-supported mechanisms to ensure sustainability and inclusivity.

Its spatial layout is organized into five key zones: child care areas, caregiver support areas, volunteer spaces, outdoor therapeutic gardens, and psychological counseling rooms. This setup enables a balance between medical treatment and psychosocial interventions, creating a compassionate and dignified care environment.

Driven by the core mission—*"to ensure that every child and family is loved and respected, whether in life or parting"*—Butterfly Home is committed to leading, collaborating, advocating, and educating to promote the development of pediatric palliative care across China. It upholds the belief that every child's life, regardless of its length, is inherently valuable and deserves dignity, comfort, and protection at life's end.

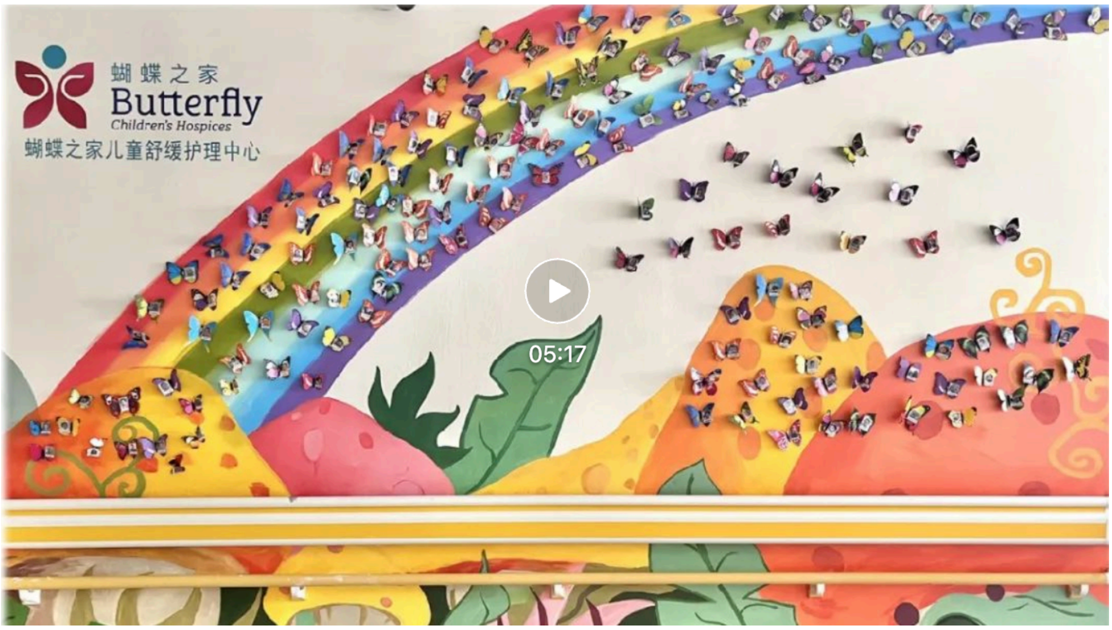


Figure 4.1 Butterfly home (from its website)

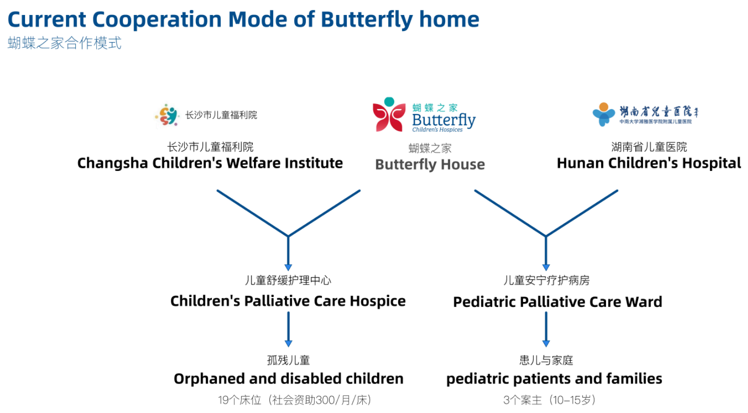


Figure 4.2 Butterfly home current cooperation mode (drawn by the author)

Annual operations include routine care, therapeutic rituals, psychological counseling, birthday parties, concerts, and regular nursing training programs, evidencing a holistic service model that bridges physical care and emotional relief.

① Preparation before work for staff, proper handover procedures, and precautions for cleaning children.
② Precautions for feeding and administering medication to children, as well as how to correctly administer nebulization to children.
③ Correct feeding process for children with indwelling gastric tubes and precautions for changing diapers.
④ Precautions for evening cleaning, preparation before shift handover, and formal handover procedures.

Figure 4.3 Activities in Butterfly House（Drawn by the author）

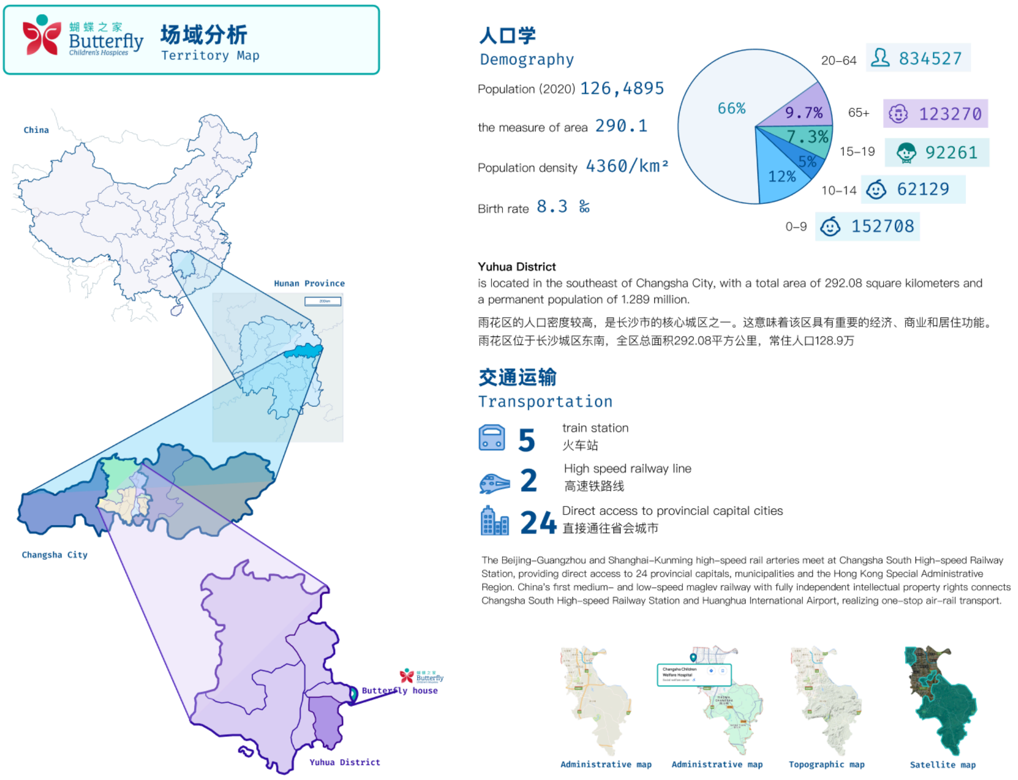
4.2 Territorial Context and Policy Environment

Butterfly Home is situated in **Yuhua District**, a southeastern district of Changsha with a permanent population of 1.27 million. It is supported by an advanced urban infrastructure, including 5 train stations, 2 high-speed railways, 24-city connections, dense medical and educational resources, and proximity to policy hubs.

1) Demographic Profile

Yuhua District is located in the southeast of Changsha City, with a total population of about 1.289 million, a population density of 4,360 people/km², and a birth rate of 8.3%. Among them, the number of children (0-14 years old) exceeds 210,000, accounting for nearly 17% of the total population, providing a clear service target basis for the development of children's palliative care. The age structure is mainly young and middle-aged, and the elderly population (65 years old and above) is 124,000, accounting for about 9.7%, indicating the future demand trend for palliative care across age groups.

This population structure not only means that children's palliative care services have a solid social foundation, but also echoes the service path proposed in this study, which should cover the multi-level docking model of "early intervention, long-term care" and "family-community-institution".



Yuhua District
is located in the southeast of Changsha City, with a total area of 292.08 square kilometers and a permanent population of 1.289 million.

雨花区的人口密度较高，是长沙市的核心城区之一。这意味着该区具有重要的经济、商业和居住功能。雨花区位于长沙城区东南，全区总面积292.08平方公里，常住人口128.9万

The Beijing–Guangzhou and Shanghai–Kunming high–speed rail arteries meet at Changsha South High–speed Railway Station, providing direct access to 24 provincial capitals, municipalities and the Hong Kong Special Administrative Region. China's first medium– and low–speed maglev railway with fully independent intellectual property rights connects Changsha South High–speed Railway Station and Huanghua International Airport, realizing one–stop air–rail transport.

Figure 4.4 Territory map of Butterfly home (drawn by the author)

However, in terms of policies, pediatric palliative care is still in a policy blind spot. There are only 4 relevant policies at the Changsha city level, which mainly focus on the elderly and comprehensive palliative care services. There is no special mechanism for children. In addition, although Hunan Province actively promotes the training of relevant talents, there is still a lack of specific local practice guidance. Studies have found that the incidence of childhood tumors in Changsha is high, especially leukemia, which provides an urgent need for promoting children's palliative care services.

2) Education and Human Resources

Yuhua District has concentrated educational resources: there are 16 colleges and universities in the district, accounting for 26.7% of the total number in Changsha; in terms of basic education, there are 90 primary schools and 261 kindergartens, providing rich scenarios for family and community cooperative care models (such as family support programs and community participation courses).

In the supporting medical education, three universities offer majors related to child health and social work, including Central South University, Hunan Normal University and Hunan Women's College. This provides a solid talent foundation for the construction of interdisciplinary service teams (doctors, nurses, social workers, psychologists, etc.) in the future, and is deeply related to the "training and internship linkage mechanism" proposed in this study.

The district has **16** universities, **4** regular high schools, **20** junior high schools, **90** regular primary schools and **261** kindergartens.

全区拥有16所高校，普通高中4所，初中学校20所，普通小学90所，儿园261所

Within the province, the total number of students in compulsory education is **7.89** million. Yuhua District accounts for a large proportion of educational resources in Changsha City, with primary and kindergarten schools accounting for **over 10%**. The district has a large population of school–age children. The 16 universities in Yuhua District account for approximately 26.7% of the 60 universities in Changsha, and hold a significant position in the city's higher education system.

全省范围内，义务教育阶段的学生总数为789万人，雨花区在长沙市的教育资源中占有较大的比例，小学和幼儿园占比超过10%，该区的学龄儿童人口较多。雨花区的16所高校占长沙市60所高校的约26.7%，在长沙市的高等教育体系中占据相当重要的地位。

3 colleges offering majors related to children healthcare and social work

全区拥有艺术表演团体18个，文化馆2个。拥有公共图书馆（区级）1个，
图书分馆（含街道、社区两级）13个

The district has 18 art performance groups and 2 cultural centers. It has 1 public library (district level) and 13 branch libraries (including street and community levels).

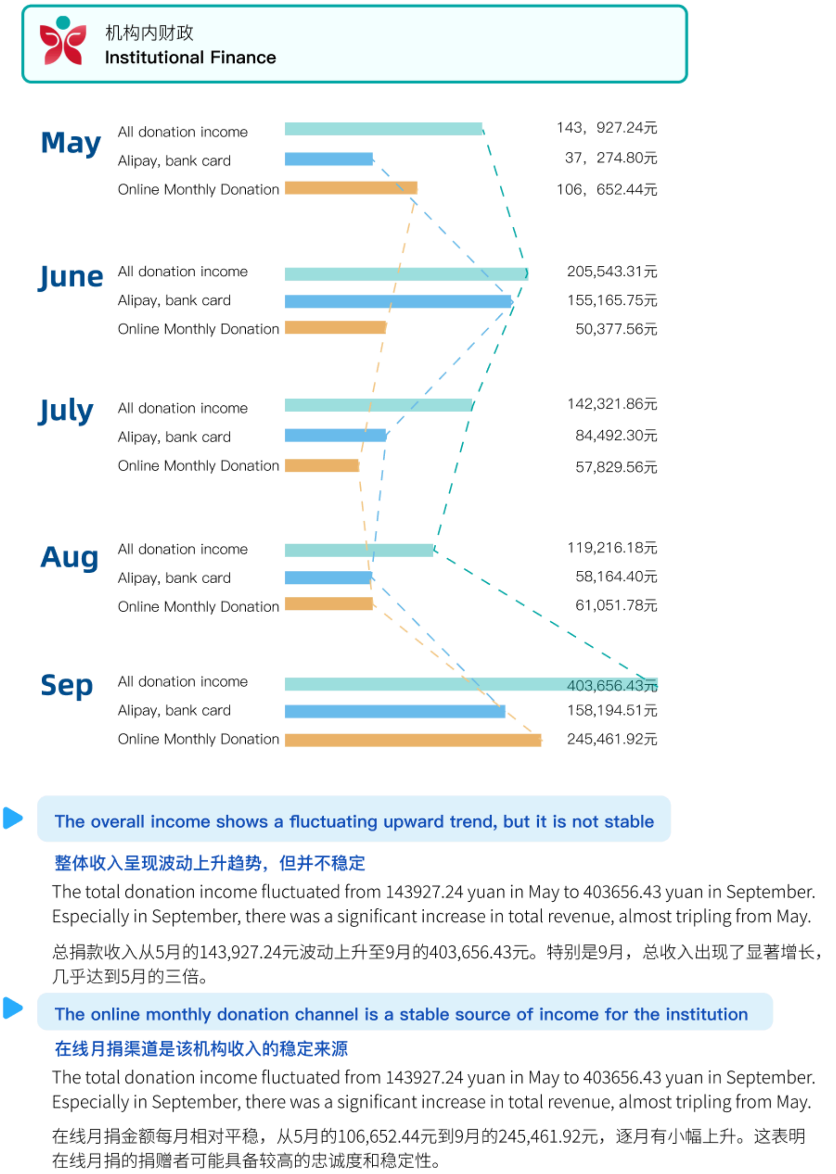
Figure 4.5 Educational aspects of the territory (drawn by the author)

Butterfly Home actively builds a cross-institutional collaboration network, including major pediatric hospitals in the province, teaching institutions such as Hunan Normal University and Central South University, and policy units such as the Civil Affairs Bureau of Changsha City. At the same time, it raises resources through online monthly donation mechanisms, social media promotion, and the sale of cultural and creative products.

3) Institutional Finance

Butterfly House's main financial income currently comes from corporate donations and online monthly donation channels. As can be seen from the figure, the total monthly donation amount increased from about 140,000 to 400,000 between May and September 2024, showing a fluctuating upward trend. In particular, online monthly donations have outstanding stability, accounting for more than 60% of the monthly donations.

Stable but limited sources of funds limit the continued expansion of services. Therefore, the "productized donation mechanism" and "community-driven participation" emphasized in service design are not only a strategic response to financial sustainability, but also reflect the urgent need for "diversified fundraising tools" in the current financial structure.



The overall income shows a fluctuating upward trend, but it is not stable

整体收入呈现波动上升趋势，但并不稳定

The total donation income fluctuated from 143927.24 yuan in May to 403656.43 yuan in September. Especially in September, there was a significant increase in total revenue, almost tripling from May.

总捐款收入从5月的143,927.24元波动上升至9月的403,656.43元。特别是9月，总收入出现了显著增长，几乎达到5月的三倍。

The online monthly donation channel is a stable source of income for the institution

在线月捐渠道是该机构收入的稳定来源

The total donation income fluctuated from 143927.24 yuan in May to 403656.43 yuan in September. Especially in September, there was a significant increase in total revenue, almost tripling from May.

在线月捐金额每月相对平稳，从5月的106,652.44元到9月的245,461.92元，逐月有小幅上升。这表明在线月捐的捐赠者可能具备较高的忠诚度和稳定性。

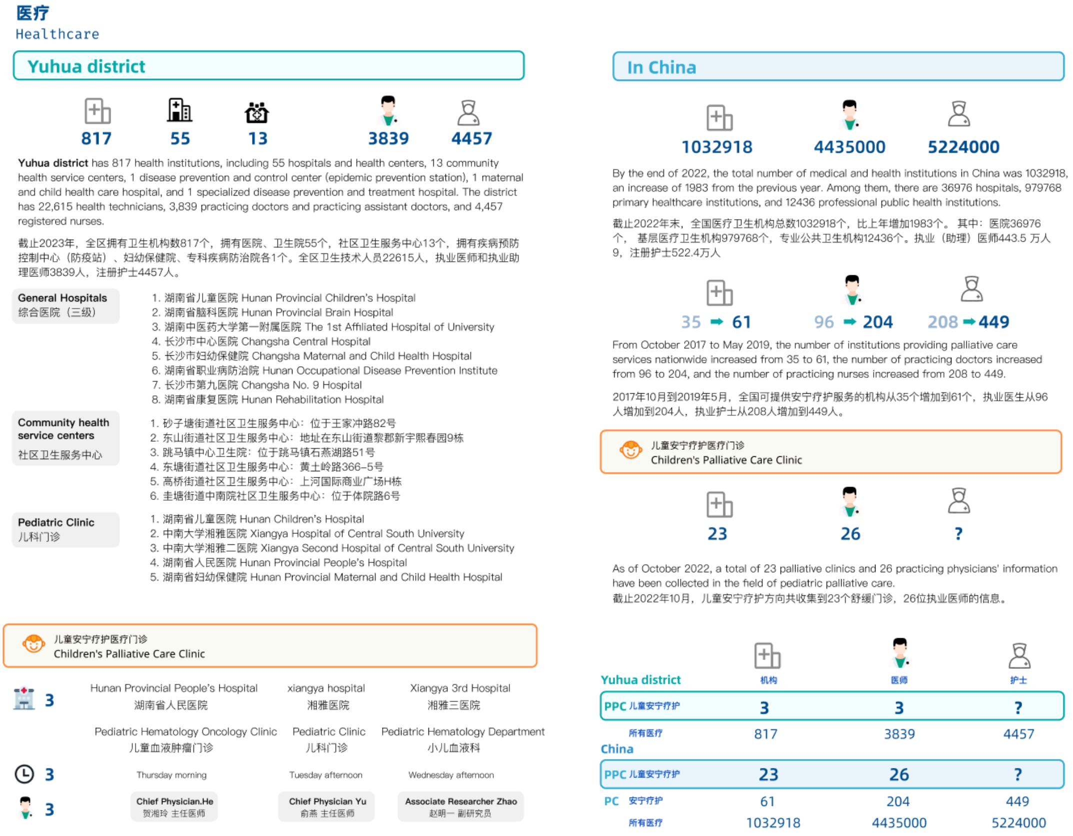
Figure 4.6 The trends of donation income (drawn by the author)

Recent data shows the center's donation income has grown steadily, with September revenue reaching ¥403,656.43—almost tripling since May. However, specialized fundraising for PPC still faces challenges due to a lack of public awareness.

4) Healthcare Infrastructure

Yuhua District currently has 817 medical and health institutions, including 13 community health service centers, 1 maternal and child health care hospital, and 55 hospitals. Among them, there are 3 medical institutions with specialized pediatric palliative care services, accounting for 13% of the total 23 in the country, and the number of doctors accounts for 11.5% of the country.

Although the number of institutions is acceptable, there is still room for improvement compared with the country, especially in the construction of talent teams. The "AI-assisted nursing path" and "standardized recording system" proposed in this study are precisely to solve the problems of tight front-line medical resources and uneven service load.



医疗
Healthcare

Yuhua district

817	55	13	3839	4457

Yuhua district has 817 health institutions, including 55 hospitals and health centers, 13 community health service centers, 1 disease prevention and control center (epidemic prevention station), 1 maternal and child health care hospital, and 1 specialized disease prevention and treatment hospital. The district has 22,615 health technicians, 3,839 practicing doctors and practicing assistant doctors, and 4,457 registered nurses.

截止2023年，全区拥有卫生机构数817个，拥有医院、卫生院55个，社区卫生服务中心13个，拥有疾病预防控制中心（防疫站）、妇幼保健院、专科疾病防治院各1个。全区卫生技术人员22615人，执业医师和执业助理医师3839人，注册护士4457人。

General Hospitals
综合医院（三级）

1. 湖南省儿童医院 Hunan Provincial Children's Hospital
2. 湖南省脑科医院 Hunan Provincial Brain Hospital
3. 湖南中医药大学第一附属医院 The 1st Affiliated Hospital of University
4. 长沙市中心医院 Changsha Central Hospital
5. 长沙市妇幼保健院 Changsha Maternal and Child Health Hospital
6. 湖南省职业病防治院 Hunan Occupational Disease Prevention Institute
7. 长沙市第九医院 Changsha No. 9 Hospital
8. 湖南省康复医院 Hunan Rehabilitation Hospital

Community health service centers
社区卫生服务中心

1. 砂子塘街道社区卫生服务中心：位于王家冲路82号
2. 东山街道社区卫生服务中心：地址在东山街道黎郡新宇熙春园9栋
3. 跳马镇中心卫生院：位于跳马镇石燕湖路51号
4. 东塘街道社区卫生服务中心：黄土岭路366-5号
5. 高桥街道社区卫生服务中心：上河国际商业广场H栋
6. 圭塘街道中南院社区卫生服务中心：位于体院路6号

Pediatric Clinic
儿科门诊

1. 湖南省儿童医院 Hunan Children's Hospital
2. 中南大学湘雅医院 Xiangya Hospital of Central South University
3. 中南大学湘雅二医院 Xiangya Second Hospital of Central South University
4. 湖南省人民医院 Hunan Provincial People's Hospital
5. 湖南省妇幼保健院 Hunan Provincial Maternal and Child Health Hospital

儿童安宁疗护医疗门诊
Children's Palliative Care Clinic

3	Hunan Provincial People's Hospital 湖南省人民医院	xiangya hospital 湘雅医院	Xiangya 3rd Hospital 湘雅三医院
	Pediatric Hematology Oncology Clinic 儿童血液肿瘤门诊	Pediatric Clinic 儿科门诊	Pediatric Hematology Department 小儿血液科
3	Thursday morning	Tuesday afternoon	Wednesday afternoon
3	**Chief Physician.He** 贺湘玲 主任医师	**Chief Physician Yu** 俞燕 主任医师	**Associate Researcher Zhao** 赵明一 副研究员

In China

1032918	4435000	5224000

By the end of 2022, the total number of medical and health institutions in China was 1032918, an increase of 1983 from the previous year. Among them, there are 36976 hospitals, 979768 primary healthcare institutions, and 12436 professional public health institutions.

截止2022年末，全国医疗卫生机构总数1032918个，比上年增加1983个。 其中：医院36976个， 基层医疗卫生机构979768个，专业公共卫生机构12436个。执业（助理）医师443.5 万人9，注册护士522.4万人

35 ➡ 61	96 ➡ 204	208 ➡ 449

From October 2017 to May 2019, the number of institutions providing palliative care services nationwide increased from 35 to 61, the number of practicing doctors increased from 96 to 204, and the number of practicing nurses increased from 208 to 449.

2017年10月到2019年5月，全国可提供安宁疗护服务的机构从35个增加到61个，执业医生从96人增加到204人，执业护士从208人增加到449人。

儿童安宁疗护医疗门诊
Children's Palliative Care Clinic

23	26	?

As of October 2022, a total of 23 palliative clinics and 26 practicing physicians' information have been collected in the field of pediatric palliative care.
截止2022年10月，儿童安宁疗护方向共收集到23个舒缓门诊，26位执业医师的信息。

Yuhua district	机构	医师	护士
PPC 儿童安宁疗护	3	3	?
所有医疗	817	3839	4457
China			
PPC 儿童安宁疗护	23	26	?
PC 安宁疗护	61	204	449
所有医疗	1032918	4435000	5224000

Figure 4.7 The situation of healthcare (drawn by the author)

5) Policy and Governance

Hunan Province and Changsha City have issued a number of policies related to children's palliative care, such as the "Notice on the Second Batch of Palliative Care Pilot Work" and the "Action Plan for Further Improving Nursing Services". The policy encourages "institution-family" linkage, "multidisciplinary team collaboration" and "service inclusion in medical insurance".

Policy support provides institutional soil for "cross-institutional collaboration model" and "data-driven decision-making mechanism". The suggestions in the study, such as "regional service platform" and "medical insurance performance-oriented mechanism", are all based on the current policy orientation, reflecting the resonance between theory and practice.

社会福利

Social Welfare

Hunan Province has also established a special fund, especially for the rehabilitation treatment of diseases such as developmental delay, cerebral palsy, and intellectual disabilities

湖南省还设立了专项基金，特别是针对发育迟缓、脑瘫、智力障碍等疾病的康复治疗

In 2023, Changsha Maternal and Child Health Hospital provided rehabilitation medical services for disadvantaged children through multiple assistance projects, which helped over 1500 children in total

2023年，长沙市妇幼保健院通过多个救助项目为困境儿童提供康复医疗服务，此类项目共救助了1500多名儿童

社会政策

Policy

《国家卫生健康委办公厅关于开展第二批安宁疗护试点工作的通知》（2019.12.15）

建立工作机制

探索建立机构和居家安宁疗护相结合的工作机制。探索形成机构与机构间、机构与居家间的通畅合理的转介制度。

探索制度保障

探索制定安宁疗护服务收费项目及标准，推动心理疏导、上门服务等项目纳入收费范围。探索推动将居家和机构安宁疗护服务费用逐步纳入基本医疗保险、长期护理保险以及其他补充医疗保险范畴。探索实施安宁疗护按床日付费制度。

加强队伍建设

1. 组建多学科团队。配齐安宁疗护服务团队，组建包括医学、护理、心理、营养、社会工作在内的多学科专业人才团队。
2. 加强教育培训。结合本地继续医学教育基地建设规划，遴选有相关工作基础的地市级及以上医院、符合条件的行业组织、高等医学院校等设立安宁疗护教育培训基地，开展安宁疗护专业培训，确保安宁疗护服务质量。
3. 鼓励社会组织和志愿者共同参与安宁疗护服务。
4. 加强宣传教育。开展对医学生、医护人员的安宁疗护理念和知识教育，开展对社会公众尤其是重症疾病患者及其家属的生命教育，为提高疾病终末期患者的生命质量创造良好的社会氛围。

《进一步改善护理服务行动计划》

护理服务政策：医院要加强儿科护理，并发展安宁疗护服务。此政策还支持创新护理模式，利用“互联网+护理服务”延伸至家庭和社区，帮助出院后儿童患者接受延续性护理。

基层医疗支持：通过医联体和护理联盟等方式，推动优质护理资源下沉至基层医疗机构，帮助提升社区和居家护理能力。

Encourage the integration of institutional and home-based palliative care

The policy encourages the exploration of mechanisms that combine institutional and home-based palliative care. It emphasizes smooth transitions between institutions, communities, and homes.

政策鼓励探索机构与居家安宁疗护相结合的工作机制，强调机构与居家之间的顺畅衔接。

Establish a multidisciplinary team including doctors, psychologists, nurses, etc., and ensure service quality through education and training.

The policy calls for the formation of multi-disciplinary teams, including medical professionals, social workers, and psychological counselors. It also stresses the need for specialized training programs in palliative care to ensure high-quality services.

政策要求**组建包括医生、心理、护理等多学科团队**，并强调需要安宁疗护专业的**教育与培训**，确保服务质量。

Policy exploration to include palliative care service fees in the medical insurance system

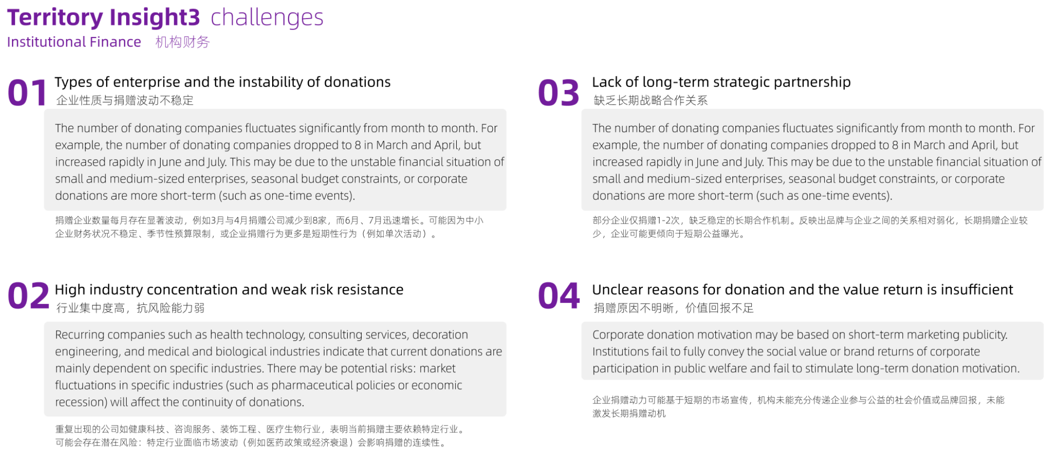
The policy seeks to explore fixed service charges for palliative care, integrating it into basic medical insurance. This would provide long-term financial protection for palliative care services.

政策探索**将安宁疗护服务费用纳入医保体系**，提供长期的医疗保险保障。

Figure 4.8 The situation of policy (drawn by the author)

Through a comprehensive analysis of population structure, financial status, education and medical resources, and policy environment, Yuhua District, where Butterfly House is located, has a multi-dimensional foundation for the development of children's palliative care. The service system design and governance recommendations of this study are proposed in this multi-level ecological field, responding to the key challenges of actual resource allocation and future development trends. Subsequent chapters will further explore how to incubate sustainable, interdisciplinary, and child-centered innovative service paths in this soil.

4.3 Challenge Identification



Territory Insight3 challenges
Institutional Finance 机构财务

01 Types of enterprise and the instability of donations
企业性质与捐赠波动不稳定

The number of donating companies fluctuates significantly from month to month. For example, the number of donating companies dropped to 8 in March and April, but increased rapidly in June and July. This may be due to the unstable financial situation of small and medium-sized enterprises, seasonal budget constraints, or corporate donations are more short-term (such as one-time events).

捐赠企业数量每月存在显著波动，例如3月与4月捐赠公司减少到8家，而6月、7月迅速增长。可能因为中小企业财务状况不稳定、季节性预算限制，或企业捐赠行为更多是短期性行为（例如单次活动）。

02 High industry concentration and weak risk resistance
行业集中度高，抗风险能力弱

Recurring companies such as health technology, consulting services, decoration engineering, and medical and biological industries indicate that current donations are mainly dependent on specific industries. There may be potential risks: market fluctuations in specific industries (such as pharmaceutical policies or economic recession) will affect the continuity of donations.

重复出现的公司如健康科技、咨询服务、装饰工程、医疗生物行业，表明当前捐赠主要依赖特定行业。可能会存在潜在风险：特定行业面临市场波动（例如医药政策或经济衰退）会影响捐赠的连续性。

03 Lack of long-term strategic partnership
缺乏长期战略合作关系

The number of donating companies fluctuates significantly from month to month. For example, the number of donating companies dropped to 8 in March and April, but increased rapidly in June and July. This may be due to the unstable financial situation of small and medium-sized enterprises, seasonal budget constraints, or corporate donations are more short-term (such as one-time events).

部分企业仅捐赠1-2次，缺乏稳定的长期合作机制。反映出品牌与企业之间的关系相对弱化，长期捐赠企业较少，企业可能更倾向于短期公益曝光。

04 Unclear reasons for donation and the value return is insufficient
捐赠原因不明晰，价值回报不足

Corporate donation motivation may be based on short-term marketing publicity. Institutions fail to fully convey the social value or brand returns of corporate participation in public welfare and fail to stimulate long-term donation motivation.

企业捐赠动力可能基于短期的市场宣传，机构未能充分传递企业参与公益的社会价值或品牌回报，未能激发长期捐赠动机

Figure 4.9 Challenge from Insight 3 (drawn by the author)

The institutional finance challenges faced by local pediatric palliative care initiatives reveal four core issues. First, donation sources are unstable due to the financial fragility of small and medium-sized enterprises, with contributions often limited to short-term or one-off events. Second, donations are highly concentrated in specific industries like healthcare and consulting, making the funding base vulnerable to economic shifts or policy changes. Third, the lack of long-term strategic partnerships weakens sustained support, as corporate engagement often remains superficial. Finally, many institutions struggle to articulate the social value of donations, leading to unclear motivation and insufficient perceived returns for corporate donors. These factors combined create a fragmented and uncertain financial environment.

4.4 Key Insights from Territorial Diagnosis

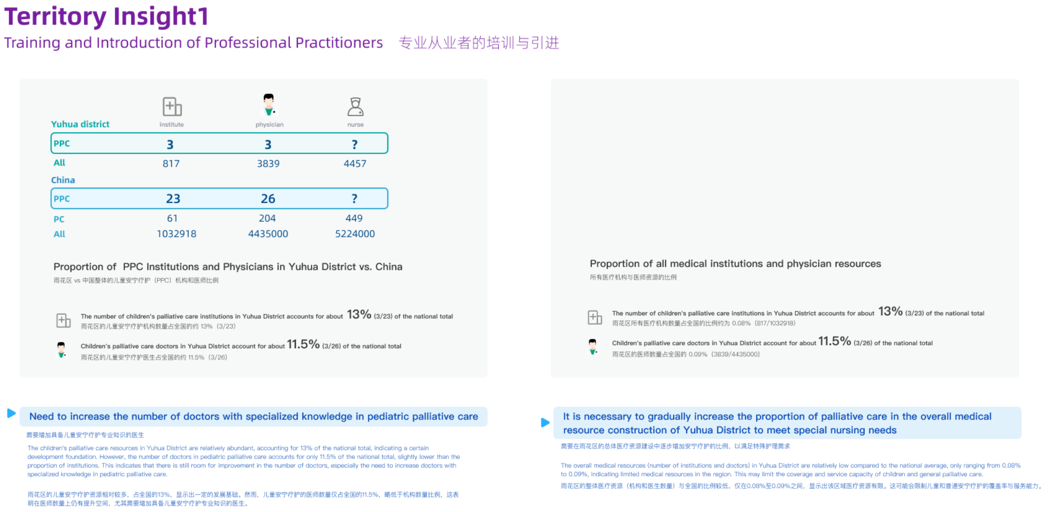
Insight 1: PPC Professionals

There are currently three pediatric palliative care (PPC) institutions in Yuhua District, accounting for 13% of the total number in the country. Although this proportion is relatively considerable, from the perspective of professional physicians, the number is still relatively small, accounting for only 11.5% of the total number of relevant doctors in the country. This shows that professional human resources have not yet formed an effective scale, especially the lack of pediatricians with palliative care knowledge. We found that the current training programs focus on general nursing skills, and the coverage of content such as children's emotional support and family communication is insufficient. Most medical staff have not received systematic children's palliative care education, and they are prone to feel overwhelmed when facing children and families.

First, the current interdisciplinary team building is seriously lagging behind. Palliative care requires not only doctors and nurses, but also psychological counselors, social workers and clinical pharmacists to work together. However, the actual training resources are relatively single, the training cycle is short and the form is fragmented, which makes it difficult to meet the needs of clinical front-line team building.

Second, the training coverage rate in first-tier cities is still low. Across the country, although Beijing, Shanghai, Guangzhou and other places have successively held many related training sessions, the total number of trainees is still less than 500. Especially at the grassroots and community levels, the medical staff's knowledge of palliative care is almost blank.

This kind of structural shortage not only restricts the improvement of service coverage, but also increases the care pressure on existing medical staff. We believe that future training design should focus more on the needs of children's specialties. In addition to the standardized curriculum setting, it should strengthen emotional expression training and family communication skills, and strengthen the humanistic care ability of children's palliative care.



Territory Insight1

Training and Introduction of Professional Practitioners 专业从业者的培训与引进

Yuhua district	institute	physician	nurse
PPC	3	3	?
All	817	3839	4457
China			
PPC	23	26	?
PC	61	204	449
All	1032918	4435000	5224000

Proportion of PPC Institutions and Physicians in Yuhua District vs. China

雨花区 vs 中国整体的儿童安宁疗护（PPC）机构和医师比例

The number of children's palliative care institutions in Yuhua District accounts for about 13% (3/23) of the national total

雨花区的儿童安宁疗护机构数量占全国的约 13%（3/23）

Children's palliative care doctors in Yuhua District account for about 11.5% (3/26) of the national total

雨花区的儿童安宁疗护医生占全国的约 11.5%（3/26）

Proportion of all medical institutions and physician resources

所有医疗机构与医师资源的比例

The number of children's palliative care institutions in Yuhua District accounts for about 13% (3/23) of the national total

雨花区所有医疗机构数量占全国的比例约为 0.08%（817/1032918）

Children's palliative care doctors in Yuhua District account for about 11.5% (3/26) of the national total

雨花区的医师数量占全国的 0.09%（3839/4435000）

Need to increase the number of doctors with specialized knowledge in pediatric palliative care

需要增加具备儿童安宁疗护专业知识的医生

The children's palliative care resources in Yuhua District are relatively abundant, accounting for 13% of the national total, indicating a certain development foundation. However, the number of doctors in pediatric palliative care accounts for only 11.5% of the national total, slightly lower than the proportion of institutions. This indicates that there is still room for improvement in the number of doctors, especially the need to increase doctors with specialized knowledge in pediatric palliative care.

雨花区的儿童安宁疗护资源相对较多，占全国的13%，显示出一定的发展基础。然而，儿童安宁疗护的医师数量仅占全国的11.5%，略低于机构数量比例，这表明在医师数量上仍有提升空间，尤其需要增加具备儿童安宁疗护专业知识的医生。

It is necessary to gradually increase the proportion of palliative care in the overall medical resource construction of Yuhua District to meet special nursing needs

需要在雨花区的总体医疗资源建设中逐步增加安宁疗护的比例，以满足特殊护理需求

The overall medical resources (number of institutions and doctors) in Yuhua District are relatively low compared to the national average, only ranging from 0.08% to 0.09%, indicating limited medical resources in the region. This may limit the coverage and service capacity of children and general palliative care.

雨花区的整体医疗资源（机构和医生数量）与全国的比例较低，仅在0.08%至0.09%之间，显示出该区域医疗资源有限。这可能会限制儿童和普通安宁疗护的覆盖率与服务能力。

Figure 4.10 Territory insight 1 (drawn by the author)

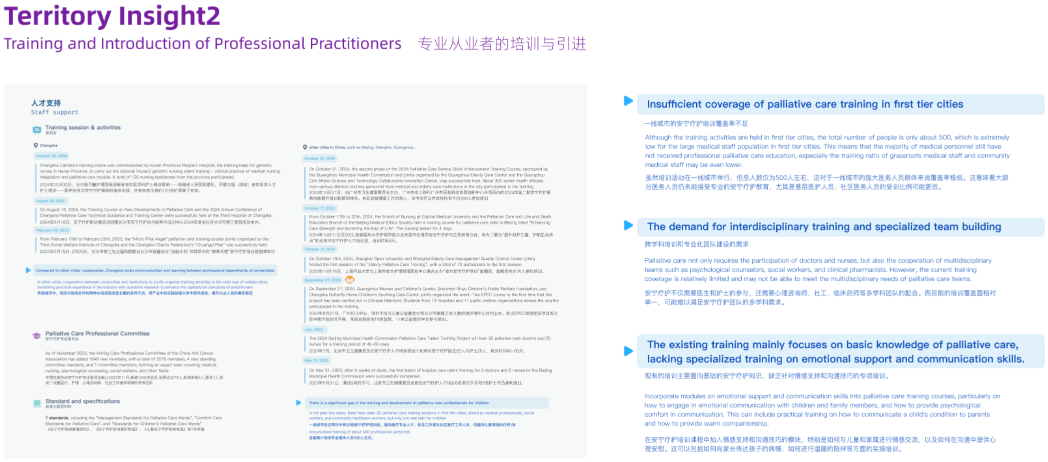
Insight 2: Institutional financial fluctuations and supporting structures

The operating funds of Butterfly House mainly come from donations. Between May and September 2024, the total income of the organization jumped from 140,000 to 400,000, showing a certain growth trend. However, we noticed that this increase was not stable, and the income fluctuated significantly after June. Although offline donations (such as bank transfers and Alipay) account for a large proportion, they lack sustainability. In contrast, online monthly donation channels are more stable, contributing more than 240,000 in September, accounting for more than half of the total income. It can be seen that the monthly donation group has become the backbone of the financial security of the organization.

First, the retention and growth of the monthly donation group requires more frequent emotional incentives. We found that the surge in income in September is often accompanied by special nodes (such as charity festivals, public activities or media exposure). This kind of interactive form with a sense of ritual enhances the donor's sense of participation and belonging.

Second, the awareness of the issue of children's palliative care itself is still limited. In our survey, we found that the public's understanding of "children's hospice care" mostly stays at the end of the disease, and lacks awareness of the multi-dimensional value and actual needs of the service system. This directly affects the efficiency of monthly donation conversion.

In the future, we recommend that organizations build more emotionally resonant communication content and explore long-term incentive mechanisms. For example, through transparent financial weekly reports, exclusive stories for donors, etc., the public's value recognition of continuous support can be enhanced.



Territory Insight2

Training and Introduction of Professional Practitioners 专业从业者的培训与引进

人才支持
Staff support

Training session & activities
培训会

Changsha

October 30, 2024

Changsha Carnation Nursing Home was commissioned by Hunan Provincial People's Hospital, the training base for geriatric nurses in Hunan Province, to carry out the national (Hunan) geriatric nursing talent training – clinical practice of medical nursing integration and palliative care module. A total of 120 nursing backbones from the province participated.

2024年10月30日，长沙康乃馨护理院受湖南省老年医学科护士培训基地——湖南省人民医院委托，开展全国（湖南）老年医学人才护士培训——医养结合与安宁疗护模块的临床实践，共有来自全省约120名护理骨干参加。

August 18, 2024

On August 18, 2024, the Training Course on New Developments in Palliative Care and the 2024 Annual Conference of Changsha Palliative Care Technical Guidance and Training Center were successfully held at the Third Hospital of Changsha.

2024年8月18日，安宁疗护新进展培训班暨长沙市安宁疗护技术指导与培训中心2024年度会议在长沙市第三医院成功举办。

February 20, 2023

From February 15th to February 20th, 2023, the "Micro Filial Angel" palliative care training course jointly organized by the Third Social Welfare Institute of Changsha and the Changsha Charity Federation's "Chuangyi Plan" was successfully held

2023年2月15日-2月20日，长沙市第三社会福利院联合长沙市慈善总会"创益计划"共同举办的"微孝天使"安宁疗护培训班圆满举行

Compared to other cities' cooperation, Changsha lacks communication and learning between professional departments of universities

In other cities, cooperation between universities and institutions to jointly organize training activities is the main way of collaboration, combining practical experience in the industry with academic research to enhance the operational standards of practitioners

其他城市中，高校与机构合作共同举办培训活动是主要的合作方式，将产业中的实践经验与学术研究结合，提升从业人员的操作规范

Palliative Care Professional Committee
安宁疗护专业委员会

As of November 2023, the Anning Care Professional Committee of the China Anti Cancer Association has added 1640 new members, with a total of 3276 members, 4 new standing committee members, and 7 committee members, forming an expert team covering medical, nursing, psychological counseling, social workers, and other fields

中国抗癌协会安宁疗护专业委员会截止2023年11月,新增1640名会员,发展达3276人,新增常委4人,委员7人,形成了涵盖医疗、护理、心理咨询师、社会工作者等领域的专家团队

Standard and specifications
标准与规范材料

7 standards, including the "Management Standards for Palliative Care Wards", "Comfort Care Standards for Palliative Care", and "Standards for Children's Palliative Care Wards"

《安宁疗护病房管理规范》、《安宁疗护舒适照护标准》、《儿童安宁疗护病房标准》等7本标准

other cities in China, such as Beijing, Shanghai, Guangzhou...

October 21, 2024

On October 21, 2024, the second phase of the 2024 Palliative Care Service Skills Enhancement Training Course, sponsored by the Guangzhou Municipal Health Commission and jointly organized by the Guangzhou Elderly Care Center and the Guangzhou Civil Affairs Science and Technology Collaborative Innovation Center, was successfully held. About 300 senior health officials from various districts and key personnel from medical and elderly care institutions in the city participated in the training

2024年10月21日，由广州市卫生健康委员会主办，广州市老人院和广州市民政科技协同创新中心共同承办的2024年第二期安宁疗护服务技能提升培训班顺利举办。各区老龄健康工作负责人、全市医疗及养老机构骨干约300人参加培训

October 17, 2024

From October 17th to 20th, 2024, the School of Nursing at Capital Medical University and the Palliative Care and Life and Death Education Branch of the Beijing Medical Ethics Society held a training course for palliative care talks in Beijing titled "Enhancing Care Strength and Escorting the End of Life". The training lasted for 4 days.

2024年10月17日至20日,首都医科大学护理学院与北京医学伦理学会安宁疗护与生死教育分会，举办了题为"提升照护力量，护航生命终点"的北京市安宁疗护人才培训班，培训时间4天。

October 15, 2024

On October 15th, 2024, Shanghai Open University and Shanghai Elderly Care Management Quality Control Center jointly hosted the first session of the "Elderly Palliative Care Training", with a total of 70 participants in the first session.

2024年10月15日，上海开放大学与上海市老年护理管理质控中心联合主办"老年安宁疗护培训"首期班，首期班共计70人参加培训。

September 27, 2024

On September 27, 2024, Guangzhou Women and Children's Center, Shenzhen Shiyu Children's Public Welfare Foundation, and Changsha Butterfly Home Children's Soothing Care Center jointly organized the event. This EPEC course is the first time that the project has been carried out in Chinese Mainland. Students from 19 hospitals and 11 public welfare organizations across the country participated in the training

2024年9月27日，广州妇儿中心、深圳市拾玉儿童公益基金会和长沙市蝴蝶之家儿童舒缓护理中心共同主办。本次EPEC课程是该项目首次在中国大陆地区开展。来自全国各地19家医院，11家公益组织学员参与培训。

July, 2024

The 2024 Beijing Municipal Health Commission Palliative Care Talent Training Project will train 25 palliative care doctors and 25 nurses for a training period of 40–60 days.

2024年7月，北京市卫生健康委员会安宁疗护人才培训项目计划培训安宁疗护医生25人与护士25人，培训时间40–60天。

May 31, 2023

On May 31, 2023, after 6 weeks of study, the first batch of hospice care talent training for 5 doctors and 5 nurses by the Beijing Municipal Health Commission were successfully completed.

2023年5月31日，通过6周的学习，北京市卫生健康委员会首批安宁疗护人才培训5名医生学员和5名护士学员顺利结业。

There is a significant gap in the training and development of palliative care professionals for children

In the past two years, there have been 25 palliative care training sessions in first tier cities, aimed at medical professionals, social workers, and community healthcare workers, but only one was held for children

一线城市在近两年中有25场安宁疗护培训会，面向医疗专业人才，社会工作者与社区医疗工作人员，但面向儿童领域的仅有1场

Accumulated training of about 500 professional personnel.

全国累计培训专业相关人员500人左右。

Insufficient coverage of palliative care training in first tier cities

一线城市的安宁疗护培训覆盖率不足

Although the training activities are held in first tier cities, the total number of people is only about 500, which is extremely low for the large medical staff population in first tier cities. This means that the majority of medical personnel still have not received professional palliative care education, especially the training ratio of grassroots medical staff and community medical staff may be even lower.

虽然培训活动在一线城市举行，但总人数仅为500人左右，这对于一线城市的庞大医务人员群体来说覆盖率极低。这意味着大部分医务人员仍未能接受专业的安宁疗护教育，尤其是基层医护人员、社区医务人员的受训比例可能更低。

The demand for interdisciplinary training and specialized team building

跨学科培训和专业化团队建设的需求

Palliative care not only requires the participation of doctors and nurses, but also the cooperation of multidisciplinary teams such as psychological counselors, social workers, and clinical pharmacists. However, the current training coverage is relatively limited and may not be able to meet the multidisciplinary needs of palliative care teams.

安宁疗护不仅需要医生和护士的参与，还需要心理咨询师、社工、临床药师等多学科团队的配合。而目前的培训覆盖面相对单一，可能难以满足安宁疗护团队的多学科需求。

The existing training mainly focuses on basic knowledge of palliative care, lacking specialized training on emotional support and communication skills.

现有的培训主要面向基础的安宁疗护知识，缺乏针对情感支持和沟通技巧的专项培训。

Incorporate modules on emotional support and communication skills into palliative care training courses, particularly on how to engage in emotional communication with children and family members, and how to provide psychological comfort in communication. This can include practical training on how to communicate a child's condition to parents and how to provide warm companionship.

在安宁疗护培训课程中加入情感支持和沟通技巧的模块，特别是如何与儿童和家属进行情感交流，以及如何在沟通中提供心理安慰。这可以包括如何向家长传达孩子的病情、如何进行温暖的陪伴等方面的实操培训。

Figure 4.11 Territory insight 2 (drawn by the author)

Insight 3: Cultural and creative product sales and donation incentive model
The organization is currently trying to raise funds by selling cultural and creative products, such as canvas bags, calendars, thermos cups, etc., to build an interactive donation model of "donation + product". However, data shows that the overall conversion rate is low. As of the statistical time, only 9 canvas bags, 3 calendars, and thermos cups have been sold. The total sales of the three types of products are 510 yuan, which only completes 1.15% of the fundraising target.

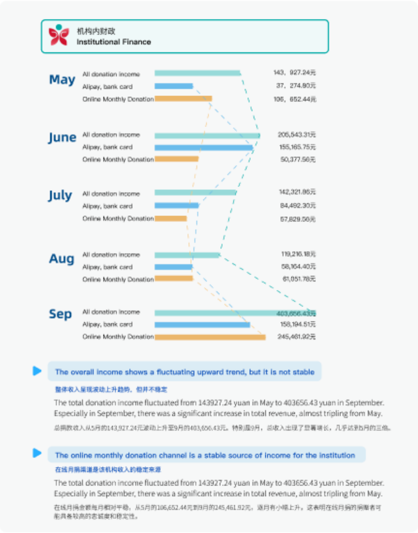
First, the product price positioning is too high, which makes it difficult to convert potential donors. As for the thermos cup, the price is 200 yuan, which is much higher than the psychological expectations of general consumers for donated souvenirs. In contrast, the affordable canvas bags have the best sales, which shows that practicality and cost-effectiveness are the main considerations for the current audience to buy.

Second, there is a lack of differentiation in product types and content design. The functions of many types of products are similar, the visual recognition is not strong, and it is difficult to stimulate emotional resonance. We believe that we should start from the perspective of the audience and develop more small souvenirs with a price range of 20-50 yuan, such as key chains, stickers, mini calendars, etc., which are suitable for young groups and those with low consumption intentions.

In addition, a "combination package" strategy can be introduced to package cultural and creative products with project stories and thank-you cards, set a unified discount price, and form a set of "light charity gifts" paths to improve conversion efficiency.

Territory Insight3

Institutional Finance　机构财务



The overall income shows a fluctuating upward trend, but it is not stable

整体收入呈现波动上升趋势，但并不稳定

The total donation income fluctuated from 143927.24 yuan in May to 403656.43 yuan in September. Especially in September, there was a significant increase in total revenue, almost tripling from May.

总捐款收入从5月的143,927.24元波动上升至9月的403,656.43元。特别是9月，总收入出现了显著增长，几乎达到5月的三倍。

The online monthly donation channel is a stable source of income for the institution

在线月捐渠道是该机构收入的稳定来源

The total donation income fluctuated from 143927.24 yuan in May to 403656.43 yuan in September. Especially in September, there was a significant increase in total revenue, almost tripling from May.

在线月捐金额每月相对平稳，从5月的106,652.44元到9月的245,461.92元，逐月有小幅上升。这表明在线月捐的捐赠者可能具备较高的忠诚度和稳定性。

- **Maintain the group of monthly donation channels to enhance their sense of gain and achievement**

  维护月捐渠道群体，提升获得感与成就感

- **Learn from the successful model of September**

  确定9月收入激增的原因（如节日活动、媒体曝光、知名人士的支持等），借鉴9月的成功模式

- **Lack of specialized promotion focused on children's palliative care makes it difficult to attract new donors to become monthly supporters.**

  缺乏专注于儿童安宁疗护的专项推广，吸引新捐赠者成为月捐支持者较为困难。


Territory Insight3 Motivation of donors 捐赠者动机
Institutional Finance 机构财务

260. 2024-12-13 12:18:49 龚*丝 给 爱的小窝—让孩子安然入睡 捐赠 164.00 元
参加蝴蝶之家的月捐，始于2022年的5月11日，这是当时的留言：“去年11月，在龚老师生日的时候，通过起意9291的微博，读到了蝴蝶之家的故事，那时候我站在马路边，一边看那些文字一边流泪。今年到了张老师的生日，我们总在记得他说过的‘分享爱传递爱’，我也在想除了祝福我还能做点什么，于是找到了这里。绵薄之力不足道，一点点心意，传递爱意。感谢蝴蝶之家为孩子们为这个世界付出的一切。”今年依然不变。

539. 2024-12-04 14:25:29 D*w 给 爱的小窝—让孩子安然入睡 捐赠 300.00 元
距离上次捐赠已经好久了，刚上班攒钱有点难。最近天气变冷了，一点点心意祝愿小朋友们能过个开心的圣诞节。我也曾面临过很严重的疾病，但好在坚持下来可以正常生活工作了，希望能将勇气和好运也带给小朋友们。也提前祝福工作人员圣诞快乐和新年快乐，辛苦你们啦

Emotional resonance and story-driven
情感共鸣与故事驱动

Incentives for special nodes
特殊节点的激励作用

Long-term companionship and commitment
长期陪伴与承诺
动机：捐赠者提到自己已经持续捐赠，体现了对长期陪伴蝴蝶之家的承诺与认可。
机会：
- 强化月捐者的身份认同，例如为月捐者提供“爱心陪伴者”称号或专属徽章。
- 定期向月捐者反馈他们的捐赠成果，通过故事、数据报告等形式，让他们看到长期捐赠的影响。

Sending small but powerful love
传递小而有力的爱
动机：捐赠者提到“微薄之力” “一点点心意”，认为自己的小贡献也有价值。
机会：推广”小额定期捐赠”的概念，如“1天1元，点亮孩子的微笑”，降低捐赠门槛，吸引更多普通人参与月捐。

Figure 4.12 Territory insight 3 (drawn by the author)


Territory Insight3 analysis
Donating companies 捐赠企业

Sep 10 ⬆2 ⬇2
Guangzhou Renhao Health Technology Co., Ltd
NEW Hunan Red Star Qiangu Small Loan
Hunan Huizhong Huimei Technology Co., Ltd
Lai Yushan and her friends
NEW Shanghai Hexuan Interior Decoration Co., Ltd
Shanghai Guardian Butterfly Swarm
Sichuan Dieyun Chuangzhi Health Consulting Co., Ltd
Zhongshan Hengtai Chuangzhan Industrial Co., Ltd
Zhongshan Weilida Bag Co., Ltd
Zeng Xiaobai Cake National Chain

广州仁好健康科技有限公司
湖南红星钱谷小贷
湖南慧中汇美科技有限公司
賴玉珊及友人
NEW 上海和绚室内装饰有限公司
上海守护蝴蝶群
四川蝶运创智健康咨询有限公司
中山市恒泰创展实业有限公司
中山市伟利达包袋有限公司
曾小白蛋糕全国连锁

July 10 ⬆4 ⬇5
NEW Zhongtai Hongyuan Engineering Technology Co., Ltd
Guangzhou Renhao Health Technology Co., Ltd
NEW Hunan Huizhong Huimei Technology Co., Ltd
Lai Yushan and her friends
NEW Shanghai Paiside Biochemical Co., Ltd
Shanghai Guardian Butterfly Swarm
Sichuan Dieyun Chuangzhi Health Consulting Co., Ltd
NEW Zeng Xiaobai Cake National Chain
Zhongshan Hengtai Chuangzhan Industrial Co., Ltd
Zhongshan Weilida Bag Co., Ltd

NEW 东莞市中泰宏元工程科技有限公司
广州仁好健康科技有限公司
NEW 湖南惠中汇美科技有限公司
賴玉珊及友人
NEW 上海派斯德生化有限公司
上海守护蝴蝶群
四川蝶运创智健康咨询有限公司
NEW 曾小白蛋糕全国连锁
中山市恒泰创展实业有限公司
中山市伟利达包袋有限公司

June 11 ⬆4 ⬇1
NEW Changsha Fudie Guardian Group
Guangzhou Renhao Health Technology Co., Ltd
Lai Yushan and her friends
Small butterfly groups on both sides of the Taiwan Strait
NEW Shanghai Guardian Butterfly Swarm
NEW Shenzhen Kelimu Industrial Co., Ltd
Sichuan Dieyun Chuangzhi Health Consulting Co., Ltd
Zhongshan Hengtai Chuangzhan Industrial Co., Ltd
Zhongshan Weilida Bag Co., Ltd
Night Navigation Star
NEW Charity groups named “Yingyoujinyou”

NEW 长沙福蝶守护群
广州仁好健康科技有限公司
賴玉珊及友人
两岸小蝴蝶群
NEW 上海守护蝴蝶群
NEW 深圳市可丽牧实业有限公司
四川蝶运创智健康咨询有限公司
中山市恒泰创展实业有限公司
中山市伟利达包袋有限公司
夜航星
NEW 英有尽有慈善小组

May 8 ⬆1 ⬇4
Guangzhou Renhao Health Technology Co., Ltd.
Lai Yushan and friends
Small butterfly groups on both sides of the strait
NEW Qianfoshan Huade Zen Temple
Sichuan Dieyun Chuangzhi Health Consulting Co., Ltd.
Yehangxing
Zhongshan Hengtai Chuangzhan Industrial Co., Ltd.
Zhongshan Weilida Bag Co., Ltd.

广州仁好健康科技有限公司
賴玉珊及友人
两岸小蝴蝶群
NEW 千佛山华德禅寺
四川蝶运创智健康咨询有限公司
夜航星
中山市恒泰创展实业有限公司
中山市伟利达包袋有限公司

April 11 ⬆3 ⬇0
NEW Friends of the Tea Exploration Bureau
Guangzhou Renhao Health Technology Co., Ltd.
Lai Yushan and friends
Strait Butterfly Group
NEW Shanghai Paiside Biochemical Co., Ltd.
NEW Shanghai Guardian Butterfly Group
Sichuan Dieyun Chuangzhi Health Consulting Co., Ltd.
Yehangxing
Changsha Dongqiao Technology Co., Ltd.
Zhongshan Hengtai Chuangzhan Industrial Co., Ltd.
Zhongshan Weilida Bag Co., Ltd.

NEW 茶的探索局的小伙伴
广州仁好健康科技有限公司
賴玉珊及友人
两岸小蝴蝶群
NEW 上海派斯德生化有限公司
NEW 上海守护蝴蝶群
四川蝶运创智健康咨询有限公司
夜航星
长沙东桥科技有限公司
中山市恒泰创展实业有限公司
中山市伟利达包袋有限公司

March 8
Guangzhou Renhao Health Technology Co., Ltd.
Lai Yushan and friends
Little Butterflies on both sides of the Taiwan Strait
Sichuan Dieyun Chuangzhi Health Consulting Co., Ltd.
Yehangxing
Changsha Dongqiao Technology Co., Ltd.
Zhongshan Hengtai Chuangzhan Industrial Co., Ltd.
Zhongshan Weilida Bags Co., Ltd.

广州仁好健康科技有限公司
賴玉珊及友人
两岸小蝴蝶群
四川蝶运创智健康咨询有限公司
夜航星
长沙东桥科技有限公司
中山市恒泰创展实业有限公司
中山市伟利达包袋有限公司

In the donation data of the past three months, corporate donors have shown a stable trend, but there are still fluctuations
在近三个月的捐赠数据中，企业捐赠人呈现稳定趋势，但仍有波动

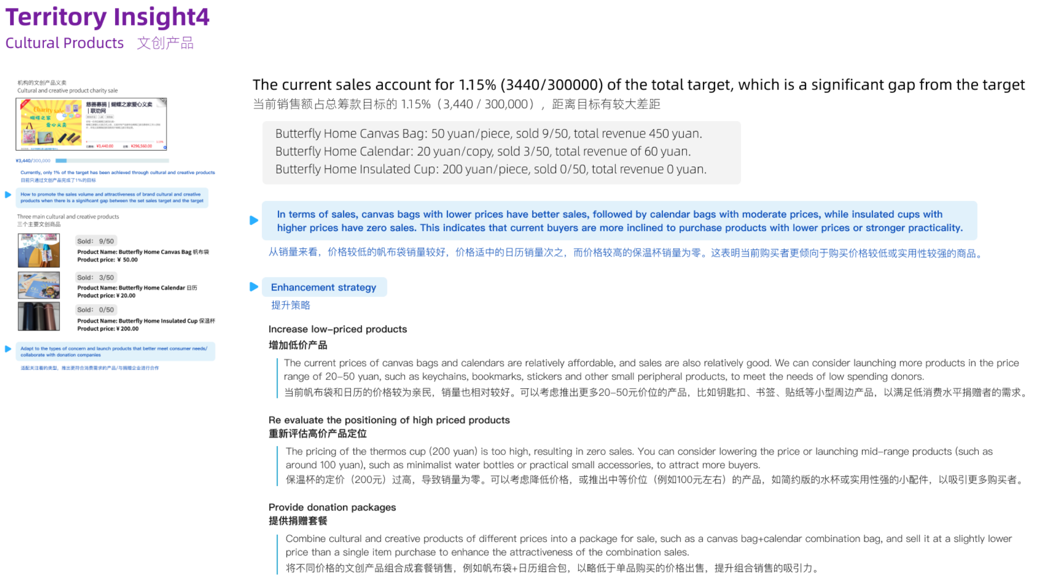
Figure 4.13 Territory insight 3 (drawn by the author)

Insight 4: Limitations and opportunities of professional talent training ecosystem
In terms of talent supply, palliative care currently faces a more prominent structural problem. Although Yuhua District has three PPC institutions, the corresponding number of medical and nursing staff is seriously insufficient, especially the gap in nurse resources is the most obvious. This asymmetric configuration reflects two structural dilemmas: one is that the professional training system is not sound; the other is that the cross-departmental cooperation mechanism is not perfect.

First, most trainings are still at the level of basic care knowledge, failing to cover key links such as "how to communicate with children about their condition" and "how to convey bad news to parents". In the joint training we participated in, many trainees reported that there was a lack of practical guidance on "emotional companionship" and "family psychological support". This lack will result in the inability of medical and nursing staff to form effective empathy with families in actual service.

Second, there is a lack of deep coordination between the medical care system and universities. At present, most trainings rely on hospitals to initiate independently or public welfare organizations to promote, the participation of universities is low, and the course content lacks a clinical feedback mechanism. In the long run, if we want to truly improve the quality of service, we need to promote medical schools to include children's palliative care in the compulsory system and establish a specialist tutor and internship mechanism.

We suggest that more support be given to pilot cities in teacher training and curriculum development from the policy side, and at the same time, strengthen the standardized guidance role of professional associations to build a closed loop of "curriculum standards-practical certification-job transformation" to fill the current gap in talent team building.



Territory Insight4

Cultural Products 文创产品

机构的文创产品义卖
Cultural and creative product charity sale

¥3,440/300,000

Currently, only 1% of the target has been achieved through cultural and creative products
目前只通过文创产品完成了1%的目标

How to promote the sales volume and attractiveness of brand cultural and creative products when there is a significant gap between the set sales target and the target

Three main cultural and creative products
三个主要文创商品

Sold: 9/50
Product Name: Butterfly Home Canvas Bag 帆布袋
Product price: ¥ 50.00

Sold: 3/50
Product Name: Butterfly Home Calendar 日历
Product price: ¥ 20.00

Sold: 0/50
Product Name: Butterfly Home Insulated Cup 保温杯
Product price: ¥ 200.00

Adapt to the types of concern and launch products that better meet consumer needs/ collaborate with donation companies

适配关注着的类型，推出更符合消费需求的产品/与捐赠企业进行合作

The current sales account for 1.15% (3440/300000) of the total target, which is a significant gap from the target
当前销售额占总筹款目标的 1.15%（3,440 / 300,000），距离目标有较大差距

Butterfly Home Canvas Bag: 50 yuan/piece, sold 9/50, total revenue 450 yuan.
Butterfly Home Calendar: 20 yuan/copy, sold 3/50, total revenue of 60 yuan.
Butterfly Home Insulated Cup: 200 yuan/piece, sold 0/50, total revenue 0 yuan.

In terms of sales, canvas bags with lower prices have better sales, followed by calendar bags with moderate prices, while insulated cups with higher prices have zero sales. This indicates that current buyers are more inclined to purchase products with lower prices or stronger practicality.

从销量来看，价格较低的帆布袋销量较好，价格适中的日历销量次之，而价格较高的保温杯销量为零。这表明当前购买者更倾向于购买价格较低或实用性较强的商品。

Enhancement strategy
提升策略

Increase low-priced products
增加低价产品

The current prices of canvas bags and calendars are relatively affordable, and sales are also relatively good. We can consider launching more products in the price range of 20-50 yuan, such as keychains, bookmarks, stickers and other small peripheral products, to meet the needs of low spending donors.
当前帆布袋和日历的价格较为亲民，销量也相对较好。可以考虑推出更多20-50元价位的产品，比如钥匙扣、书签、贴纸等小型周边产品，以满足低消费水平捐赠者的需求。

Re evaluate the positioning of high priced products
重新评估高价产品定位

The pricing of the thermos cup (200 yuan) is too high, resulting in zero sales. You can consider lowering the price or launching mid-range products (such as around 100 yuan), such as minimalist water bottles or practical small accessories, to attract more buyers.
保温杯的定价（200元）过高，导致销量为零。可以考虑降低价格，或推出中等价位（例如100元左右）的产品，如简约版的水杯或实用性强的小配件，以吸引更多购买者。

Provide donation packages
提供捐赠套餐

Combine cultural and creative products of different prices into a package for sale, such as a canvas bag+calendar combination bag, and sell it at a slightly lower price than a single item purchase to enhance the attractiveness of the combination sales.
将不同价格的文创产品组合成套餐销售，例如帆布袋+日历组合包，以略低于单品购买的价格出售，提升组合销售的吸引力。

Figure 4.14 Territory insight 4 (drawn by the author)

4.5 Stakeholder System Mapping

This section presents a stakeholder system map for the children's palliative care center embedded within a welfare institute in Changsha. The map identifies core actors, system phases, and the circulation of information, material, and financial resources. The system is divided into three nested spatial layers: **China (macro)**, **Changsha City (meso)**, and **Welfare Institute (micro)**.

4.5.1 System Stages and Core Structure

The Butterfly House's children's palliative care service builds a multi-stage, cross-professional, and continuous care system around the dynamic needs of children and their families at different stages of life. The entire service system consists of four main stages: pre-hospitalization, initial period, stabilization period (daily care), and outpatient treatment. Each stage is different in terms of goals, service content, and participant collaboration.

1) **First, pre-hospitalization stage: referral and placement (Pre-hospitalization)**

Before the child is officially admitted to the hospital, the institution and the child's family will have initial contact. At this time, social workers and doctors will jointly evaluate the child's disease development, the family's basic situation, the information of the referral agency, and determine whether the conditions for palliative care are met. The agency usually coordinates ward vacancies, confirms medical support capabilities, and initiates family communication mechanisms. The most core task of this stage is to enable the family to establish basic trust in the agency's services, while assisting them in completing the psychological transition from "active treatment" to "palliative care."

2) **Second, the initial stage of hospitalization: adaptation period (Initial period: adaptation)**

When a child first enters Butterfly House, he will go through a short adaptation process. The focus of services at this stage shifts from pure medical behavior to emotional support and trust building. The nursing team will establish a personalized care plan for the child, and arrange for psychologists and volunteers to intervene to create a stable and safe living environment. Most family members will feel anxious or uncertain at this stage, so nursing staff and social workers need to provide companionship and explanations to family members at the same time to stabilize their emotional response to the child's current situation.

3) **Third, stable care period: daily care (Stable period: Daily care)**

When the child's condition is stable, enter the daily care rhythm. The care content includes basic life support, diet and nutrition management, analgesia, sleep care, and regular psychological companionship. Family members will also participate in this stage to assist in care work. The institution will adjust the care plan according to the child's physical and mental condition, such as music therapy, gardening interaction, parent-child companionship and other activities, to help them get gentle companionship and life dignity at the end of their lives.

4) **Fourth, outpatient and follow-up stage: special treatment and response to worsening of the condition (Outpatient treatment)**

When the child no longer needs to be hospitalized continuously, or because the condition is temporarily relieved, he or she can be transferred to the outpatient support mode. Most of these children are taken home by their families for care, and Butterfly House provides regular follow-up, remote guidance and door-to-door services. When sudden symptoms occur or the condition worsens, the institution will re-evaluate whether it needs to be re-admitted. This stage emphasizes the principle of family-centered care, encourages relatives to accompany and empowers family members to become active participants in care.

Overall, these four stages together constitute a continuous and responsive hospice care system, emphasizing the coherent closed loop of "early intervention-emotional stability-life care-hospice arrangements". We have observed that the psychological changes of children and their families are highly correlated with the service intensity of the care system. Therefore, the staffing and intervention strategies of the institution at different stages need to be flexibly adjusted to maintain the stable operation of the team.

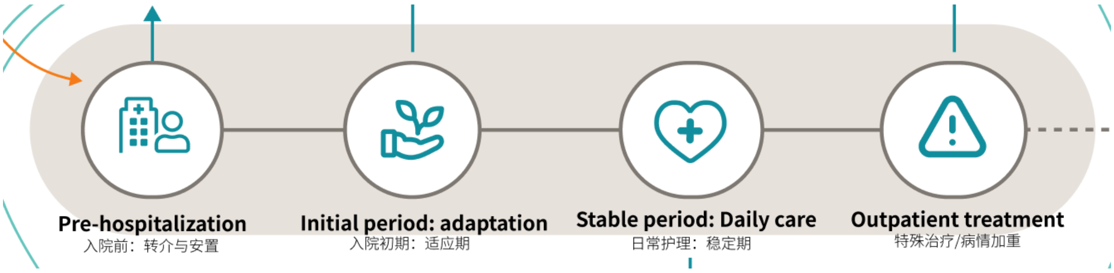


Figure 4.15 Core flows (drawn by the author)

4.5.2 Key Stakeholders and Flows

The service system of Butterfly House is composed of multiple participants, forming a collaborative network with children as the core. We divide them into three categories: internal executors, external supporters, and system promoters. Each category has a different position in the service operation and bears different responsibilities.

1) First, internal executors (Internal Actors)

The main body of daily care work is undertaken by the internal team of the institution, including sick children, family members, caregivers, social workers and volunteers. Children are the core of the entire system, and their physical and psychological state directly determines the focus of the service. Caregivers are responsible for basic care and medical intervention, social workers deal with family relationships and psychological support, and volunteers routinely assist in non-medical affairs, such as companionship, reading or outings. Family members also participate in some care tasks in the process, forming a semi-open collaborative relationship with the institution.

2) Second, external supporters (External Partners)

The extended part of the service system relies on the collaboration of multiple local cooperative institutions and administrative units. Among them, the Changsha Municipal Health Commission, Education Bureau and other departments assume the role of policy translation and resource coordination. Xiangya Hospital, Provincial Children's Hospital and other tertiary institutions provide remote consultation and emergency referral services. At the same time, public welfare foundations (such as Tencent Charity, One Foundation) and online platforms (such as Xiaohongshu and WeChat Video Account) provide important support for fundraising, communication and public awareness. These external networks have built a framework for the interface of medical-education-public welfare resources for Butterfly House.

3) Third, System Supporters

The continued operation of the system also relies on the driving force from the social and national levels, including donors, professional volunteer networks, and national associations engaged in child palliative care policy advocacy. These entities do not directly participate in the care process, but provide key support in terms of funding, training, public opinion and system construction. For example, the "Palliative Care Pilot Notice" issued by the National Health Commission provides basic guarantees for the legitimacy of the institution; the Palliative Care Committee, Nursing College and other units also continue to output professionals to the grassroots through talent training projects.

4.5.3 Flows and Relationships

1) Information Flow

The information transmission within the institution is mainly verbal and instant, and there is a lack of a unified information system. Although nursing staff and social workers maintain daily communication, the recording, sharing and updating of patient information mostly rely on paper and pen or personal experience. This unstructured information processing method leads to omissions in work handover. The transmission of external information is mostly through manual reporting or scattered presentation on online platforms, which makes it difficult to form systematic feedback to external hospitals or donors.

2) Material Flow

From care facilities, play and teaching tools, drug consumables, to living resources such as clothing and food, material support relies on the collaboration of caregivers, administrative staff and logistics volunteers. Online crowdfunding platforms are also often used for targeted procurement of specific equipment. Some resources (such as cultural and creative products and rehabilitation teaching aids) need to be obtained through customization or donation, and the entire circulation chain needs to form a good allocation logic within the institution.

3) Financial Flow

The institution mainly relies on donations to maintain operations, and the sources of donations include enterprises, individuals, foundations and community organizations. There are multiple funding channels, including Alipay, WeChat monthly donations, Xiaohongshu promotion, offline charity sales, etc. After the funds flow in, they are used for daily expenses, medical procurement and staff salary payments. We noticed that online monthly donations are a stable source of funds, but it is difficult to increase them; there are large seasonal fluctuations, such as the total income in September is significantly higher than other months, which is related to certain activities or media exposure.

Although the overall system runs stably, there are still structural bottlenecks: first, the information flow is severely fragmented, and there is a lack of a unified data platform for real-time updates and evaluation; second, the service quality is highly dependent on the support of external institutions, and the endogenous professional strength is still insufficient; third, although there are many donation channels, there is a lack of targeted communication strategies for the field of children's peace. These issues will be further discussed in the recommended chapters later.

System Map

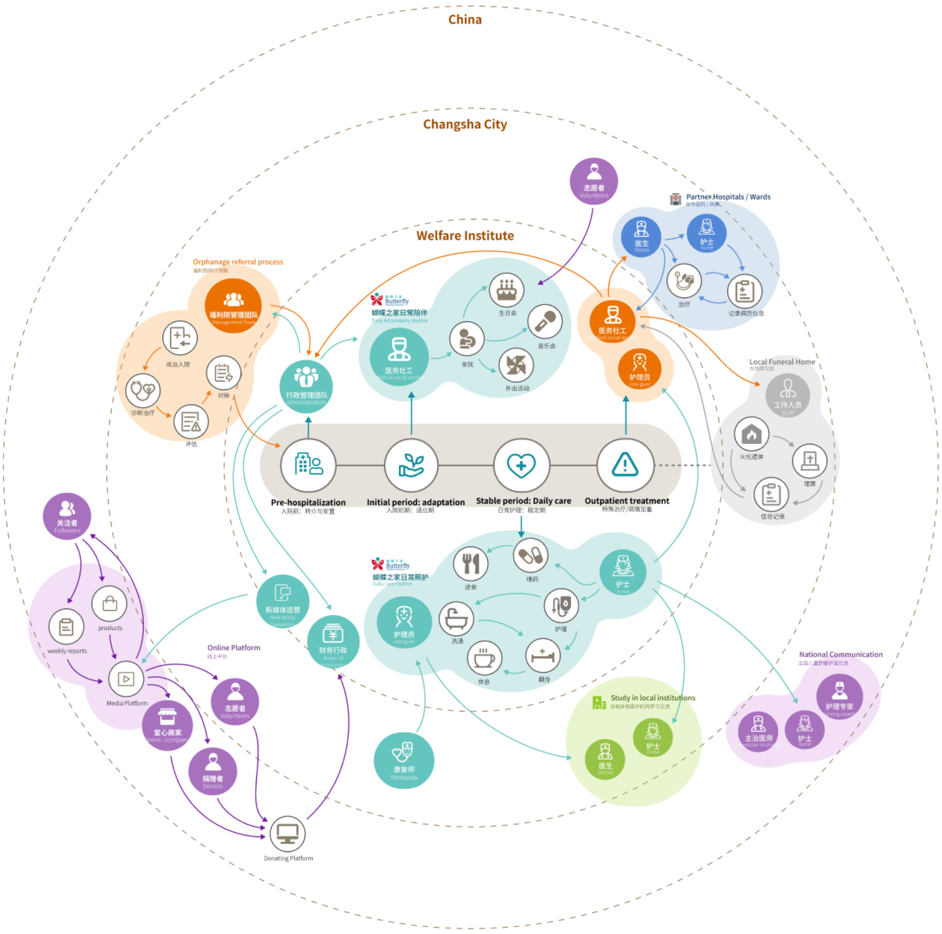


Figure 4.16 Original system (drawn by the author)

4.6 Core User Identification & User Journey Mapping

Based on in-depth interviews and participant observation, user journey maps were created for three key roles: children, caregivers, volunteers and social workers.

Based on qualitative interviews and local observations, this study mapped the user's behavioral path and emotional fluctuations, revealing the system nodes and emotional tension points in multi-party interactions:

Most of them are seriously ill children or in the late stage of chronic diseases. They often live in a highly controlled and cared-for state due to high medical dependence. They experience the emotional curve of "anxiety-attachment-loneliness-acceptance" in disability, physical discomfort, social isolation and psychological confusion, and are particularly sensitive and emotionally volatile when faced with the abstract concept of "final farewell".

1) Persona 1丨Child patient: Sunny

“I need to be understood and I want to express myself.”

Sunny is a 10-year-old boy who has suffered from a serious congenital disease since birth and has lost his basic ability to live independently. He has lived in Butterfly House, a hospice facility, for a year and is cared for by caregivers all day. He is quiet and introverted, but he strongly desires company and attention.

During his long-term bedridden life, Sunny's behavior and emotions are often constrained by physical discomfort. He is almost completely dependent on others to complete his daily life. When communicating with others, he cannot use complete language and can only express his needs or emotions through expressions, gestures or crying. This non-verbal expression requires us to interpret every tiny reaction more sensitively when caring for him.

Sunny's emotional changes are mostly ups and downs. When he first entered the institution, he showed obvious anxiety and resistance; after gradually adapting, he would become attached to a caregiver and show loneliness and sadness when separated or lacking interaction. When the disease recurs or worsens, his emotions will be particularly unstable, especially when he hears words such as "goodbye" and "transfer to another hospital".

Sunny is not a passive recipient of care. His reactions and emotional changes will affect the rhythm of the entire care process and will also affect the emotional state of the caregivers. We believe that as long as a warmer and responsive care relationship is established and a stable interactive environment is created, Sunny can have a dignified and understood quality of life within a limited time.

Persona (child)

name: Sunny

age: 10

gender: male

Time in BH: 1year

Introverted Have a strong need for care and companionship

Sunny suffers from congenital disability, **poor self-care ability**
小明患有先天性残疾，生活自理能力较差

He is currently receiving hospice care at Butterfly House, where he is being cared for daily by the care givers
目前正在蝴蝶之家接受安宁疗护，由机构的护理人员照顾日常起居

Due to their young age and certain physical disabilities, they have weak communication skills and tend to express themselves through non-verbal means (such as **gestures and expressions**)
由于年纪较小且存在某些身体障碍，沟通能力较弱，倾向于通过非语言的方式（如手势、表情）表达自己

Figure 4.17 User Persona of the child patient(drawn by the author)

Responsible for the daily life, medication feeding and vital sign management of children, they are the closest companions to children. Under the high-intensity nursing load, they often face emotional exhaustion and burnout, especially when facing the death of children, they need to rely on the psychological support mechanism provided by the system.

2) Caregiver: Grandma Zhang

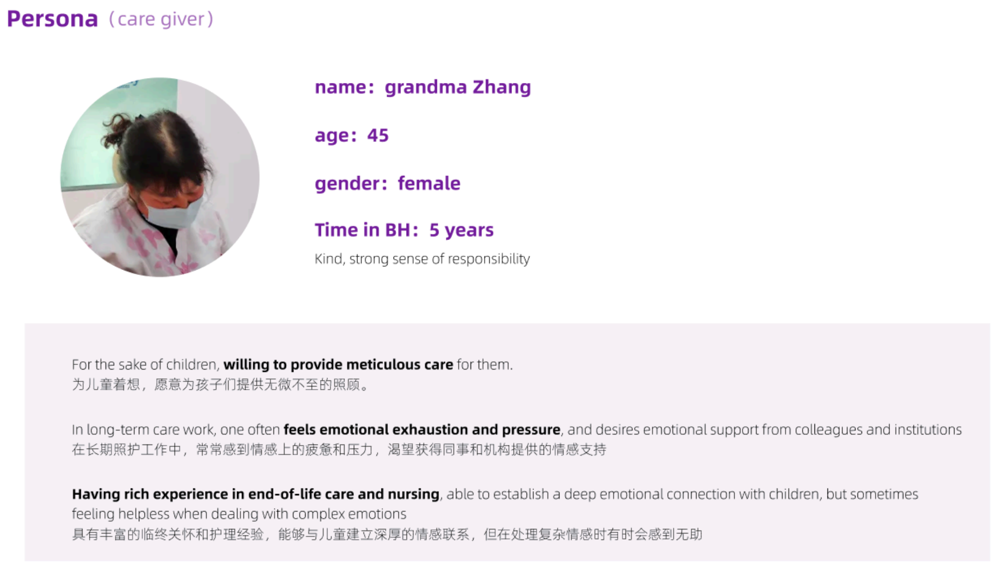
"I can't let go of the children, but sometimes I can't hold on any longer."

Grandma Zhang is an experienced female caregiver in the nursing team. She is 45 years old and has worked at Butterfly House for more than 5 years. She is kind and meticulous, and is responsible for the children's daily medication, cleaning, turning over, recording vital signs and other highly repetitive tasks.

She regards care work as a responsibility and invests a lot of emotions in it. Faced with young and seriously ill children, Grandma Zhang is willing to spend time talking to them and coaxing them to sleep, and often stays in the ward with the children after work. But this job also brings heavy psychological pressure - facing the risk of death of children for a long time, she often feels tired and powerless. Sometimes, the departure of a child will make her unable to sleep for several consecutive nights.

In the day-to-day care, she longs for more support, especially psychological comfort from professional social workers or colleagues. She really wants to learn how to regulate her emotions, and she also needs an outlet to talk and relieve stress. When faced with sudden illness or when the child loses control of his emotions, she can only rely on her own experience to judge and react.

Grandma Zhang is an important bridge between children and the medical system. She not only takes care of the children's bodies, but also soothes their emotions. We believe that if there is a more complete emotional support mechanism, it can provide caregivers like Grandma Zhang with breathing space, and indirectly improve the quality and warmth of child care.



Persona （care giver）

name：grandma Zhang

age：45

gender：female

Time in BH：5 years

Kind, strong sense of responsibility

For the sake of children, **willing to provide meticulous care** for them.
为儿童着想，愿意为孩子们提供无微不至的照顾。

In long-term care work, one often **feels emotional exhaustion and pressure**, and desires emotional support from colleagues and institutions
在长期照护工作中，常常感到情感上的疲惫和压力，渴望获得同事和机构提供的情感支持

Having rich experience in end-of-life care and nursing, able to establish a deep emotional connection with children, but sometimes feeling helpless when dealing with complex emotions
具有丰富的临终关怀和护理经验，能够与儿童建立深厚的情感联系，但在处理复杂情感时有时会感到无助

Figure 4.18 User Persona of the child patient(drawn by the author)

As a bridge role in the system, social workers play a key role in disease cognition communication, end-of-life companionship, emotional regulation and grief education. They need to coordinate the medical team and caregivers at the same time, and carry out group counseling, end-of-life rituals and service coordination.

3) Persona 3 | Social Worker: Li Jie

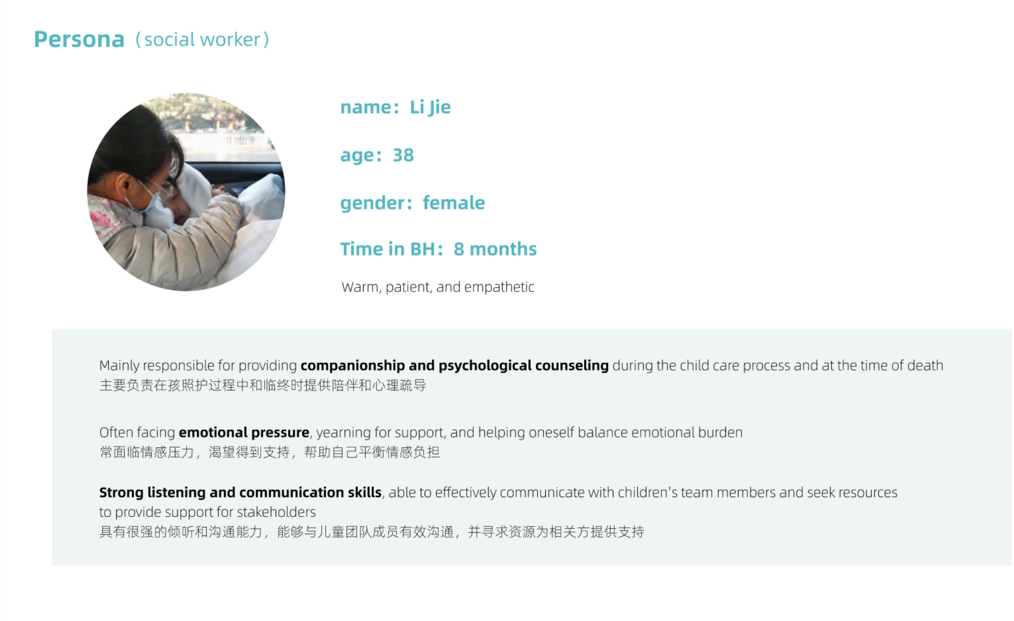
"I hope every child is seen with tenderness, and I also hope that I am understood."

Li Jie is a 38-year-old professional social worker who has been serving at Butterfly House for 8 months. She has a gentle personality, is patient, and is very good at listening. She is deeply involved in every stage of the child's life from admission to the end of life, and is responsible for companionship, emotional support, communication and coordination.

She is a bridge between the medical team and caregivers, and an important link between children and institutions and families. Every day, she has to communicate with doctors, nurses, volunteers and children at the same time, dealing with constantly changing information and sudden emotions. Sometimes, she feels very tired after answering questions and soothing emotions all day.

Li Jie also has her own vulnerable moments. She admits that she can't help crying when facing the end of life. She is eager to establish a more mature support system within the institution, including emotional relief, group supervision or professional growth support. She attaches great importance to respecting and listening to children, and often guides children to gradually accept reality through picture books, games or rituals. She also actively introduced external resources, organized group activities, and improved the children's emotional state and social skills.

Sister Li's role is not only to perform tasks, but also to be an emotional guide within the system. Her observations and feedback often promote the adjustment of service processes and also drive the delicate progress of care methods. We are well aware that giving social workers like Sister Li more support and professional growth paths is the key to maintaining the humanization and resilience of the care system.



Persona (social worker)

name：Li Jie

age：38

gender：female

Time in BH：8 months

Warm, patient, and empathetic

Mainly responsible for providing **companionship and psychological counseling** during the child care process and at the time of death
主要负责在孩照护过程中和临终时提供陪伴和心理疏导

Often facing **emotional pressure**, yearning for support, and helping oneself balance emotional burden
常面临情感压力，渴望得到支持，帮助自己平衡情感负担

Strong listening and communication skills, able to effectively communicate with children's team members and seek resources to provide support for stakeholders
具有很强的倾听和沟通能力，能够与儿童团队成员有效沟通，并寻求资源为相关方提供支持

Figure 4.19 User Persona of the social worker (drawn by the author)

4) Volunteers

Provide flexible support resources in daily companionship, game interactions and short-term activities for children. Their entry rhythm is uncertain and their roles are often changing, which poses a challenge to the continuity of services, but they play a positive role in emotional injection and the introduction of cultural resources.

These roles jointly maintain the quality of life of sick children through informal communication (such as verbal handover), system information flow (such as nursing records), and material resource allocation (such as personalized supplies). The journey map reveals multiple system breakpoints and potential opportunities, such as information lag, difficulty in resource coordination, and concentrated emotional burden, which provide a basis for strategic intervention.

4.7 Key Service Scenarios and Situations

Based on spatial observation and interview analysis, the following five types of service situations with systematic significance were identified, and the opportunity point identification and service intervention structure were constructed accordingly:

1) Initial contact and admission stage

The adaptation period after the child is admitted to the hospital is usually accompanied by physiological assessment, stable condition, and unfamiliarity with the space. Social worker introduction, nursing companionship and environmental guidance at this stage become key intervention points.

2) Interactive links in daily care

The high-frequency contact between the nurse and the child forms a micro-system in emotional support, attachment establishment and non-verbal communication, which is the emotional pillar of children's "sense of security" and "sense of existence".

3) Individualized emotional and game support

The introduction of volunteers enables children to obtain interesting activities and psychological relaxation outside of standardized care, but its discontinuity and lack of guidance also bring a sense of interference, emphasizing the necessity of "accompanying training" and "case continuity" mechanisms.

4) Collaborative communication across roles

The collaboration between caregivers, social workers and medical staff often reflects the difficulty of system coordination in the communication of treatment plans, psychological assessment and mourning farewell ceremony, especially the lack of unified communication records and emotional feedback mechanisms.

5) Terminal stage and "farewell ceremony" design

In the terminal period of children, social workers often lead the case-based emotional guidance, life education and memorial ceremony design to build a "complete and dignified farewell". However, its visibility and institutional support still need to be strengthened.

In each of these scenes, the behavior and emotions of multiple participants are affected, forming the logical starting point for subsequent service intervention and strategy introduction, and are highly corresponding to the information flow, role flow and material flow in the System Map.

5. Gigamap & System Mapping

To comprehensively understand the stakeholder relationships, service flow, and physical/informational networks surrounding children’s palliative care, a gigamap was developed. The gigamap visualizes the organizational structure of the welfare institute and its links with healthcare systems, public sector agencies, NGOs, family networks, and volunteers. This complex relational web was analyzed based on categories of actors (institutional, professional, people, business) and types of relationships (action, flow of money/matter, information, etc.), providing a full-system view to locate design leverage points.

5.1 Challenges and Opportunities Mapping: B-D-A-T

Using the B-D-A-T framework (Before entering: During stay, After discharge, and Territory-wide), system-level challenges were mapped according to the child's care journey. A total of 19 specific challenges were identified: 4 pre-institutional (B), 6 in-institutional (D), 4 post-institutional (A), and 5 territorial/systemic (T). Each challenge was rated on two criteria:

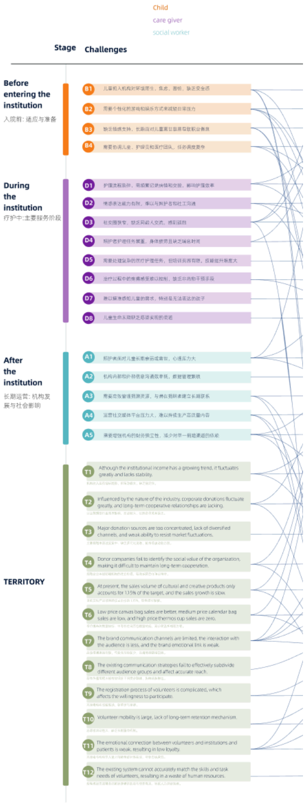

Challenges

Figure 5.1 Challenges identified (drawn by the author)

For each challenge, an initial set of opportunity points was co-created through workshops with stakeholders, leading to 29 opportunities mapped across the care spectrum.

5.2 Systemic Impact Assessment

To assess the system-wide value and feasibility of each opportunity point, this study constructed a comprehensive evaluation framework that integrates systemic leverage, stakeholder value, and local adaptability. Rather than evaluating opportunities in isolation, we adopted a matrix approach to understand their interconnected impact on the institutional ecosystem. Each opportunity was assessed according to three major dimensions: its ability to trigger system-level change with limited input (i.e., leverage), its relevance to core stakeholders such as children, caregivers, and social workers, and its compatibility with the practical and cultural conditions of the welfare institution and local community.

The result was presented through a system matrix, where the scores were visualized using bubble graphs for comparative clarity. Opportunities with high scores in both leverage and feasibility dimensions emerged as potential priorities for immediate implementation. These included the digital emotion tracking system, the redesign of care handover tools, and resilience-building training for frontline social workers. Their high relevance to core users and relatively low implementation barriers make them strong candidates for short-term piloting and iterative development.

In contrast, several initiatives that demonstrated strong systemic impact but lacked current stakeholder support, such as the national pediatric palliative care certification pathway or large-scale data integration infrastructure, were identified as long-term strategic directions. While their implementation may require external resources, policy support, or broader system restructuring, their long-term value in transforming sectoral capacity remains significant.

Meanwhile, interventions that showed high appeal but relatively low systemic output—such as personalized comfort packages or volunteer gamification strategies—were noted for their emotional and cultural value. These points, though not prioritized for systemic reform, contribute to service warmth and user experience, especially in environments that rely heavily on emotional labor.

Ultimately, this scoring approach provided a grounded and nuanced lens to filter out not only what is desirable, but also what is truly achievable and worthwhile. By aligning user needs, systemic gaps, and contextual readiness, the matrix helped prioritize interventions that are not only needed but also viable—strategies that can drive change from within and sustain it through institutional momentum.

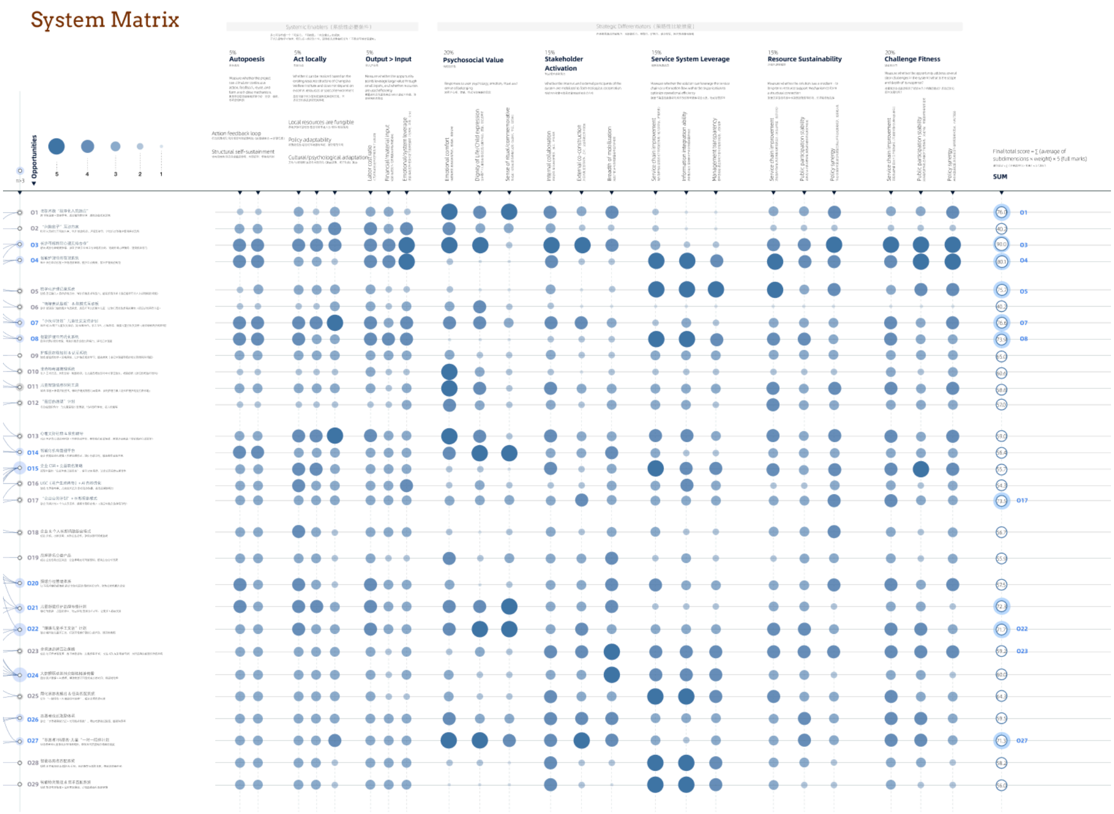


Figure 5.2 Assessment system (drawn by the author)

5.3 Opportunity Generation and Classification: Microarea division and system clustering

The 29 opportunity points were not randomly proposed. Each originated from field-based insights, drawn from participatory observations, user interviews, and multi-stakeholder co-creation sessions across various service stages. These observations revealed not only fragmented service experiences but also unspoken needs and systemic blind spots. By capturing these insights and abstracting them into discrete interventions, I gradually formed a pool of high-potential opportunities with varied thematic focuses and implementation conditions.

To organize these scattered innovations and align them with system-level planning, we introduced the method of “Micro-area Clustering.” A micro-area refers to a specific yet systemic sub-zone within the institutional ecology where targeted interventions can exert leverage. Each micro-area consists of several related opportunity points, grouped by common user needs, workflow similarities, or service touchpoints. This approach allows us to shift from single-point optimization to modular planning, designing solutions that mutually reinforce within a defined service scope.

Form 5.1 Five main micro-areas were identified through this process

Microarea Code	**Category**	**Example Opportunities**
A	Emotional Support	O1, O5, O27
B	Institutional Process & Efficiency	O4, O8
C	Information Infrastructure	O23
D	Territory & External Partnerships	O9, O17
E	Cultural & Symbolic Interventions	O7, O22

1) **A: Emotional Support Microarea**

   Focuses on children's emotional wellbeing, grief processing, and relational trust-building. Representative points include the establishment of the Changsha Psychological Support System (O1), child companionship programs (O5), and the One-on-One Mentorship Initiative (O27). These opportunities reflect the urgent need for systematic and long-term emotional care in the pediatric palliative context.

2) **B: Institutional Process & Efficiency**
   Includes tools and platforms that enhance daily care efficiency and reduce staff burnout. Examples are the Intelligent Record System for Nursing Shifts (O4) and the Smart Scheduling System (O8). These are highly compatible with the existing operation model of the welfare institute and directly address process bottlenecks.

3) **C: Information Infrastructure**
   Currently represented by the Social Media Sentiment Analysis Tool (O23), this micro-area targets data gaps in the evaluation and dissemination of care. By using digital technologies, it helps institutions gather feedback, monitor public sentiment, and optimize communication with stakeholders.

4) **D: Territory & External Partnerships**
   Includes innovations related to inter-institutional logistics and resource circulation, such as the Medical Asset Coordination Mechanism (O9) and Volunteer Feedback Loop (O17). These interventions improve systemic resilience and reduce dependency on any single entity.

5) **E: Cultural & Symbol**
   Involves symbolic, educational, or commemorative initiatives, like the Child-Led Role Exploration Toolkit (O7) and Volunteer Recognition and Growth Mechanism (O22). Although these points may have less immediate operational impact, they help enhance dignity, meaning, and a sense of belonging within the institution.

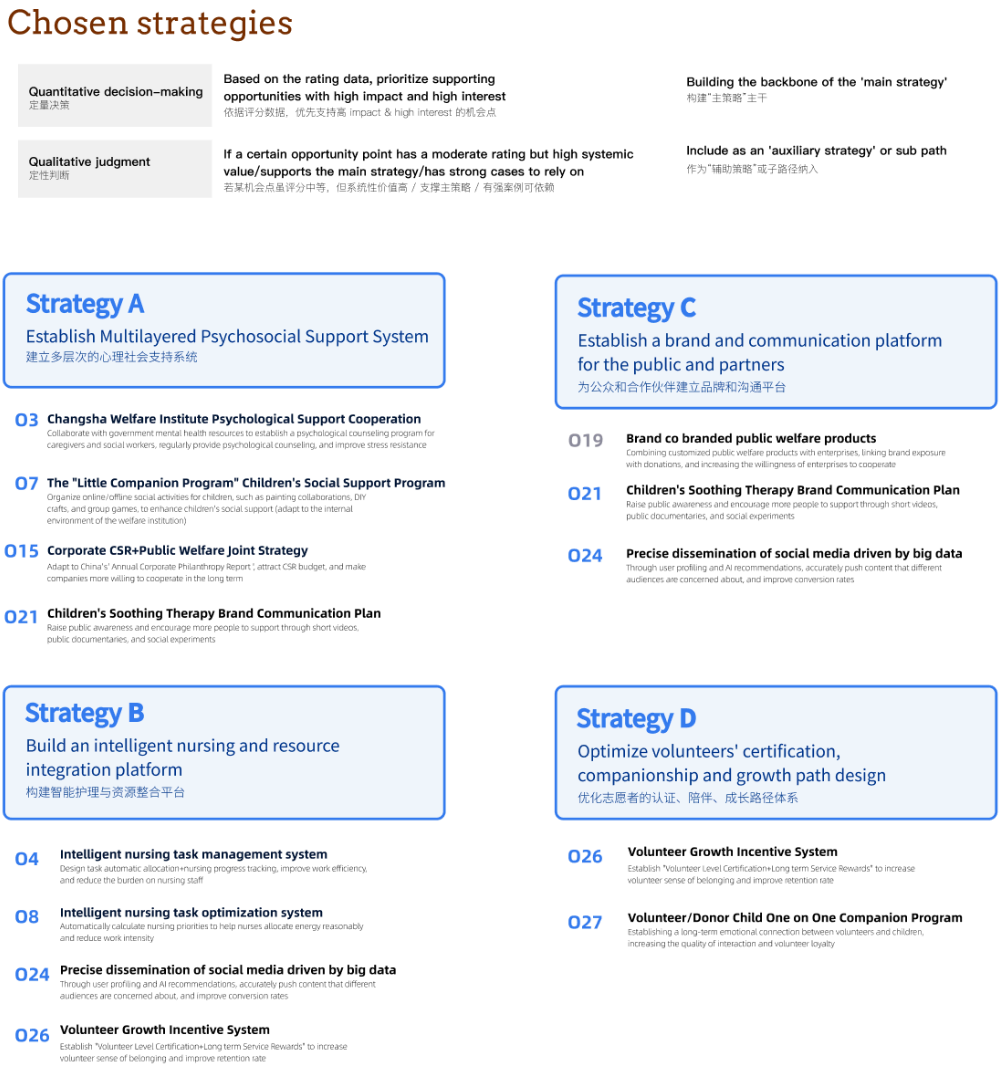
These classifications provide the groundwork for Chapter 6, where we propose modular design strategies based on the micro-area framework. The cross-referencing with best practices and real cases, detailed in Chapter 7, further validates the relevance and potential impact of each cluster.

6. Opportunities Identification & Assessment

This chapter focuses on the process of identifying, evaluating, and prioritizing potential design interventions based on systemic and strategic criteria. Unlike the strategic synthesis and roadmap development in later chapters, here the emphasis lies on the diagnostic and analytical foundation of the project.

6.1 Evaluation Matrix and Selection: Identifying Priority Interventions

To systematically identify the most promising design interventions, a weighted evaluation matrix was constructed, integrating eight sub-criteria: **Autopoiesis, Act Locally, Output>Input, Psychosocial Value, Stakeholder Activation, Service System Leverage, Resource Sustainability, and Challenge Fitness**. Each of the 29 opportunity points was scored based on qualitative and quantitative inputs from expert consultations, case analysis, and stakeholder interviews.



Chosen strategies

Quantitative decision-making 定量决策	Based on the rating data, prioritize supporting opportunities with high impact and high interest 依据评分数据，优先支持高 impact & high interest 的机会点	Building the backbone of the 'main strategy' 构建"主策略"主干
Qualitative judgment 定性判断	If a certain opportunity point has a moderate rating but high systemic value/supports the main strategy/has strong cases to rely on 若某机会点虽评分中等，但系统性价值高 / 支撑主策略 / 有强案例可依赖	Include as an 'auxiliary strategy' or sub path 作为"辅助策略"或子路径纳入

Strategy A
Establish Multilayered Psychosocial Support System
建立多层次的心理社会支持系统

03 **Changsha Welfare Institute Psychological Support Cooperation**
Collaborate with government mental health resources to establish a psychological counseling program for caregivers and social workers, regularly provide psychological counseling, and improve stress resistance

07 **The "Little Companion Program" Children's Social Support Program**
Organize online/offline social activities for children, such as painting collaborations, DIY crafts, and group games, to enhance children's social support (adapt to the internal environment of the welfare institution)

015 **Corporate CSR+Public Welfare Joint Strategy**
Adapt to China's' Annual Corporate Philanthropy Report ', attract CSR budget, and make companies more willing to cooperate in the long term

021 **Children's Soothing Therapy Brand Communication Plan**
Raise public awareness and encourage more people to support through short videos, public documentaries, and social experiments

Strategy B
Build an intelligent nursing and resource integration platform
构建智能护理与资源整合平台

04 **Intelligent nursing task management system**
Design task automatic allocation+nursing progress tracking, improve work efficiency, and reduce the burden on nursing staff

08 **Intelligent nursing task optimization system**
Automatically calculate nursing priorities to help nurses allocate energy reasonably and reduce work intensity

024 **Precise dissemination of social media driven by big data**
Through user profiling and AI recommendations, accurately push content that different audiences are concerned about, and improve conversion rates

026 **Volunteer Growth Incentive System**
Establish "Volunteer Level Certification+Long term Service Rewards" to increase volunteer sense of belonging and improve retention rate

Strategy C
Establish a brand and communication platform for the public and partners
为公众和合作伙伴建立品牌和沟通平台

019 **Brand co branded public welfare products**
Combining customized public welfare products with enterprises, linking brand exposure with donations, and increasing the willingness of enterprises to cooperate

021 **Children's Soothing Therapy Brand Communication Plan**
Raise public awareness and encourage more people to support through short videos, public documentaries, and social experiments

024 **Precise dissemination of social media driven by big data**
Through user profiling and AI recommendations, accurately push content that different audiences are concerned about, and improve conversion rates

Strategy D
Optimize volunteers' certification, companionship and growth path design
优化志愿者的认证、陪伴、成长路径体系

026 **Volunteer Growth Incentive System**
Establish "Volunteer Level Certification+Long term Service Rewards" to increase volunteer sense of belonging and improve retention rate

027 **Volunteer/Donor Child One on One Companion Program**
Establishing a long-term emotional connection between volunteers and children, increasing the quality of interaction and volunteer loyalty

Figure 6.1 chosen strategies (drawn by the author)

Each of the 29 identified opportunity points was scored by a panel of stakeholders and experts, with references drawn from participatory co-design workshops, institutional case analysis, and impact research in similar healthcare-social domains. Among the 29, the following 10 opportunities received the highest average scores and were shortlisted as priority design actions.

Form 6.1 Opportunity Point (drawn by the author)

Code	Opportunity Point	Keyword	Primary Function
O1	Changsha Psychosocial Support System	Emotional Relief	Alleviates psychological burden for caregivers and children
O4	Intelligent Nursing Task Logging System	Process Efficiency	Reduces task omission and workload
O5	Children's Social Companion Project	Social Reintegration	Enhances children’s recovery and social participation
O7	“Little Care Officer” Child Social Work Mechanism	Social Role	Establishes child-led emotional support roles
O8	Smart Scheduling and Transfer Coordination System	System Optimization	Improves human resource deployment and operational efficiency
O9	Medical Resource Donation and Allocation Platform	Resource Assurance	Strengthens resource availability and reduces systemic waste
O17	Volunteer Feedback and Interaction Channel	Service Quality	Enhances engagement experience and interaction transparency
O22	Volunteer Growth Incentive System	Service Sustainability	Improves volunteer retention and sense of contribution
O23	Social Media Profile and Data Analytics Mechanism	Data Insight	Enhances communication efficiency and targeting precision
O27	One-on-One Child Companion Recognition Program	Personalized Support	Provides stable and enduring psychological companionship

These opportunities were selected not only for their individual impact, but also for their potential **interconnected leverage** across emotional, informational, and operational layers of the system.

6.2 Cluster Preview: Toward Strategy Formation

While detailed strategy formation is elaborated in Chapter 7, this section briefly previews how the above opportunities begin to **cluster thematically**, hinting at their role in the emergent design ecosystem:

Form 6.2 Opportunity Cluster (drawn by the author)

Initial Cluster	**Representative Opportunities**	**Orientation**	**Thematic Focus**
Cluster A	O1, O5, O7	Emotional-psychosocial	Build emotional support and role mechanisms
Cluster B	O4, O8, O23	Digital-process	Improve operational efficiency and information feedback
Cluster C	O9, O17	Resource-activation	Open up resource entry points and interactive feedback
Cluster D	O22, O27	Volunteer-socialization	Strengthen the sense of belonging and the relationship of companionship

Each cluster contains complementary short- term, mid- term, and long-term potential, preparing the ground for strategy synthesis in the following chapters.

6.3 From Evaluation to System Mapping

Building on the opportunity evaluation matrix from the previous chapter, ten high-priority interventions were selected and embedded into the overall system map. This visual integration was not only a spatial exercise, but also a methodological bridge, translating analytical scores into design action. Through this process, abstract concepts and localized interventions were situated within a concrete institutional ecology, revealing how design leverage can operate within and across different layers of the welfare system.

The mapping process focused on three design visibility dimensions:

1) **Actor Linkage**

   Each intervention was linked to its associated actors—whether direct service users such as children and caregivers, or peripheral stakeholders like donors, volunteers, and municipal officials. This clarified the collaborative responsibility across the ecosystem. For example, the intervention "Grief Companion Program" spans caregivers, social workers, and institutional policy teams, revealing its reliance on cross-role collaboration to succeed.

2) **Flow Integration**

   The interventions were examined in terms of how they integrated three types of flows—emotional, operational, and informational. For instance, the "Digital

Nursing Shift Recorder" not only streamlines caregiving tasks but also captures caregivers' stress levels, making it a dual-channel system for task execution and emotional monitoring.

3) **Temporal Readiness**

Each selected opportunity was assessed for its temporal alignment with the existing service system. Some, such as "Volunteer Recognition System," can be deployed in the short-term using current resources. Others, like "Inter-agency Referral Mechanism," require phased coordination with external actors and thus belong to a mid-to-long-term implementation track. This temporal layering helps stagger intervention entry points to avoid overloading staff capacity.

This system-based remapping lays the groundwork for Chapter 7, where we will move from diagnosis to design, developing integrated design strategies grounded in real-world constraints and driven by stakeholder needs.

7. Good Case Studies

7.1 Case Overview and Selection Criteria

To explore how other regions and institutions address similar challenges in pediatric palliative care, we systematically selected eight benchmark cases from international and domestic sources. These cases came from academic literature, NGO archives, and expert consultations. Each one reflects distinct yet practical responses to issues such as emotional stress, communication breakdown, limited funding, or fragmented service structures—challenges that are also present in the Chinese context.

The selection was guided by three main criteria. The first was thematic relevance. All cases needed to resonate with the core challenges identified through our fieldwork, whether the goal was to ease emotional burdens for children or to improve stakeholder collaboration. The second was system-level value. We prioritized interventions that triggered structural changes within the service system, rather than isolated or temporary improvements. The third was adaptability. Each case was reviewed not only for its innovation but also for how it could be contextualized and locally adapted, especially within culturally nuanced care settings like China.

Take "Memory Boxes" and "Bravery Beads" as examples. They both offer simple, low-cost solutions that carry high emotional impact by giving children a sense of identity and continuity. "Camp Sunshine" and "VR Pain Management" show how immersive experiences can reduce medical anxiety and enhance communication between families and caregivers. "Emotion Recognition Robots" and "Schwartz Rounds" provide systemic responses to emotional labor and burnout, especially for long-term staff. The last two cases, "TikTok #ForGood" and "UNICEF Pledge" Program, demonstrate how digital media and monthly giving can be leveraged to sustain funding, engage youth, and increase public awareness in a crowded media landscape.

These diverse yet complementary approaches provide not only inspiration but also actionable insight. They serve as valuable learning sources for the strategic proposals presented in Chapter 7.3, where their principles are reinterpreted in culturally appropriate and resource-sensitive ways.

7.2 Case Summary

Form 7.1 Case summary (drawn by the author)

Case Name	**Target Group**	**Core Strategy**	**Notable Benefits**	**Local Adaptation Suggestion**
Memory Boxes	Seriously ill children	Personalized emotional items for familiarity	Reduce anxiety, enhance environmental adjustment	Add cultural elements to personalize boxes (e.g., Chinese motifs)
Bravery Beads	Pediatric patients undergoing treatments	Milestone-based symbolic beads	Improve emotional resilience, facilitate story narration	Use culturally symbolic beads to support local meaning
Camp Sunshine	Seriously ill children & families	Therapeutic recreation and family retreat	Strengthen family bonds, reduce stress	Develop Chinese family-based care camps with hospital linkage
VR Pain Management	Children with acute/chronic pain	Immersive VR distraction to reduce pain	Reduce anxiety and drug use, enhance cooperation	Use culturally themed VR (e.g., ink painting, animated stories)
Emotion Recognition Robot	Long-term hospitalized children	AI-based emotion analysis and interaction	Improve emotion expression and care quality	Embed local cultural visuals, adapt AI model to local emotional cues
Schwartz Rounds	Healthcare workers	Structured emotional reflection sessions	Reduce burnout, improve empathy and teamwork	Develop smaller "carer support groups" for Chinese nursing homes
TikTok #ForGood	NGOs, Donors, Youth	Viral video and gamified fundraising campaigns	Increase visibility, youth engagement, and donations	Use WeChat/Douyin for culturally aligned short video advocacy
UNICEF Pledge Program	Children in crisis (war, disease, hunger)	Monthly donation and long-term donor engagement	Ensure sustainable funding, build trust	Create "Loving Guardian" program for regular donation to hospice services

7.3 Good Case Analysis

Case 01: Memory Boxes – Helen & Douglas House (UK)

Memory Boxes were designed to address the emotional maladjustment and anxiety faced by seriously ill children frequently moved across unfamiliar care environments. The intervention aims to enhance their sense of safety and familiarity through personalized storage of emotionally significant items (e.g., photos, letters). The design encourages children to create emotional connections by decorating their own boxes, promoting a sense of ownership. Key resources include emotional support tools, human resources (social workers), and institutional coordination. The project primarily involves children, caregivers, and psychosocial professionals.

It reduces anxiety during hospitalization and enhances staff-child communication. Adaptation potential lies in culturally tailoring the boxes to local symbolic elements (e.g., Chinese motifs).

Good Case Study

01 **Memory Boxes**

Helen & Douglas House

Brief Intro

Memory Boxes 由 Helen & Douglas House 推出，旨在帮助入住的儿童建立归属感，减少入院焦虑。儿童可以使用盒子存放个人物品（如玩具、照片、家人信件），以在医疗环境中保留熟悉感，以提升儿童的心理安全感。

Citation

Helen & Douglas House. (n.d.). Memory Boxes for children in hospice care.
https://www.helenanddouglas.org.uk

Introduction

Locations
Oxford

country
the UK

Period
2000-now

Benefit Group
Seriously ill children and their families

Sphere of influence

Regionale
Covers some children's hospice facilities in the UK

Key direction 重点方向
- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源
- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者
- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers

Key Outcomes 关键成果
- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness

Project background

Many seriously ill children are prone to environmental maladjustment and lack of security when they are frequently moved to medical facilities, and Memory Boxes are designed to enhance children's sense of familiarity and emotional support through personalized storage of items

许多重症儿童在频繁转移医疗机构时，容易产生 环境不适应 & 安全感缺失，Memory Boxes 旨在通过 个性化物品存储，增强儿童的熟悉感和情感支持

Goals and values
- Through personalized storage boxes, children can carry their own toys, photos, family letters, etc.
- to make the medical environment more home and reduce children's anxiety
- 通过 个性化存储盒，让儿童随身携带自己的玩具、照片、家人信件等
- 让医疗环境更具"家"的感觉，降低儿童焦虑

Major player
- Helen & Douglas House (Lead agency)
- Health Care Worker Social Worker Child Psychologist

Design Methods
- Emotional Connection: Storing important items for children to reduce the strangeness of the environment
- Personalization: Each storage box can be decorated by children themselves
- 情感链接:存储儿童重要物品，减少环境陌生感
- 个性化体验:个存储盒可以由儿童自己装饰

Key Benefits
- Child level: Reduce anxiety and adaptation disorders, and improve emotional support during hospitalization
- Nursing staff level: Help nursing staff establish trust with children faster and reduce communication difficulties
- Institutional level: Improve the environment for children's palliative care and increase social attention to palliative care
- Social level: Enhance the participation of social volunteers and improve public awareness of children's palliative care

- 儿童层面：减少焦虑和适应障碍，提高住院期间的情感支持
- 护理员层面：帮助护理人员更快建立与儿童的信任关系，减少沟通难度
- 机构层面：改善儿童安宁疗护环境，提高社会对舒缓疗护的关注度
- 社会层面：增强社会志愿者的参与度，提高儿童舒缓疗护的公共认知

Takeaways & Adaptability 借鉴点 & 适用性
- Reference point: Butterfly Home can develop a "Welcome Package for Admission", which includes a personalized storage bag for children to bring their own belongings when checking in.
- Applicability adjustment: Compared to the UK project, Butterfly Home can add cultural elements (such as calligraphy and picture books) to make the storage box more suitable for the needs of Chinese children.

- 借鉴点：蝴蝶之家可以开发 "入院欢迎包"，包括一个个性化存储袋，让儿童可以带自己的物品入住。
- 适用性调整：相比英国项目，蝴蝶之家可以增加 文化元素（如书法、绘本），让存储盒更贴合中国儿童的需求。

Figure 7.1 Good case study: Memory Box (drawn by the author)

Case 02: Bravery Beads – BC Children's Hospital (Canada)

Bravery Beads were created to help children cope with repeated medical interventions by commemorating treatment milestones. Each bead represents a specific medical act or achievement, symbolizing bravery.The design focuses on ritualized recognition and personalization, giving children control over narrating their medical journey.Resources include symbolic materials, clinical staff participation, and volunteer support. It activates caregivers, medical workers, and family engagement.

This program improves psychological resilience and emotional expression in children, with potential for localization through integrating cultural symbols into bead designs.

Good Case Study

02 **Bravery Beads**

BC Children's Hospital温哥华儿童医院

Brief Intro

Bravery Beads 由 温哥华儿童医院（BC Children's Hospital）开发，旨在帮助患病儿童通过收集珠子来记录他们的治疗旅程。每当孩子完成一次治疗或经历一个重要的医疗步骤（如手术、化疗、住院天数等），就可以获得一个具有象征意义的珠子。该项目广泛应用于北美多家儿童医院，帮助儿童建立勇气和成就感。

Citation

Dengler, K. A., Wilson, V., Redshaw, S., & Scarfe, G. (2012). Appreciation of a child's journey: Implementation of a cardiac action research project. Nursing Research and Practice, 2012(1), 145030.
📎: https://metaso.cn/s/t2rzl1Z
https://braveryhearts.com/

Introduction

Locations country
Oxford **the UK**

Period
2000-now

Benefit Group
Seriously ill children and their families

Sphere of influence

Regionale
Covers some children's hospice facilities in the UK

Key direction 重点方向

- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源

- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者

- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers

Key Outcomes 关键成果

- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness

Project background

Many seriously ill children are prone to environmental maladjustment and lack of security when they are frequently moved to medical facilities, and Memory Boxes are designed to enhance children's sense of familiarity and emotional support through personalized storage of items

许多重症儿童在频繁转移医疗机构时，容易产生 环境不适应 & 安全感缺失，Memory Boxes 旨在通过 个性化物品存储，增强儿童的熟悉感和情感支持

Goals and values

- Through personalized storage boxes, children can carry their own toys, photos, family letters, etc.
- to make the medical environment more home and reduce children's anxiety

- 通过 个性化存储盒，让儿童随身携带自己的玩具、照片、家人信件等
- 让医疗环境更具"家"的感觉，降低儿童焦虑

Major player

- Helen & Douglas House (Lead agency)
- Health Care Worker Social Worker Child Psychologist

- Helen & Douglas House（主导机构）
- 医护人员 - 社会工作者 - 儿童心理学家

Design Methods

- Emotional Connection: Storing important items for children to reduce the strangeness of the environment
- Personalization: Each storage box can be decorated by children themselves

- 情感链接:存储儿童重要物品，减少环境陌生感
- 个性化体验:个存储盒可以由儿童自己装饰

Key Benefits

- Child level: Reduce anxiety and adaptation disorders, and improve emotional support during hospitalization
- Nursing staff level: Help nursing staff establish trust with children faster and reduce communication difficulties
- Institutional level: Improve the environment for children's palliative care and increase social attention to palliative care
- Social level: Enhance the participation of social volunteers and improve public awareness of children's palliative care

- 儿童层面：减少焦虑和适应障碍，提高住院期间的情感支持
- 护理员层面：帮助护理人员更快建立与儿童的信任关系，减少沟通难度
- 机构层面：改善儿童安宁疗护环境，提高社会对舒缓疗护的关注度
- 社会层面：增强社会志愿者的参与度，提高儿童舒缓疗护的公共认知

Takeaways & Adaptability 借鉴点 & 适用性

- Reference point: Butterfly Home can develop a "Welcome Package for Admission", which includes a personalized storage bag for children to bring their own belongings when checking in.
- Applicability adjustment: Compared to the UK project, Butterfly Home can add cultural elements (such as calligraphy and picture books) to make the storage box more suitable for the needs of Chinese children.

- 借鉴点：蝴蝶之家可以开发 "入院欢迎包"，包括一个个性化存储袋，让儿童可以带自己的物品入住。
- 适用性调整：相比英国项目，蝴蝶之家可以增加 文化元素（如书法、绘本），让存储盒更贴合中国儿童的需求。

Figure 7.2 Good case study: Bravery Beads (drawn by the author)

Case 03: Camp Sunshine – UK-based Pediatric Camp

Camp Sunshine provides year-round therapeutic recreation for children with life-threatening illnesses and their families. It creates a supportive environment that blends healthcare support with leisure and psychosocial engagement. The intervention emphasizes immersive experiences including art, swimming, and group bonding, while offering emotional relief. Infrastructure and trained volunteers are central, alongside social work and psychological support teams. The model supports family-centered care and social reintegration.

It enhances family cohesion and reduces treatment stress. Adaptation in Chinese contexts could focus on localized family retreat models with institutional care partnerships.

Good Case Study

03 **Camp Sunshine**

缅因州塞巴戈湖畔

Brief Intro

Camp Sunshine 是一个为患有严重疾病（如癌症）的儿童及其家庭提供支持和娱乐的疗养营。该营地成立于1984年，位于缅因州塞巴戈湖畔，至今已服务了来自美国50个州和27个国家的6万多名儿童、兄弟姐妹和父母。

Citation

Jordan, D. H. (Ed.). (2020). It's Like Heaven: Stories from Camp Sunshine. University of Georgia Press.

: https://usa.sika.com/dam/dms/us01/r/CampSunshine.pdf

https://www.campsunshine.org/

Introduction

Locations: **Oxford**

country: **the UK**

Period: **2000-now**

Benefit Group: **Seriously ill children and their families**

Sphere of influence

Regionale

Covers some children's hospice facilities in the UK

Key direction 重点方向

- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源

- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者

- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers

Key Outcomes 关键成果

- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness

Project background

Camp Sunshine's programs are open all year round and are designed to provide a relaxing and supportive environment for the whole family. The camp offers a variety of activities, including swimming, craft making, kayaking and more, as well as facilities such as an indoor pool, games room and multi-purpose restaurant. In addition, the camp provides on-site medical support and psychosocial support to help families cope with their child's illness.

Camp Sunshine 的项目全年开放，旨在为整个家庭提供一个放松和支持的环境。营地提供多种活动，包括游泳、手工艺品制作、皮划艇等，同时设有室内游泳池、游戏室和多功能餐厅等设施。此外，营地还提供现场医疗支持和心理社会支持，帮助家庭应对孩子的疾病。

Goals and values

- Through personalized storage boxes, children can carry their own toys, photos, family letters, etc.
- to make the medical environment more home and reduce children's anxiety

- 通过 个性化存储盒，让儿童随身携带自己的玩具、照片、家人信件等
- 让医疗环境更具"家"的感觉，降低儿童焦虑

Major player

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- Health Care Worker Social Worker Child Psychologist

- Helen & Douglas House（主导机构）
- 医护人员 - 社会工作者 - 儿童心理学家

Design Methods

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Key Benefits

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- 护理员层面：帮助护理人员更快建立与儿童的信任关系，减少沟通难度
- 机构层面：改善儿童安宁疗护环境，提高社会对舒缓疗护的关注度
- 社会层面：增强社会志愿者的参与度，提高儿童舒缓疗护的公共认知

Takeaways & Adaptability 借鉴点 & 适用性

- Reference point: Butterfly Home can develop a "Welcome Package for Admission", which includes a personalized storage bag for children to bring their own belongings when checking in.
- Applicability adjustment: Compared to the UK project, Butterfly Home can add cultural elements (such as calligraphy and picture books) to make the storage box more suitable for the needs of Chinese children.

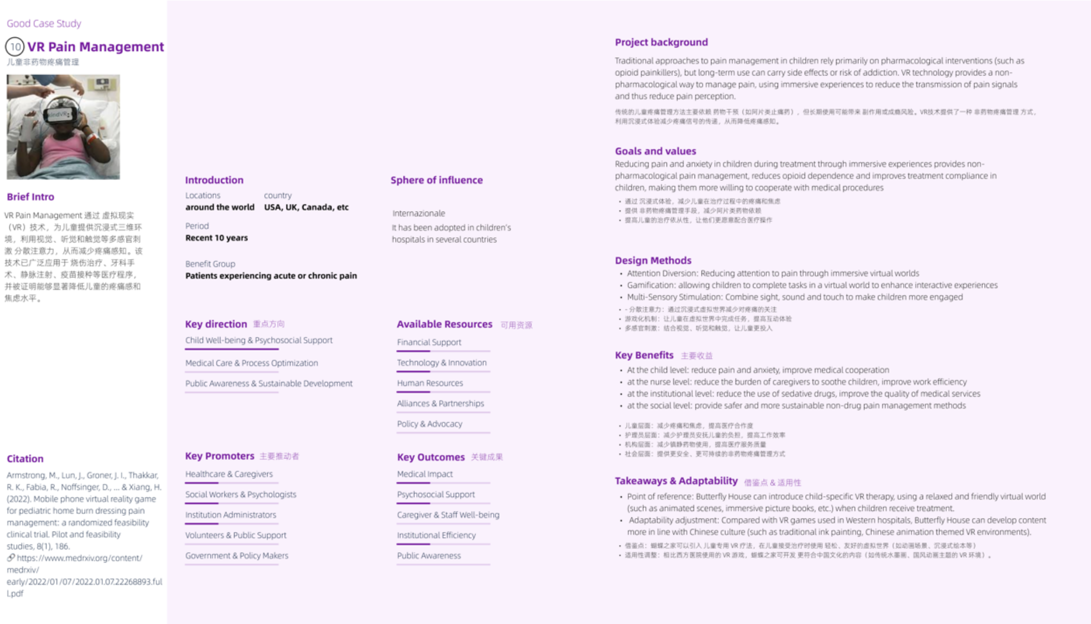
- 借鉴点：蝴蝶之家可以开发 "入院欢迎包"，包括一个个性化存储袋，让儿童可以带自己的物品入住。
- 适用性调整：相比英国项目，蝴蝶之家可以增加 文化元素（如书法、绘本），让存储盒更贴合中国儿童的需求。

Figure 7.3 Good case study: Camp Sunshine (drawn by the author)

Case 10: VR Pain Management (USA, UK, Canada)

VR Pain Management addresses pediatric pain through immersive distraction rather than pharmacological means, targeting both acute and chronic cases.Children are engaged through virtual experiences, reducing procedural anxiety and enhancing cooperation. The approach leverages innovation, financial support, and clinical protocols. Stakeholders include hospital staff, donors, and child participants.

It significantly reduces drug use and improves care quality. Adaptation in China can involve VR tools incorporating culturally familiar aesthetics (e.g., animation or painting styles).



Good Case Study

⑩ **VR Pain Management**

儿童非药物疼痛管理

Brief Intro

VR Pain Management 通过 虚拟现实（VR）技术，为儿童提供沉浸式三维环境，利用视觉、听觉和触觉等多感官刺激 分散注意力，从而减少疼痛感知。该技术已广泛应用于 烧伤治疗、牙科手术、静脉注射、疫苗接种等医疗程序，并被证明能够显著降低儿童的疼痛感和焦虑水平。

Citation

Armstrong, M., Lun, J., Groner, J. I., Thakkar, R. K., Fabia, R., Noffsinger, D., ... & Xiang, H. (2022). Mobile phone virtual reality game for pediatric home burn dressing pain management: a randomized feasibility clinical trial. Pilot and feasibility studies, 8(1), 186.

🔗 https://www.medrxiv.org/content/medrxiv/early/2022/01/07/2022.01.07.22268893.full.pdf

Introduction

Locations
around the world

country
USA, UK, Canada, etc

Period
Recent 10 years

Benefit Group
Patients experiencing acute or chronic pain

Sphere of influence

Internazionale

It has been adopted in children's hospitals in several countries

Key direction 重点方向

- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源

- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者

- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers

Key Outcomes 关键成果

- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness

Project background

Traditional approaches to pain management in children rely primarily on pharmacological interventions (such as opioid painkillers), but long-term use can carry side effects or risk of addiction. VR technology provides a non-pharmacological way to manage pain, using immersive experiences to reduce the transmission of pain signals and thus reduce pain perception.

传统的儿童疼痛管理方法主要依赖 药物干预（如阿片类止痛药），但长期使用可能带来 副作用或成瘾风险。VR技术提供了一种 非药物疼痛管理 方式，利用沉浸式体验减少疼痛信号的传递，从而降低疼痛感知。

Goals and values

Reducing pain and anxiety in children during treatment through immersive experiences provides non-pharmacological pain management, reduces opioid dependence and improves treatment compliance in children, making them more willing to cooperate with medical procedures

- 通过 沉浸式体验，减少儿童在治疗过程中的疼痛和焦虑
- 提供 非药物疼痛管理手段，减少阿片类药物依赖
- 提高儿童的治疗依从性，让他们更愿意配合医疗操作

Design Methods

- Attention Diversion: Reducing attention to pain through immersive virtual worlds
- Gamification: allowing children to complete tasks in a virtual world to enhance interactive experiences
- Multi-Sensory Stimulation: Combine sight, sound and touch to make children more engaged

- - 分散注意力：通过沉浸式虚拟世界减少对疼痛的关注
- 游戏化机制：让儿童在虚拟世界中完成任务，提高互动体验
- 多感官刺激：结合视觉、听觉和触觉，让儿童更投入

Key Benefits 主要收益

- At the child level: reduce pain and anxiety, improve medical cooperation
- at the nurse level: reduce the burden of caregivers to soothe children, improve work efficiency
- at the institutional level: reduce the use of sedative drugs, improve the quality of medical services
- at the social level: provide safer and more sustainable non-drug pain management methods

- 儿童层面：减少疼痛和焦虑，提高医疗合作度
- 护理员层面：减少护理员安抚儿童的负担，提高工作效率
- 机构层面：减少镇静药物使用，提高医疗服务质量
- 社会层面：提供更安全、更可持续的非药物疼痛管理方式

Takeaways & Adaptability 借鉴点 & 适用性

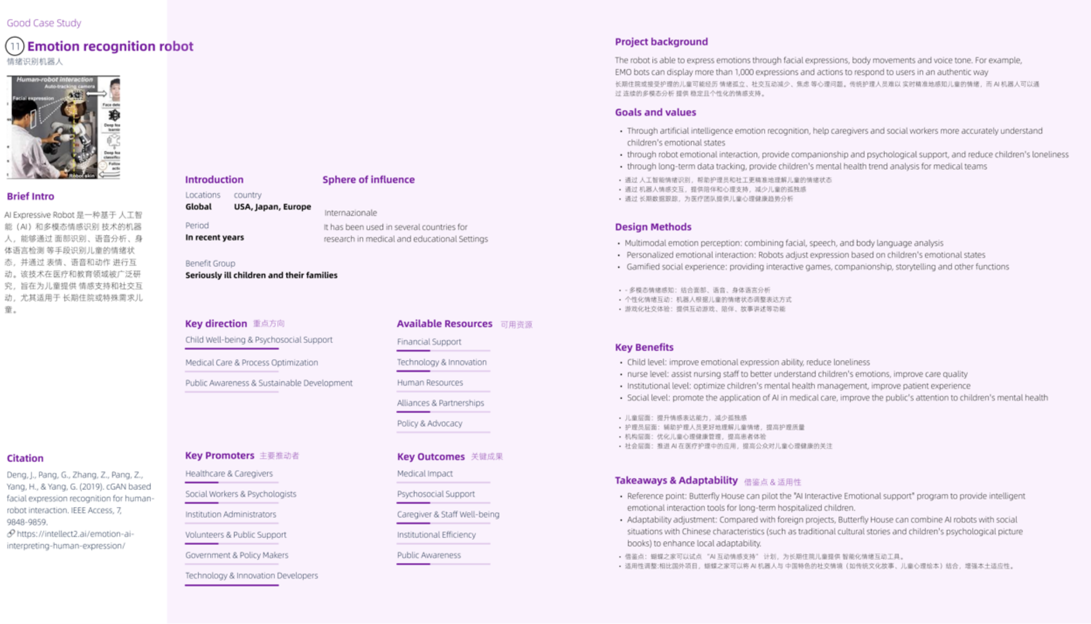
- Point of reference: Butterfly House can introduce child-specific VR therapy, using a relaxed and friendly virtual world (such as animated scenes, immersive picture books, etc.) when children receive treatment.
- Adaptability adjustment: Compared with VR games used in Western hospitals, Butterfly House can develop content more in line with Chinese culture (such as traditional ink painting, Chinese animation themed VR environments).

- 借鉴点：蝴蝶之家可以引入 儿童专用 VR 疗法，在儿童接受治疗时使用 轻松、友好的虚拟世界（如动画场景、沉浸式绘本等）
- 适用性调整：相比西方医院使用的 VR 游戏，蝴蝶之家可开发 更符合中国文化的内容（如传统水墨画、国风动画主题的 VR 环境）。

Figure 7.4 Good case study: VR Pain Management (drawn by the author)

Case 11: Emotion Recognition Robot (Global – USA, Japan, EU)

This AI robot uses multimodal recognition to assess children's emotional states via facial, speech, and body analysis. It helps caregivers understand unspoken needs. The robot fosters emotional expression and companionship through interactive storytelling and emotion-based feedback. Requires technological resources and trained medical staff. It targets children in long-term hospitalization and their supporting social workers. Benefits include improved emotional communication, reduced loneliness, and emotional trend monitoring. Local adaptation can integrate cultural storytelling techniques and local AI providers.



Good Case Study

⑪ **Emotion recognition robot**

情绪识别机器人

Brief Intro

AI Expressive Robot 是一种基于 人工智能（AI）和多模态情感识别 技术的机器人，能够通过 面部识别、语音分析、身体语言检测 等手段识别儿童的情绪状态，并通过 表情、语音和动作 进行互动。该技术在医疗和教育领域被广泛研究，旨在为儿童提供 情感支持和社交互动，尤其适用于 长期住院或特殊需求儿童。

Citation

Deng, J., Pang, G., Zhang, Z., Pang, Z., Yang, H., & Yang, G. (2019). cGAN based facial expression recognition for human-robot interaction. IEEE Access, 7, 9848-9859.

🔗 https://intellect2.ai/emotion-ai-interpreting-human-expression/

Introduction

Locations
Global

country
USA, Japan, Europe

Period
In recent years

Benefit Group
Seriously ill children and their families

Sphere of influence

Internazionale

It has been used in several countries for research in medical and educational Settings

Key direction 重点方向

- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源

- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者

- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers
- Technology & Innovation Developers

Key Outcomes 关键成果

- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness

Project background

The robot is able to express emotions through facial expressions, body movements and voice tone. For example, EMO bots can display more than 1,000 expressions and actions to respond to users in an authentic way

长期住院或接受护理的儿童可能经历 情绪孤立、社交互动减少、焦虑 等心理问题。传统护理人员难以 实时精准地感知儿童的情绪，而 AI 机器人可以通过 连续的多模态分析 提供 稳定且个性化的情感支持。

Goals and values

- Through artificial intelligence emotion recognition, help caregivers and social workers more accurately understand children's emotional states
- through robot emotional interaction, provide companionship and psychological support, and reduce children's loneliness
- through long-term data tracking, provide children's mental health trend analysis for medical teams

- 通过 人工智能情绪识别，帮助护理员和社工更精准地理解儿童的情绪状态
- 通过 机器人情感交互，提供陪伴和心理支持，减少儿童的孤独感
- 通过 长期数据跟踪，为医疗团队提供儿童心理健康趋势分析

Design Methods

- Multimodal emotion perception: combining facial, speech, and body language analysis
- Personalized emotional interaction: Robots adjust expression based on children's emotional states
- Gamified social experience: providing interactive games, companionship, storytelling and other functions

- - 多模态情绪感知：结合面部、语音、身体语言分析
- 个性化情绪互动：机器人根据儿童的情绪状态调整表达方式
- 游戏化社交体验：提供互动游戏、陪伴、故事讲述等功能

Key Benefits

- Child level: improve emotional expression ability, reduce loneliness
- nurse level: assist nursing staff to better understand children's emotions, improve care quality
- Institutional level: optimize children's mental health management, improve patient experience
- Social level: promote the application of AI in medical care, improve the public's attention to children's mental health

- 儿童层面：提升情感表达能力，减少孤独感
- 护理员层面：辅助护理人员更好地理解儿童情绪，提高护理质量
- 机构层面：优化儿童心理健康管理，提高患者体验
- 社会层面：推进 AI 在医疗护理中的应用，提高公众对儿童心理健康的关注

Takeaways & Adaptability 借鉴点 & 适用性

- Reference point: Butterfly House can pilot the "AI Interactive Emotional support" program to provide intelligent emotional interaction tools for long-term hospitalized children.
- Adaptability adjustment: Compared with foreign projects, Butterfly House can combine AI robots with social situations with Chinese characteristics (such as traditional cultural stories and children's psychological picture books) to enhance local adaptability.

- 借鉴点：蝴蝶之家可以试点 "AI 互动情感支持" 计划，为长期住院儿童提供 智能化情绪互动工具。
- 适用性调整:相比国外项目，蝴蝶之家可以将 AI 机器人与 中国特色的社交情境（如传统文化故事、儿童心理绘本）结合，增强本土适应性。

Figure 7.5 Good case study: Emotion Recognition Robot (drawn by the author)

Case 13: Schwartz Rounds (UK, USA, Australia)

Schwartz Rounds provide structured interdisciplinary forums for medical workers to share emotional experiences and reflect on care delivery. The process involves monthly storytelling-based sessions with themes on compassion, stress, and ethical dilemmas. Key contributors include hospitals, psychologists, and policy advocates. The rounds promote mental well-being and organizational empathy.

It helps alleviate burnout and enhances team cohesion. In Chinese institutional contexts, smaller-scale peer support groups or expressive writing practices may offer effective localized alternatives.

Good Case Study

⑬ **Schwartz Rounds**

施瓦茨圆桌会议-护理员心理支持

Brief Intro

Schwartz Rounds 是一种结构化的多学科论坛，旨在为医疗保健工作者提供 心理支持，帮助他们应对 情感压力、职业倦怠和同情疲劳，提升团队协作和患者护理质量。该模式强调 共享情感经历，而非解决具体问题，已在全球多个国家的医疗机构推广。

Citation

Flanagan, E., Chadwick, R., Goodrich, J., Ford, C., & Wickens, R. (2020). Reflection for all healthcare staff: a national evaluation of Schwartz rounds. Journal of interprofessional care, 34(1), 140-142.
Pfaff, K., Hamilton, L., & Jonathan, S. (2016). Sharing the burden: Schwartz rounds® as a compassionate collaborative practice and education model in long-term care. Nurs Palliat Care, 1(4), 72-74.
🔗 https://www.theschwartzcenter.org/programs/schwartz-rounds/
The Point of Care Foundation. (n.d.). Schwartz Rounds: Supporting staff wellbeing in healthcare.
🔗 https://www.pointofcarefoundation.org.uk

Introduction

Locations
around the world

country
UK, USA, Australia

Period
1995-now

Benefit Group
Doctors, nurses, orderlies, administrative staff, etc

Sphere of influence

Internazionale

It has been promoted worldwide

Key direction 重点方向

Child Well-being & Psychosocial Support
Medical Care & Process Optimization
Public Awareness & Sustainable Development

Available Resources 可用资源

Financial Support
Technology & Innovation
Human Resources
Alliances & Partnerships
Policy & Advocacy

Key Promoters 主要推动者

Healthcare & Caregivers
Social Workers & Psychologists
Institution Administrators
Volunteers & Public Support
Government & Policy Makers

Key Outcomes 关键成果

Medical Impact
Psychosocial Support
Caregiver & Staff Well-being
Institutional Efficiency
Public Awareness

Project background

Medical workers face intense emotional labor, long-term exposure to patient suffering, death and complex decision-making, which can easily lead to compassion fatigue, job burnout and psychological stress. While traditional job training and psychological interventions struggle to meet the emotional demands of daily work, Schwartz Rounds provides ongoing support and space for reflection through a structured, shared platform.

医疗工作者面临 高强度的情感劳动，长期暴露于患者痛苦、死亡和复杂决策中，容易导致 同情疲劳、职业倦怠和心理压力。传统的职业培训和心理干预难以满足日常工作的情感需求，而 Schwartz Rounds 通过 结构化的共享平台 提供持续的支持和反思空间。

Goals and values

By sharing personal experiences, help medical staff relieve psychological stress, enhance empathy through interdisciplinary discussion, break down departmental barriers, improve teamwork by promoting reflection, enhance the emotional culture of medical institutions, and improve the quality of patient care

- 通过 共享个人经历，帮助医疗人员缓解心理压力，增强同理心
- 通过 跨学科讨论，打破科室壁垒，提高团队合作
- 通过 促进反思，提升医疗机构的情感文化，改善患者护理质量

Design Methods

- Attention Diversion: Reducing attention to pain through immersive virtual worlds
- Gamification: allowing children to complete tasks in a virtual world to enhance interactive experiences
- Multi-Sensory Stimulation: Combine sight, sound and touch to make children more engaged
- 结构化小组讨论：每月一次，60 分钟，由专业协调员主持
- 匿名与安全：提供开放环境，确保分享者的隐私和心理安全
- 跨学科参与：所有医院工作人员（包括行政人员）均可参与

Key Benefits 主要收益

- Medical staff level: Help doctors, nurses, nurses, etc., better deal with emotional stress, improve career satisfaction
- Team level: promote interdisciplinary collaboration, enhance team cohesion
- Institutional level: optimize hospital culture, improve patient care quality
- Social level: promote people-oriented medical environment, improve the public's attention to the mental health of medical staff

- 医疗人员层面：帮助医生、护士、护理员等更好地处理情感压力，提高职业满意度
- 团队层面：促进跨学科协作，增强团队凝聚力 - 机构层面：优化医院文化，提升患者护理质量
- 社会层面：推广以人为本的医疗环境，提高公众对医护人员心理健康的关注

Takeaways & Adaptability 借鉴点 & 适用性

- Reference point: Butterfly House can implement the "Carers Support Round table" program, so that carers and social workers can regularly share emotional experiences, reduce psychological stress and improve team collaboration.
- Adaptability adjustment: Compared with Western Schwartz Rounds, Butterfly House can adopt smaller and more private discussion forms, combined with writing diaries, drawing expressions and other psychological support methods suitable for nursing staff
- 借鉴点：蝴蝶之家可以实施 “护理员支持圆桌” 计划，让护理员和社工 定期分享情感经历，降低心理压力，提高团队协作
- 适用性调整：相比西方的 Schwartz Rounds，蝴蝶之家可采用 更小型、更私密的讨论形式，结合 书写日记、绘画表达 等适合护理员的心理支持方式

Figure 7.6 Good case study: Schwartz Rounds (drawn by the author)

Case 16: TikTok #ForGood (Global)

The #ForGood initiative leverages TikTok's popularity to boost visibility and support for charitable causes, especially among younger demographics. It uses viral campaigns and gamified interactions to increase engagement and donations. Resources include platform algorithms, public donors, and youth influencers. Beneficiaries range from NGOs to end users.

This approach enhances participation and reduces fundraising costs. Local adaptation in China could involve WeChat or Douyin collaborations with themed content tailored to hospice-related messaging.

Good Case Study

⑯ **TikTok #ForGood**
公益传播项目

Brief Intro

TikTok 的 #ForGood 公益传播项目利用其 全球 15 亿活跃用户 的社交影响力，为非营利组织提供 知名度提升、筹款能力增强、社会议题推广 的数字化工具。该项目通过 捐赠贴纸、直播筹款、品牌化挑战 等方式，让公益组织 更有效地与年轻一代互动，扩大公益传播的影响力。

Citation

TikTok. (n.d.). #ForGood: Empowering nonprofits through social impact.

🔗 https://gettingattention.org/tiktok-for-nonprofits/
🔗 https://donorbox.org/nonprofit-blog/tiktok-for-good
🔗 https://www.tiktok.com

Introduction

Locations
Global

country
Covering many countries and regions

Period
Ongoing implementation

Benefit Group
Non-profit organizations, public welfare organizations, donors, general users

Sphere of influence

Internazionale
It has been promoted worldwide

Key direction 重点方向

- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源

- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者

- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers
- Public Donors & Corporate Partners
- Technology & Payment Providers

Key Outcomes 关键成果

- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness
- Financial Sustainability

Project background

Traditional public welfare communication methods (such as offline fundraising and website fundraising) are less influential among the young generation, while TikTok, as a short video social platform, provides public welfare organizations with more interactive and easier to communicate tools, improving the social penetration rate of public welfare projects.

传统的公益传播方式（如线下募捐、网站筹款）在 年轻一代中的影响力较弱，而 TikTok 作为 短视频社交平台，为公益组织提供了 互动性更强、更易传播的工具，提升公益项目的社交渗透率。

Goals and values

Through the monthly donation model, establish a stable fund for children's aid so that donors can become long-term supporters, improve the sustainable and transparent management of public welfare actions, and provide clear reports on the whereabouts and impact of funds

- 提高公益项目的可见度，让更多用户参与公益传播
- 通过互动视频、直播等形式，提高筹款效率
- 构建数字化公益生态，推动社交平台在慈善领域的应用

Design Methods

- Social Amplification: Viral effects via the #ForGood hashtag
- Gamification for Charity: For example, the Brand Challenge encourages users to participate
- Live Fundraising Tools: increase fundraising conversion rates by live-streaming and donating stickers
- 社交传播：通过 #ForGood 标签形成病毒式传播效应
- 游戏化公益互动：如"品牌挑战"鼓励用户 参与公益任务
- 实时捐赠工具：通过直播和捐赠贴纸，提高筹款转化率

Key Benefits 主要收益

- Charitable organization level: Use TikTok platform to reach more young users and enhance brand awareness
- Donor level: Through fun interaction and social challenges, it is easier to stimulate the public's willingness to donate
- Institutional level: reduce fundraising and communication costs, improve the efficiency of public welfare operation
- Social level: increase the young generation's attention to public welfare issues and promote global social responsibility

- 公益组织层面：利用 TikTok 平台触达更多年轻用户，提升品牌知名度
- 捐赠者层面：通过趣味互动和社交挑战，更容易激发公众的捐赠意愿
- 机构层面：降低筹款和传播成本，提高公益运营效率
- 社会层面：增强年轻一代对公益议题的关注，促进全球社会责任感

Takeaways & Adaptability 借鉴点 & 适用性

- Reference points: Butterfly House can use short video public welfare dissemination to create a # Caring for Orphaned and Disabled Children theme challenge, and cooperate with Kols (opinion leaders) to raise public awareness.
- Adaptability adjustment: Compared with TikTok's global public welfare cooperation, Butterfly House can focus on local social platforms such as wechat video accounts and Douyin to develop public welfare communication strategies suitable for the Chinese market.
- 借鉴点：蝴蝶之家可以借助 短视频公益传播，打造 #关爱孤残儿童 主题挑战，并与 KOL（意见领袖）合作，提高公众认知度
- 适用性调整：相比 TikTok 的全球公益合作，蝴蝶之家可以重点围绕 微信视频号、抖音等本土社交平台，制定适合中国市场的公益传播策略

Figure 7.7 Good case study: TikTok #ForGood (drawn by the author)

Case 17: UNICEF Pledge Program (Global)

UNICEF's monthly donation model addresses sustainability gaps in emergency aid by ensuring long-term funding for children’s welfare globally. The strategy builds emotional ties between donors and causes, supported by transparent reporting and storytelling.

It requires international networks, digital payment systems, and institutional trust. Stakeholders include the public, children’s organizations, and policymakers. Outcomes include increased donation stability and donor retention. A Chinese adaptation might involve a “Loving Guardian” program, focusing on fixed pledges for pediatric hospice services.

Good Case Study

⑰ **UNICEF Pledge Programme**

联合国儿童基金会-定期捐赠计划

Brief Intro

UNICEF Pledge Programme 是联合国儿童基金会（UNICEF）推出的 定期捐赠计划，通过 每月固定捐赠 的方式，为全球儿童提供持续的 疫苗接种、清洁饮水、紧急援助和教育支持。该计划通过 稳定资金流 确保 UNICEF 在全球危机中迅速响应，同时提升捐赠者的 长期参与感和责任感。

Citation

UNICEF. (n.d.). Pledge Programme: Monthly giving for children in need.

https://ecare.unicef.cn/cn/pledge/WB183

https://www.unicef.org

Introduction

Locations
Global

country
Covering many countries and regions

Period
Ongoing implementation

Benefit Group
Children affected by hunger, disease, war, natural disasters

Sphere of influence

Internazionale

It has been promoted worldwide

Key direction 重点方向

- Child Well-being & Psychosocial Support
- Medical Care & Process Optimization
- Public Awareness & Sustainable Development

Available Resources 可用资源

- Financial Support
- Technology & Innovation
- Human Resources
- Alliances & Partnerships
- Policy & Advocacy

Key Promoters 主要推动者

- Healthcare & Caregivers
- Social Workers & Psychologists
- Institution Administrators
- Volunteers & Public Support
- Government & Policy Makers
- Public Donors & Corporate Partners
- Technology & Payment Providers

Key Outcomes 关键成果

- Medical Impact
- Psychosocial Support
- Caregiver & Staff Well-being
- Institutional Efficiency
- Public Awareness
- Financial Sustainability

Project background

Children around the world face the threat of disease, poverty, war and natural disasters, and traditional one-off donations cannot meet long-term aid needs. Through a regular giving model, UNICEF ensures that it can consistently provide health, nutrition, education and security support, while enhancing donors' sense of long-term commitment.

全球儿童面临 疾病、贫困、战争和自然灾害 的威胁，传统的 一次性捐款 无法满足长期援助需求。UNICEF 通过 定期捐赠模式，确保机构能够稳定提供医疗、营养、教育和安全支持，同时增强捐赠者的长期承诺感。

Goals and values

Through the monthly donation model, establish a stable fund for children's aid so that donors can become long-term supporters, improve the sustainable and transparent management of public welfare actions, and provide clear reports on the whereabouts and impact of funds

- 通过 月捐模式，建立 稳定的儿童援助资金
- 让捐赠者成为 长期支持者，提升公益行动的可持续性
- 透明化管理，提供清晰的资金去向和影响报告

Design Methods

- Attention Diversion: Reducing attention to pain through immersive virtual worlds
- Gamification: allowing children to complete tasks in a virtual world to enhance interactive experiences
- Multi-Sensory Stimulation: Combine sight, sound and touch to make children more engaged
- 定期小额捐赠：提供低门槛、灵活的捐款方式（如每月 20 元）
- 透明度管理：定期向捐赠者汇报资金使用情况
- 个性化捐赠回馈：提供纪念品、感谢信、年度影响报告

Key Benefits 主要收益

- Children's level: long-term provision of basic survival guarantees such as vaccines, water and food
- Institutional level: ensuring that UNICEF can respond quickly in crises, rather than relying on temporary fundraising
- donors Level: increasing participation, enabling the public to become long-term "global parents"
- social level: promoting a culture of small donations to make good more sustainable

- 儿童层面：长期提供疫苗、饮水、食物等基本生存保障
- 机构层面：确保 UNICEF 在危机中能 快速响应，而非依赖临时筹款
- 捐赠者层面：增强参与感，让公众成为长期“全球父母”
- 社会层面：推动 小额捐赠文化，让公益更具可持续性

Takeaways & Adaptability 借鉴点 & 适用性

- Reference point: Butterfly House can launch a "Loving guardian" program, inviting donors to make fixed monthly donations for caregiver training, children's hospice care, etc.
- Adaptability Adjustment: Compared with UNICEF's funding model for children around the world, Butterfly House can set up child-specific growth programs (such as regularly updating children's growth stories and providing personalized donation feedback).
- 借鉴点：蝴蝶之家可以推出 “爱心守护人” 计划，邀请捐赠者 每月固定捐款，用于护理员培训、儿童安宁疗护等。
- 适用性调整：相比 UNICEF 面向全球儿童的资助模式，蝴蝶之家可以设立 儿童专属成长计划（如定期更新儿童成长故事、提供个性化捐赠反馈）。

Figure 7.8 Good case study: UNICEF Pledge Program (drawn by the author)

7.4 Cross-case Synthesis and Evaluation

After analyzing the eight selected cases, a number of cross-cutting insights have emerged that help me better understand what makes pediatric palliative care interventions effective, sustainable, and locally adaptable. Although each case varies in scope and context, they converge around four strategic pillars: emotional connection, narrative empowerment, system integration, and cultural resonance.

From the child-centered interventions like *Memory Boxes*, *Bravery Beads*, and *VR Pain Management*, we see the power of personalization in reducing anxiety and building psychological resilience. These cases provide children with a sense of autonomy and familiarity, even in clinical environments that often feel sterile and disorienting. Their effectiveness lies in enabling children to emotionally reframe their experiences, using symbolic objects or immersive environments as tools of comfort.

In comparison, the adult-focused cases such as *Schwartz Rounds* and the *UNICEF Pledge Program* address structural needs of caregivers and institutions. They create platforms for emotional decompression and long-term engagement. For caregivers facing chronic burnout, the opportunity to reflect and be heard becomes a form of invisible care. For organizations struggling with financial continuity, donor-centered programs like UNICEF's provide not just funding, but also trust and institutional credibility.

Some interventions also stand out for how they navigate stakeholder relationships. *Camp Sunshine* demonstrates how family-based care can extend emotional support beyond the child, creating a communal healing context. *TikTok #ForGood* proves that innovative platforms can serve as powerful allies in mobilizing youth and reshaping donation behaviors, especially when aligned with local communication habits.

Taken together, these cases offer both theoretical direction and practical benchmarks for pediatric palliative care design. Their success does not rely solely on technical solutions, but on a systemic understanding of emotions, rituals, networks, and values. The local adaptation suggestions provided alongside each case are not mere add-ons; they point to the need for deeply contextualized design that respects cultural habits and institutional realities.

This synthesis sets the groundwork for the strategic design recommendations proposed in Chapter 8. It clarifies not just what should be done, but how and why each direction might matter in shaping a more humanized, sustainable, and integrated system for pediatric palliative care in China.

8. Systemic Design Proposal

8.1 Integration of the Four Systemic Strategic Directions

To respond to the dual systemic challenges identified in the earlier research—namely, the lack of emotional expression and psychosocial support, and the fragmentation of institutional information and resource systems—this study develops four systemic strategic directions. Each strategy aligns with specific pain points in the care ecosystem and serves as a design response path under different temporal and operational constraints.

Strategy A: Emotional Support Orientation

This strategy responds to the urgent need for emotional scaffolding at the early stage of institutional adaptation. Interventions such as therapeutic rituals and caregiver support programs are deployed to reduce initial stress and facilitate emotional relief. The long-term goal is to establish a resilient emotional ecosystem within the institution.

Strategy B: Efficiency & Resilience Orientation

This direction focuses on enhancing institutional workflows and minimizing burnout by introducing intelligent task management, volunteer retention, and service process redesign. It aims to strengthen system efficiency while improving long-term adaptability.

Strategy C: Communication & Fundraising Orientation

This strategy targets public awareness and sustainable fundraising. It introduces emotionally resonant narratives, transparent donation mechanisms, and visual identity systems to build long-term public engagement and trust.

Strategy D: Network Support Orientation

Aiming for ecosystem-level collaboration, this path constructs volunteer engagement platforms and child-centered support ecosystems. It supports service socialization and enables multi-stakeholder governance.

These four strategies are not isolated but interdependent and reinforce each other within the larger system design logic.

8.2 Strategy Implementation in System Map

Based on the role division of the above system map, the strategy is specifically embedded in five types of core actors: charities (People), healthcare Professionals (Professionals), Institutional volunteer networks (Institutional), donors and Business supporters (Businesses), and families of service recipients (People). Each strategic path is centered around specific goals, such as enhancing psychological resilience, reducing anxiety, and strengthening communication, establishing cross-node and cross-role action chains and resource flow paths.

In specific implementation, the emotional support mechanism path connects volunteer organizations, psychological counselors and families of children with disabilities, supporting children's emotional adjustment through information flow and emotional interaction. The stable fundraising mechanism path connects charitable organizations and corporate partners, building a long-term funding channel based on trust and enhancing the sustainability of the project. For example, the path of the "emotional support mechanism" connects three parties: volunteer organizations, professional counselors, and the families of children patients, and supports the improvement of children's psychological state through the interaction of information flow and emotional relationships. The "stable donation mechanism" path connects charitable organizations and enterprises to ensure financial support for the sustainability of services. To further implement the specific implementation of the strategy, this study constructed the following seven representative intervention designs:

Implementation 1：Caregiver emotional support intervention

In front-line nursing work, I observed that caregivers have been under high-pressure working environment and emotional burden for a long time, especially when dealing with terminal cases. Therefore, I designed an emotional support path to connect psychological counselors with "grandma-level" caregivers who have been stationed in welfare homes for a long time. The key to this path is to introduce regular psychological dialogue sessions and integrate professional psychological personnel into daily nursing support. This not only improves the mood of caregivers, but also enhances their ability to express emotions. Emotions flow here, no longer suppressed or consumed, but properly regulated through empathy and confession. This mechanism ultimately strengthens the trust foundation within the care team, reduces the risk of dereliction of duty due to fatigue, and improves the overall quality of care.

System Map

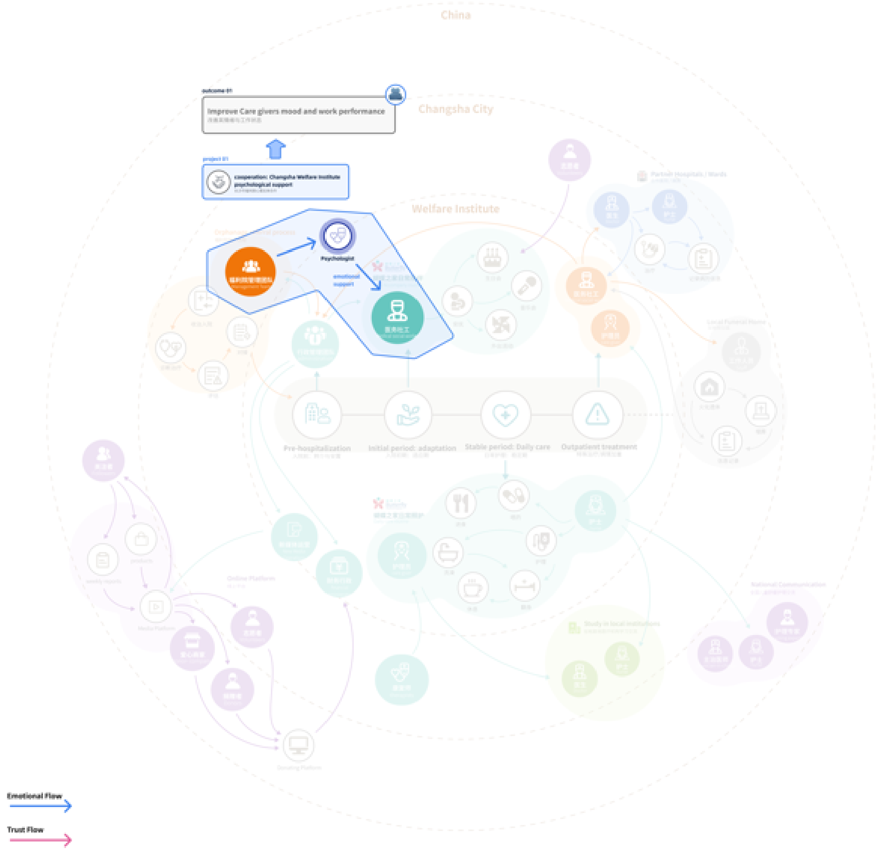


Figure 8.1 Implementation 1 in System map (drawn by the author)

Implementation **2：Intelligent task management system**

Take the task allocation in daily nursing work as an example. The traditional method relies on manual recording and verbal communication, and tasks are often missed or repeated. The core of the intelligent task management system I introduced is to present nursing tasks in a digital form and optimize the schedule through algorithms. There is a visual task board in the system, and caregivers can update the work status in real time. In this way, not only the task completion rate is significantly improved, but also some cognitive pressure is released. More importantly, management can also intervene in time to adjust the workload, so that each caregiver can focus more. This path indirectly establishes a connection with the "trust flow" through the optimization of the "task flow", making the service efficiency of the entire welfare institution more stable.

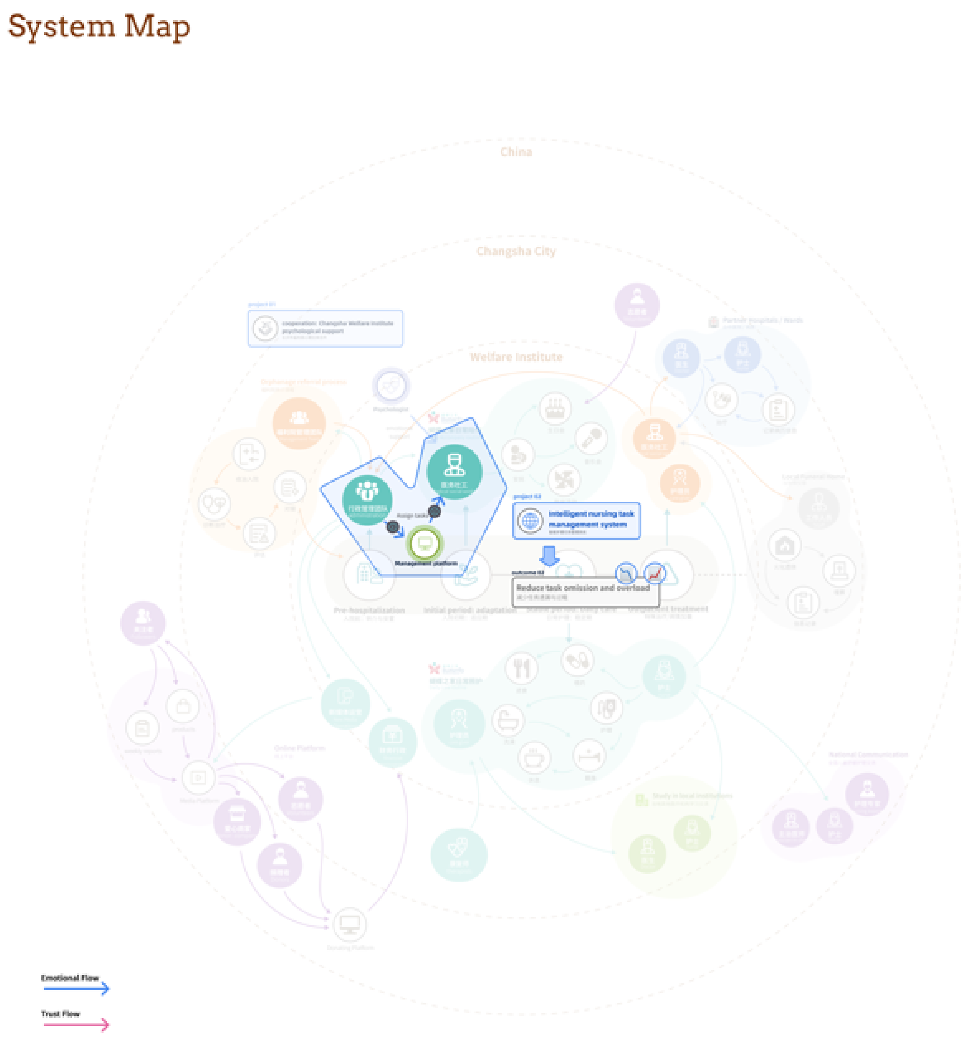


Figure 8.2 Implementation 2 in System map (drawn by the author)

Implementation 3： Children’s Social Support Program Little Buddy

In my long-term contact with the children, I found that they often lack understanding and companionship from their peers. This lack will aggravate loneliness, especially when adapting to a new environment. Based on this, the "Little Buddy Program" was established. I designed a structured social interaction mechanism to form a fixed pairing relationship between long-term volunteers, short-term visitors and sick children, and encourage them to interact steadily through games, painting or storytelling. Emotional flow plays an important role here. It flows in both directions between them, allowing children to feel trust and warmth, and also allowing volunteers to receive real feedback. This not only enhances the psychological resilience of children, but also significantly improves the overall emotional atmosphere in the institution.

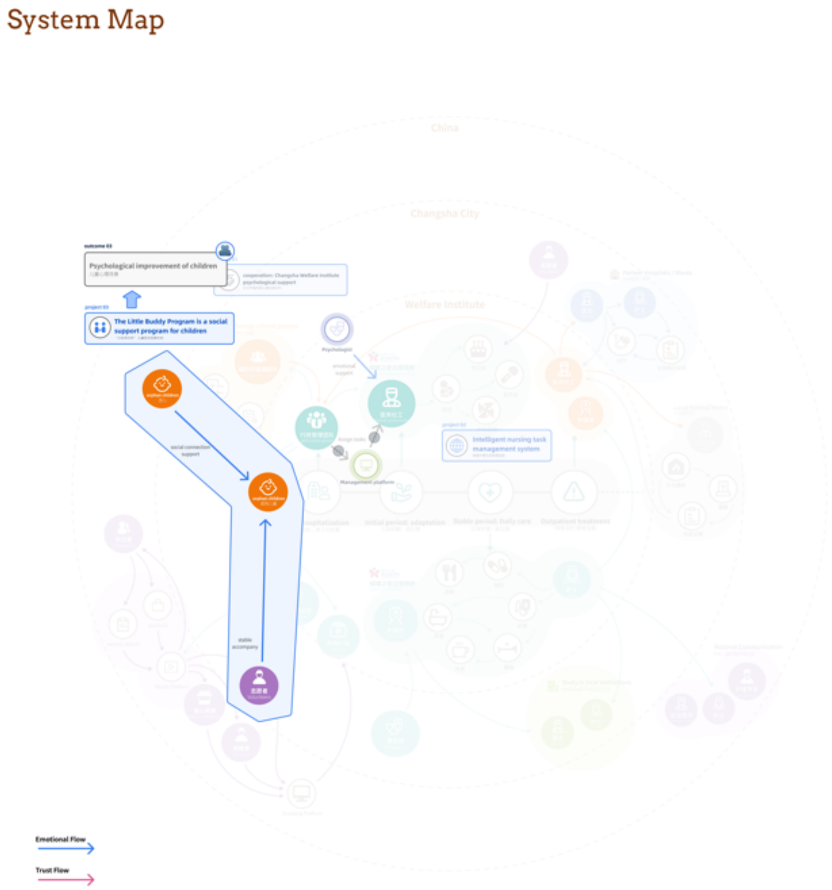


Figure 8.3 Implementation 3 in System map (drawn by the author)

Implementation 4： Brand Narrative Communication Mechanism

In my conversations with many volunteers and caregivers, they often mentioned a confusion: the outside world does not understand what they do, let alone the children's stories. Therefore, I designed a communication path to turn emotional content into narrative assets that can be perceived by the outside world. I encourage frontline staff to record real moments, such as a child's birthday party or the daily stories of caregivers, and present them in the form of pictures, texts or short videos. These contents are published through social media, which not only builds an emotional bridge between the public and the organization, but also opens a new window of trust for potential supporters. The process of communication is not only an external communication, but also a way to build internal identity.

System Map

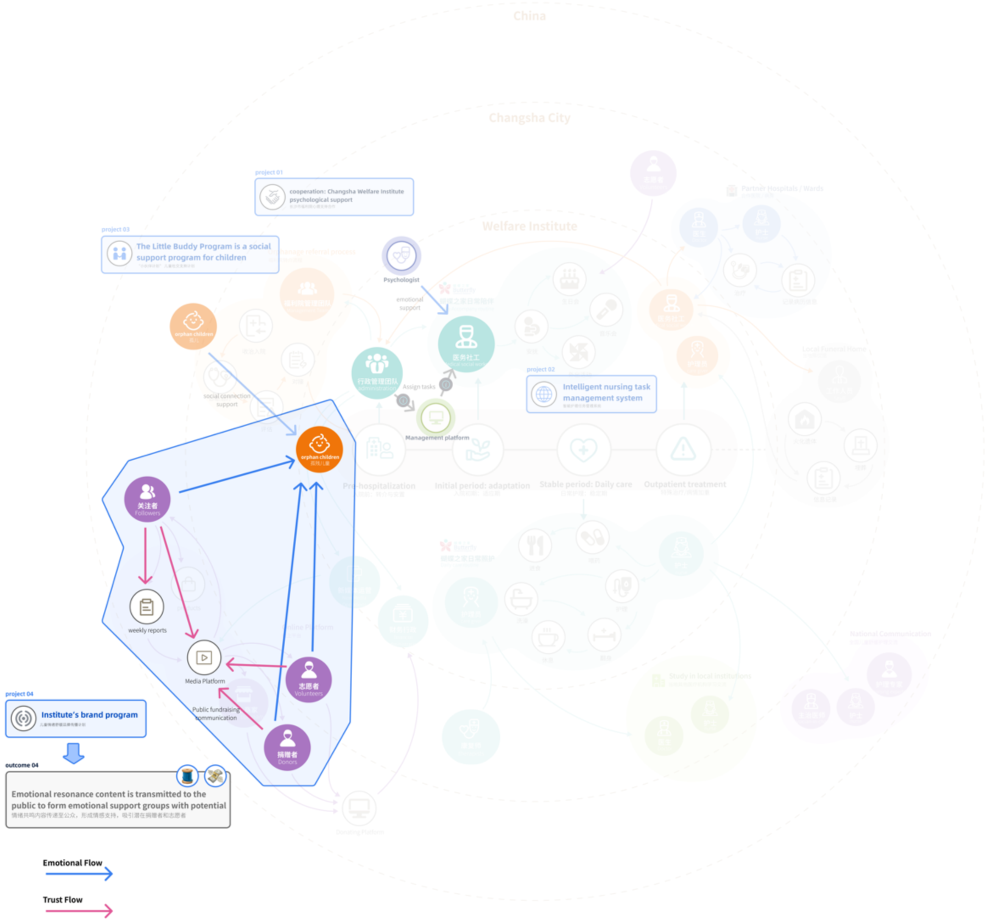


Figure 8.4 Implementation 4 in System map (drawn by the author)

Implementation 5：Handicraft and Emotional Fundraising Program

In daily activities, I noticed that children have a natural passion for handmade creations, such as painting and hand-knitting, and these works also contain strong emotional energy. Therefore, I launched the "Butterfly Handmade" project to transform children's works, whether paintings or small crafts, into emotional commodities through online platforms. These works not only allow the public to understand the inner world of children, but also become a unique fundraising medium. Through this chain path of "emotional flow-trust flow-capital flow", the project achieves the triple goals of emotional expression, social interaction and financial support. This mechanism breaks through the efficiency bottleneck of traditional charity paths and is more in line with the public's expectations for "warm support".

System Map

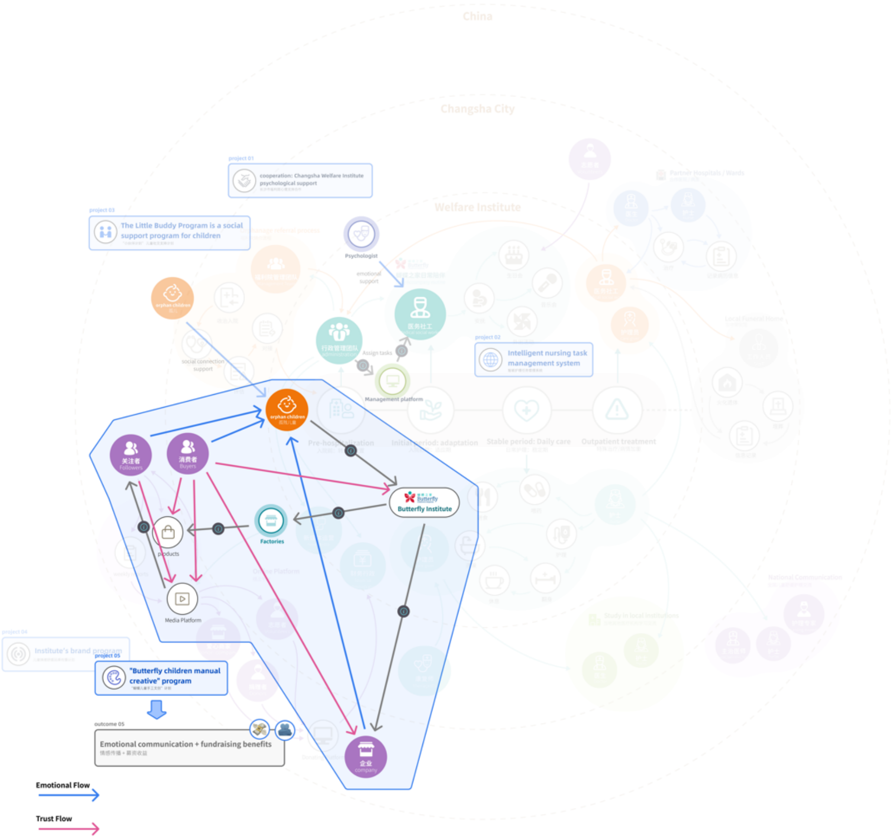


Figure 8.5 Implementation 5 in System map (drawn by the author)

Implementation 6： Enterprise Joint Fundraising Mechanism

If charitable organizations want to achieve sustainable development, a stable source of funds is essential. To this end, I designed a corporate cooperation path to actively connect welfare homes with corporate units with CSR (corporate social responsibility) demands. Through brand co-building, regular activities and transparent financial mechanisms, the two parties form long-term cooperation based on trust. This path establishes a stable donation mechanism and enhances public recognition by publicly displaying the results of donations. Not only that, internal employees of the company can also form a deeper connection with charity by participating in volunteer activities, thereby driving more resources to flow in.

System Map

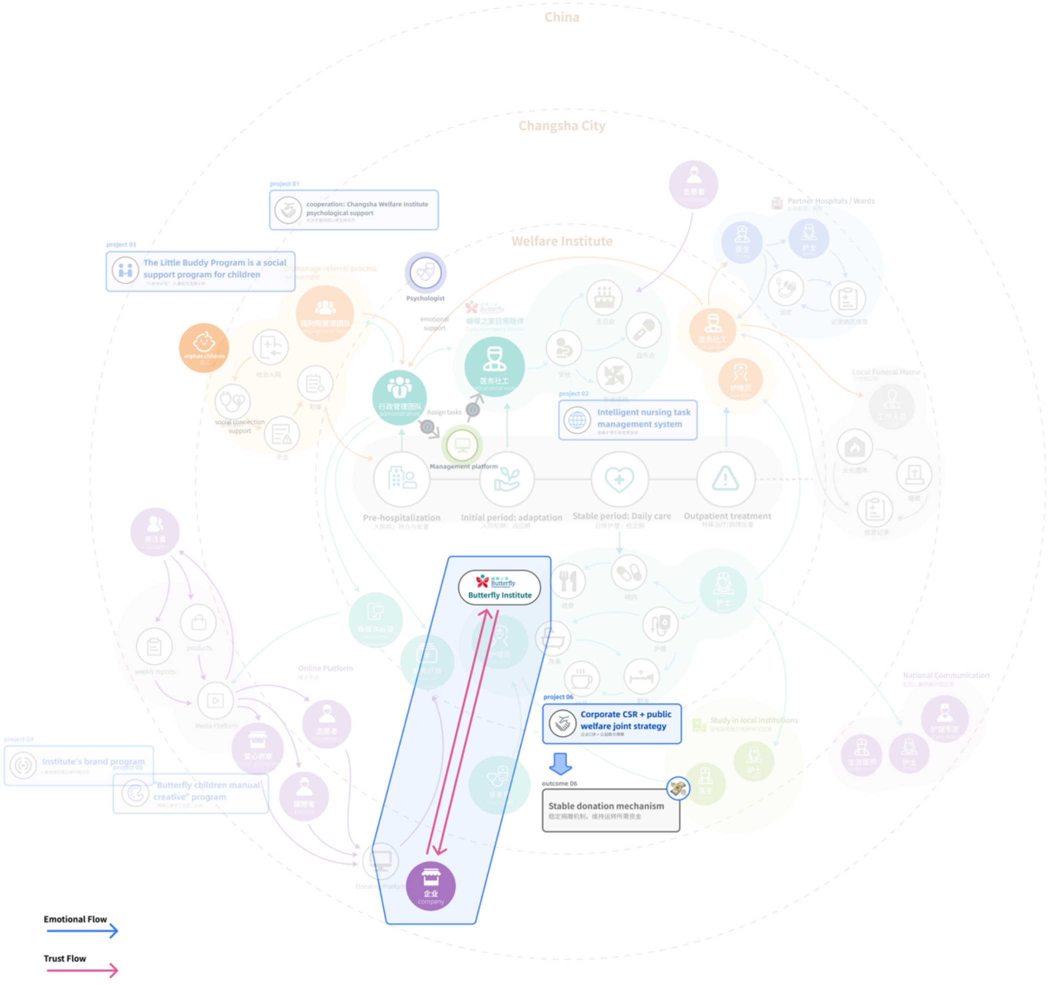


Figure 8.6 Implementation 6 in System map (drawn by the author)

Implementation 7： Volunteer Growth Incentive Mechanism

In multiple rounds of interviews, I found that many volunteers had doubts about "whether their roles are important", even myself who participated in volunteer activities at the beginning. This reflects the current lack of a formal incentive and feedback mechanism. Therefore, I proposed a "growth volunteer mechanism" to form a multi-dimensional volunteer growth file by recording the duration of volunteer service, the quality of interaction and emotional investment. These data are not only used for periodic commendation, but also as a basis for recommendation and training. The emotional flow here constantly strengthens the individual's sense of belonging to the organization, while the construction of the trust flow helps volunteer service move from "enthusiastic participation" to "professional support". By continuously providing recognition and growth channels, this mechanism effectively improves the retention rate and willingness to re-participate of volunteers.

System Map

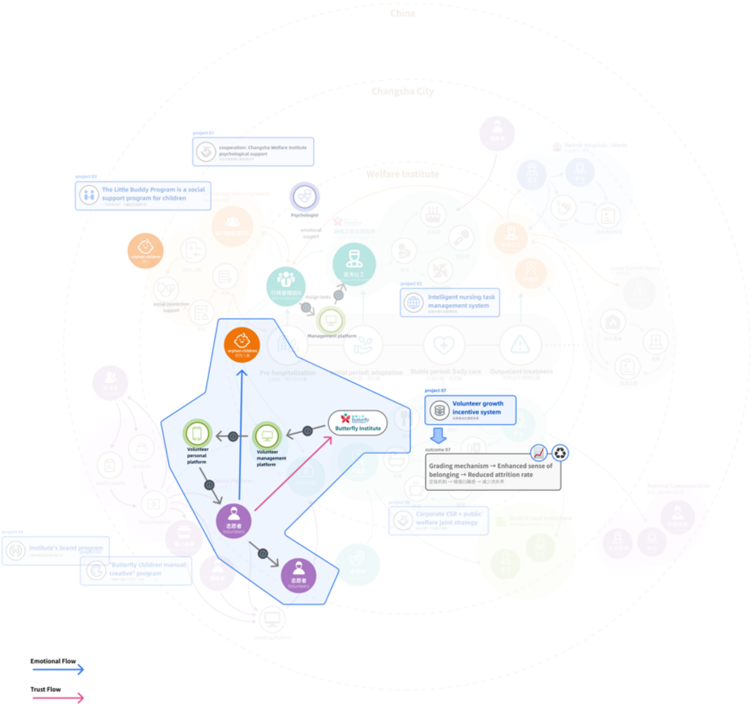


Figure 8.7 Implementation 7 in System map (drawn by the author)

These strategies together constitute the key links in the system mapping, which not only respond to the real pain points, but also build a sustainable care ecology with multi-dimensional and multi-subject participation. Each path attempts to find a warmer and more effective way of interaction between the "emotional flow" and the "trust flow", so as to promote an action trajectory that can be truly perceived, maintained, and trusted in the complex children's palliative care system.

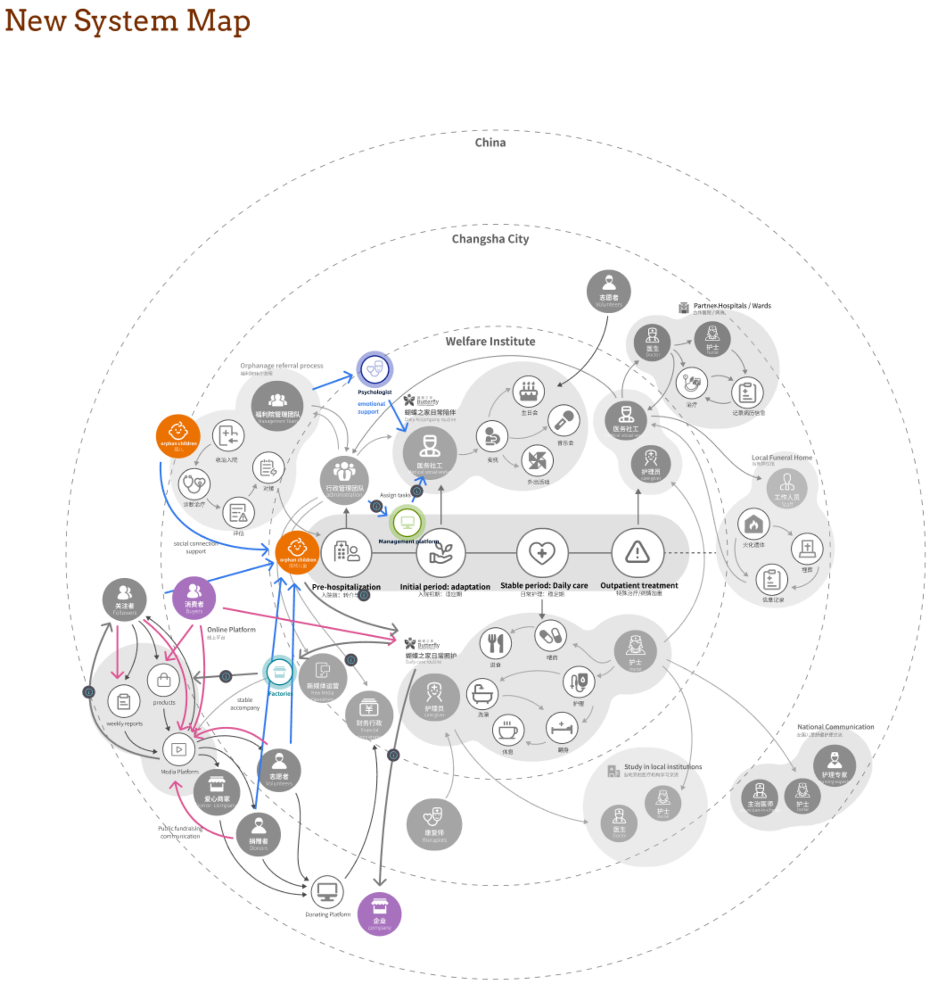


Figure 8.8 Implementations in System map (drawn by the author)

8.3 Roadmap Development: Path deployment from system intervention to strategy evolution

To support the systemic interventions in real practice, I designed a time-phased and adaptive roadmap that balances implementation feasibility, resource availability, and system readiness. The roadmap presents a phased implementation plan that distributes the four strategies (A–D) across three temporal stages: **Quick Wins**, **Trials**, and **Long-term Development**.

1) **Quick Wins**: Focused on easily implementable interventions with immediate benefits, this stage prioritizes Strategy A and C. Activities such as stress reduction rituals, emotional storytelling, and initial fundraising content are deployed to relieve emotional burden and activate public resonance.

2) **Trials**: This stage pilots more complex system redesigns, particularly from Strategy B and D. Intelligent task management, volunteer incentive models, and branding campaigns are iteratively tested to improve operational efficiency and institutional identity.

3) **Long-term**: Structural goals such as building emotional communities, retaining volunteers, and ensuring sustainable fundraising are consolidated. This stage realizes the vision of an emotionally, institutionally, and socially resilient care ecosystem.

8.3.1 implementation of strategies

1) **Strategy A: Establish Multi-layered Psychosocial Support System**

First, the emotional support mechanism focuses on the early adaptation period and the front-line care relationship. The "psychological support cooperation mechanism" and "little partner children's social support plan" implemented at the beginning can bring significant stress relief and emotional release effects in a short period (Quick Wins: stress reduction, emotional relief). In its initial phase, Strategy A launches low-cost, high-impact actions—like psychological counseling and the “Little Buddy Program”—to quickly reduce stress and improve emotional resilience among children and caregivers. Second, in the mid-term, the system will explore the co-construction of emotional communities, the introduction of collective rituals and culturally adaptable projects (such as customized memories) to foster a more stable emotional environment and community resonance network. Later, the focus shifts to building emotional support groups and cultural memory practices, forming long-term emotional ecosystems within the care facility.

emotional support

Strategy A

Establish Multilayered Psychosocial Support System

建立多层次的心理社会支持系统

03 Changsha Welfare Institute Psychological Support Cooperation

Collaborate with government mental health resources to establish a psychological counseling program for caregivers and social workers, regularly provide psychological counseling, and improve stress resistance

07 The "Little Companion Program" Children's Social Support Program

Organize online/offline social activities for children, such as painting collaborations, DIY crafts, and group games, to enhance children's social support (adapt to the internal environment of the welfare institution)

015 Corporate CSR+Public Welfare Joint Strategy

Adapt to China's' Annual Corporate Philanthropy Report ', attract CSR budget, and make companies more willing to cooperate in the long term

021 Children's Soothing Therapy Brand Communication Plan

Raise public awareness and encourage more people to support through short videos, public documentaries, and social experiments

Figure 8.9 Strategy A (drawn by the author)

2) **Strategy B: Build an Intelligent Nursing and Resource Integration Platform**

In the short term, this strategy significantly optimizes the care process through the "intelligent task management system", reducing task omissions and workload stacking (Quick Wins: task efficiency). Early implementation of the task management platform reduces workload inefficiencies and prevents miscommunication among staff.

The "transparent feedback mechanism for tasks" and "emotional motivation module" were introduced during the mid-term pilot phase, making the management platform a channel for sensing the psychological state of caregivers. (Trials: psychological improvement, emotional wellbeing) The pilot phase adds emotional status tagging and real-time feedback, improving both institutional coordination and mental health tracking. In the long run, volunteer engagement systems help retain institutional memory and reduce turnover, thereby supporting sustainable service delivery.

Strategy B

Build an intelligent nursing and resource integration platform

构建智能护理与资源整合平台

04 **Intelligent nursing task management system**
Design task automatic allocation+nursing progress tracking, improve work efficiency, and reduce the burden on nursing staff

08 **Intelligent nursing task optimization system**
Automatically calculate nursing priorities to help nurses allocate energy reasonably and reduce work intensity

024 **Precise dissemination of social media driven by big data**
Through user profiling and AI recommendations, accurately push content that different audiences are concerned about, and improve conversion rates

026 **Volunteer Growth Incentive System**
Establish "Volunteer Level Certification+Long term Service Rewards" to increase volunteer sense of belonging and improve retention rate

Figure 8.10 Strategy B (drawn by the author)

3) Strategy C: Enable Brand and Communication Platform for Public and Partners

This path emphasizes public perception and resource activation. In the early stage, through the "emotional narrative communication mechanism" co-creation with social platforms, it enhances the visibility and cultural resonance of donations. (Quick Wins: fundraising, emotional communication) This strategy focuses on amplifying emotional narratives through social media to raise funds and build cultural resonance.

In the medium term, with the help of the "Child Welfare Brand Communication Plan", we will further connect volunteer participants with the public, broaden the supporter base, and promote long-term identity building. At the trial stage, brand initiatives target emotional engagement to build an empathetic audience, which indirectly nurtures future support. As for the long term, the strategy will shift to building a stable donation mechanism and a transparent brand value assessment system to support the continued accumulation of public trust. Eventually, this leads to stable donation pipelines and systemic transparency through sustained storytelling and data feedback loops.

Information upgrade

Strategy C

Establish a brand and communication platform for the public and partners

为公众和合作伙伴建立品牌和沟通平台

019 **Brand co branded public welfare products**

Combining customized public welfare products with enterprises, linking brand exposure with donations, and increasing the willingness of enterprises to cooperate

021 **Children's palliative care Brand Communication Plan**

Raise public awareness and encourage more people to support through short videos, public documentaries, and social experiments

024 **Precise dissemination of social media driven by big data**

Through user profiling and AI recommendations, accurately push content that different audiences are concerned about, and improve conversion rates

Figure 8.11 Strategy C (drawn by the author)

4) Strategy D: Operational Certification, Governance Linkage, and Multi-Stakeholder Platform

This path uses the "corporate joint donation mechanism" as an entry point to quickly activate financial support and system cooperation willingness (Quick Win: funding injection). Strategy D uses enterprise joint donations as a fast entry point to attract funding and CSR collaboration.

In the medium term, the “Public Welfare Operation Platform” will be used to attempt to integrate task matching and data sharing among the government, NGOs and welfare institutions. The mid-phase focuses on building interoperability platforms across nonprofits, state agencies, and care institutions. In the long run, this platform facilitates institutionalized integration and promotes long-term public-private cooperation.

Strategy D

Optimize volunteers' certification, companionship and growth path design

优化志愿者的认证、陪伴、成长路径体系

026 **Volunteer Growth Incentive System**

Establish "Volunteer Level Certification+Long term Service Rewards" to increase volunteer sense of belonging and improve retention rate

027 **Volunteer/Donor Child One on One Companion Program**

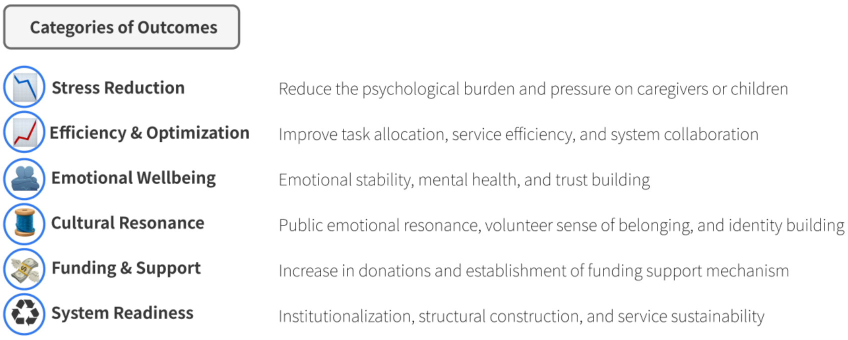
Establishing a long-term emotional connection between volunteers and children, increasing the quality of interaction and volunteer loyalty

Figure 8.12 Strategy D (drawn by the author)

Each solution is tagged with expected outcomes such as emotional well-being, operational efficiency, cultural resonance and financial stability. This dynamic layout ensures that interventions are responsive, feasible, and scalable.

8.3.2 Categories of Outcomes

When building the system roadmap, I summarized the potential benefits of all intervention options into six core outcome dimensions. Each dimension directly responds to the specific dilemmas currently faced by welfare agencies and serves as an evaluation criterion for design judgment throughout the entire process of strategy construction, priority sorting, and implementation rhythm.



Categories of Outcomes	
Stress Reduction	Reduce the psychological burden and pressure on caregivers or children
Efficiency & Optimization	Improve task allocation, service efficiency, and system collaboration
Emotional Wellbeing	Emotional stability, mental health, and trust building
Cultural Resonance	Public emotional resonance, volunteer sense of belonging, and identity building
Funding & Support	Increase in donations and establishment of funding support mechanism
System Readiness	Institutionalization, structural construction, and service sustainability

Figure 8.13 Categories of Outcomes (drawn by the author)

1) Stress Reduction

Reduce the psychological burden and pressure on caregivers or children.In welfare institutions, the long-term high-pressure care rhythm and children's resistance to unfamiliar environments often cause anxiety, emotional loss of control or burnout. Take the "psychological support cooperation mechanism" and "little buddy program" for example. They successfully help individuals relieve stress in the short term through emotional resonance and social mutual assistance. Interventions like the psychological support loop or peer companionship help reduce daily mental strain. This category is crucial in the early phase of intervention, particularly during transitions or institutional adaptation.

2) Efficiency & Optimization

Improve task allocation, service efficiency, and system collaboration. The lack of a clear role interface and task handover path within the system often leads to duplication of work or missed tasks. The "intelligent task management platform" is the key solution to this pain point, which not only simplifies the process but also serves as a tool for collaborative transparency.

3) Emotional Wellbeing

Emotional stability, mental health, and trust building. This outcome category is about inner resilience and emotional safety. It’s relevant not only to children, but also to institutional actors like staff and volunteers.

4) Cultural Resonance

Public emotional resonance, volunteer sense of belonging, and identity building. As for the "Children's Handicraft Project", it is not only a donation channel, but also a narrative outlet to showcase children's creative expression. This type of strategy conveys emotional value through cultural symbols, thereby achieving the dual purpose of dissemination and support. Interventions with high symbolic or cultural value tend to foster broader empathy. These are powerful when engaging the public or aligning collective identities.

5) Funding & Support

Increase in donations and establishment of a funding support mechanism. For example, the "corporate joint donation mechanism" and "monthly donation system" make the service financially sustainable by connecting the CSR department with the public welfare platform. These types of results are the basic guarantee for the survival of the organization and often determine whether other strategies can be implemented in the long term. This category anchors financial viability. It includes not only one-time donations, but also institutionalized channels that reduce funding unpredictability.

6) System Readiness

Institutionalization, structural construction, and service sustainability. Only when service processes, data interfaces, role relationships, etc., reach a standardized level can the entire system adapt to future expansion or new policy requirements. The "system-level volunteer support platform" and "task transparency mechanism" lay the foundation for this. This long-term outcome supports institutional evolution. It ensures the welfare institute can absorb change and scale interventions without loss of quality.

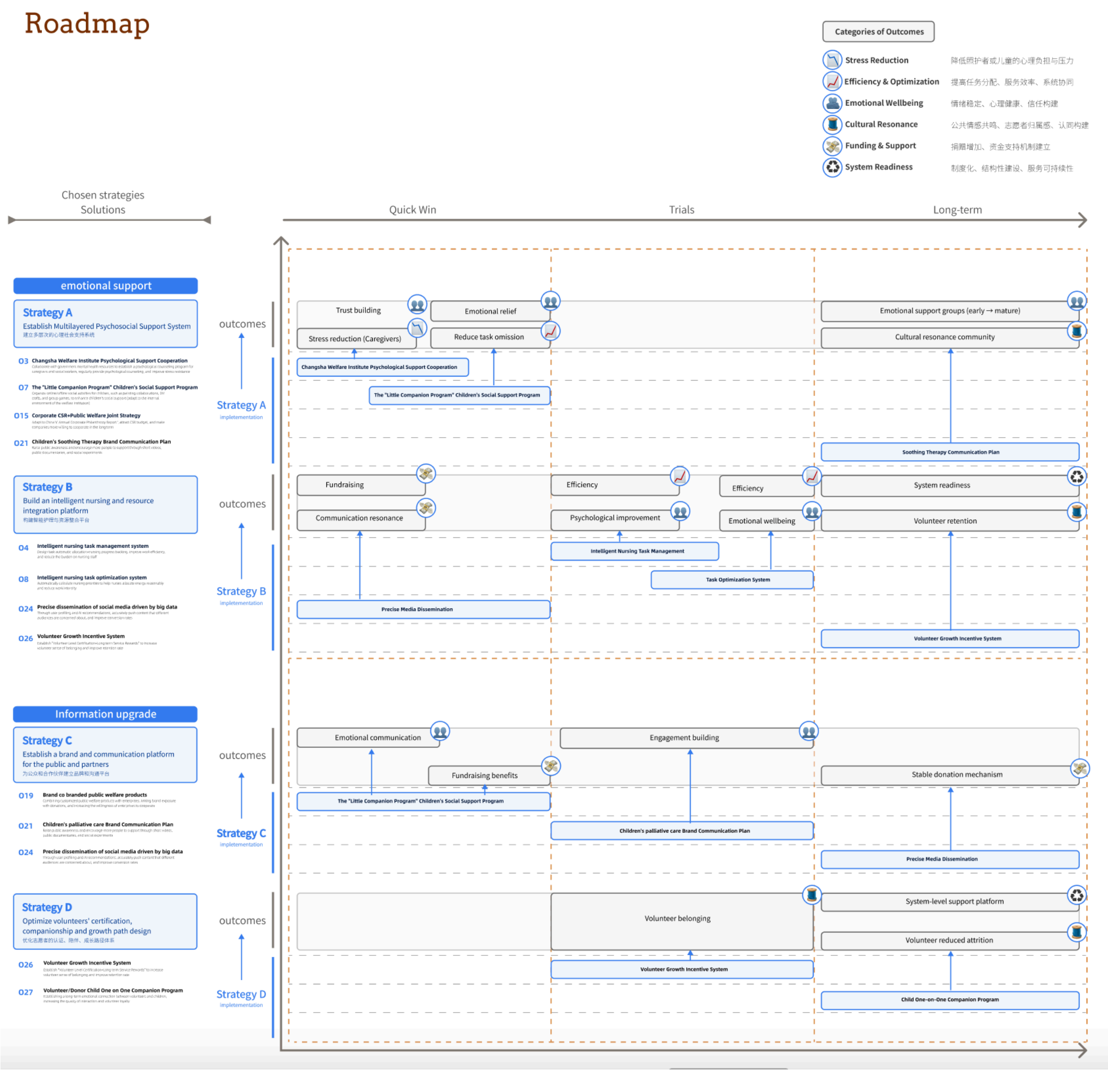


Figure 8.14 Strategies roadmap (drawn by the author)

Each strategy starts from a distinct pain point, but all converge toward systemic synergy, cultural resonance, and institutional maturity in the long term. This roadmap serves both as a temporal deployment tool and a communication interface for multi-stakeholder alignment

9. Outcomes and Systemic Impacts

This chapter aims to systematically evaluate the impact of project intervention paths at different scales and types, demonstrating that system design not only focuses on "service implementation" but also pays attention to the path of "impact evolution". In order to capture the whole process of service from point optimization to system evolution, I used the three-layer structure framework of system design (Macro, Meso, Micro) to remap the results. This division helps to distinguish the immediacy of intervention results, organizational adaptability and long-term public value, thereby supporting the action consensus of multiple subjects at different stages.

9.1 Macro-Meso-Micro Level Outcome Mapping

Based on a multi-scale framework, the outcomes are mapped across **Macro (systemic)**, **Meso (organizational)**, and **Micro (individual)** levels to represent short-, mid-, and long-term impacts. The corresponding interventions are derived from the four strategic paths introduced in Chapter 8.

9.1.1 Micro Level (Individual)

This level focuses on changes in the psychological states and daily experiences of specific people, especially the interactions between children, caregivers and volunteers.

1) Psychological improvement of children: Through the Buddy Program and the Handcraft Project, children can express their stress in a non-medical way and build a sense of identity. This support is particularly useful for children who are hospitalized for a long time or are transferred repeatedly.

2) Emotional relief through rituals: Take the "Growing Beads Project" or the "Memory Box Project" as examples. Children gain an outlet for emotional catharsis during the medical process and also give symbolic meaning to their own experiences.

3) Volunteer–child support relationships: Long-term volunteer programs provide consistent social presence, reducing anxiety and boosting trust. The two-way path of emotional flow and trust flow establishes a continuous, non-utilitarian support circle, which helps to improve children's social adaptability.

9.1.2 Meso Level (Organizational)

1) Efficiency in task distribution and management: This layer focuses on how institutional behavior changes, especially around operations, coordination, and resource sustainability. At the level of welfare institutions and cooperative organizations, systematic optimization is reflected in the improvement of operational procedures, human resource management and resource integration capabilities.

2) Communication and coordination within care teams: Take the "psychological support closed-loop mechanism," for example, it enhances the emotional mutual assistance ability among caregivers and reduces misunderstandings and stress accumulation.

3) Stabilized donation and resource systems: The corporate syndication mechanism and monthly donation model make funding sources more predictable and sustainable, reducing the organization's reliance on short-term projects.

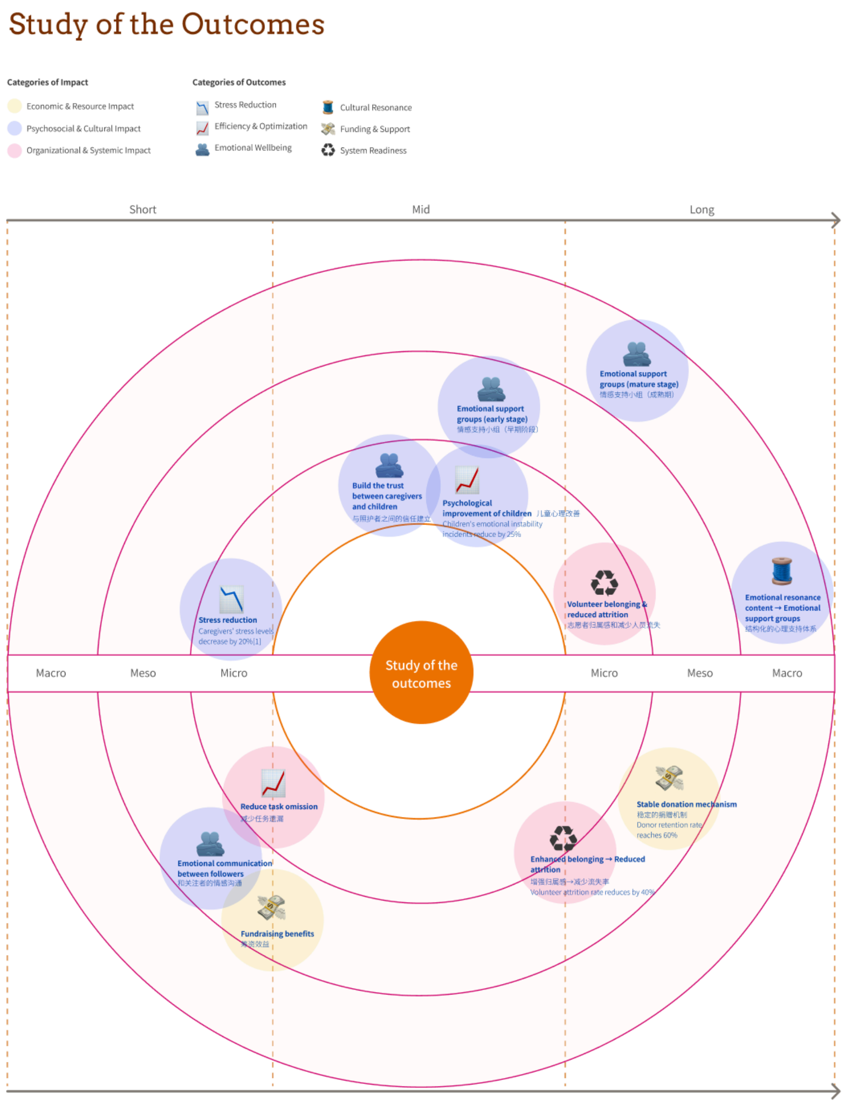
9.1.3 Macro Level (Systemic / Societal)

1) Emotional support systems recognized at the cultural level: This level refers to the broader ecosystem-level transformation, how society sees, supports, and governs pediatric palliative care. When intervention pathways gain longer-term institutional embedding, they will have the capacity for cross-sector collaboration and cultural advocacy, thereby gaining wider policy attention and social support for children’s palliative care. When widely recognized, these programs redefine what constitutes “care” in the public eye.

2) Multi-stakeholder service loops are formed between sectors: Sector-crossing loops ensure scalability and policy relevance. Take "corporate joint donations" and "public welfare communication mechanism" for example, they connect the originally independent education, medical and public welfare resources into a complete ecological network.

3) Public awareness and policy attention on children’s palliative care: Broader awareness paves the way for institutional change, research investment, and legislative attention. When the communication mechanism is linked with the donation platform to form a widely participated community issue, its long-term impact will spill over into the fields of regulations, standards and education.

Through this three-level structure, design projects can communicate their system-level values and impact paths more clearly to external stakeholders, especially policymakers and social organizations.



[1] Outcome: Caregivers' reported stress level decreased by 20% within 6 months.
Basis: Based on outcomes of similar psychosocial support programs for caregivers in pediatric care (Smith et al., 2020; Johnson & Lee, 2019), where stress reduction rates ranged from 15-30%. Therefore, a 20% target is assumed as a feasible benchmark in this project.
https://pmc.ncbi.nlm.nih.gov/articles/PMC6153380/?utm_source=chatgpt.com

Figure 8.15 Study if the outcomes (drawn by the author)

9.2 Outcome Typologies: Social, Psychological, Institutional, etc.

To more comprehensively evaluate the systemic effects of each strategic path, I subdivided all the results into five typical categories according to their impact areas: social impact, psychological impact, institutional impact, resource/economic impact, and cultural symbolic impact. This classification helps me reveal how design can promote the co-evolution of multiple system levels while meeting the needs of multiple stakeholders.

9.2.1 Social Impact

As a previously marginalized issue, child palliative care has gradually gained more public awareness and citizen participation, marking the expansion of the boundaries of social cognition.

1) Public awareness of pediatric palliative care increased: Emotional communication mechanisms (such as brand short videos and public welfare story platforms) have enabled the caring concept, which was originally within the profession, to enter the context of mass communication.
2) Enhanced civic participation in volunteer and fundraising networks: More individuals felt invited and equipped to contribute time, skills, or donations. It has stimulated more sustained participation of young people and citizens and facilitated non-material emotional connections.

9.2.2 Psychological Impact

Psychological outcomes are particularly critical, as children and caregivers often suffer in silence in emotional distress. This project opens up channels for them to express and repair through the establishment of emotional mechanisms.

1) Children's emotional resilience through companionship and rituals: Emotional companionship programs and ritual projects help children gain a sense of familiarity and security in unfamiliar environments.
2) Caregivers' stress relief and affective bonding: These mechanisms strengthen emotional safety among frontline workers. Take the "psychological support loop" for example. It not only relieves stress, but also builds understanding and resonance among peers.

9.2.3 Institutional/Systemic Impact

The change in organizational structure reflects the underlying goal of systematic design: not only to "optimize services" but also to "reshape the structure."

1) Cross-sector service integration among medical, NGO, and community sectors: System integration supports long-term coherence across fragmented services. The structural redesign of information flow and trust flow has enabled welfare homes to form a collaborative closed loop with medical institutions and public welfare organizations.
2) Volunteer retention mechanisms and digital task platforms: Digital systems reduced ambiguity and made collaboration more sustainable. Information technology tools strengthen service continuity and responsibility boundaries and reduce systemic risks caused by human resource fluctuations.

9.2.4 Economic/Resource Impact

In a welfare environment where resources are scarce, the optimization of resource management and financial support mechanisms means that the sustainability of the system is substantially guaranteed.

1) Improved fundraising efficiency and transparency: Tools like donor pledges improved consistency and accountability. The project combines digital tools with emotional communication to achieve a transformation from "single-point fundraising" to "trust-driven long-term support."

2) Reduced resource waste via task optimization: Better scheduling led to measurable gains in operational efficiency. The task management platform avoids duplication of work and omissions, and indirectly saves manpower and time costs.

9.2.5 Cultural & Symbolic Impact

Cultural influences are usually not so direct, but on extremely sensitive issues such as palliative care, it is these "non-explicit results" that shape public attitudes and institutional identity.

1) Cultural embedding of memorial rituals and emotional storytelling: These tools localize emotional support in ways people can relate to. Take the Memory Box and Growth Beads, for example, which use familiar cultural symbols to help children connect with their families.
2) Institution branding as a social trust anchor: Identity and reputation are key levers in long-term support and legitimacy. When an organization is able to convey a stable, emotional, and recognizable brand image, it has the ability to continuously mobilize social resources.

9.3 Long-term Impacts and Evolution of Governance Mechanisms

The design-led intervention has the potential to drive **systemic transitions** in the pediatric palliative care ecosystem. This section outlines three projected paths of governance evolution over the next 5–10 years.

1) **Cross-sector Governance Capacity:** As the frequency of multi-institutional collaboration increases, loose project-based cooperation will gradually transition into an institutionalized joint governance mechanism. Institutional collaboration between healthcare, NGOs, and volunteers will shift from project-based coordination to long-term co-governance models.
2) **Platformization of Care Services:** The original "single-point service" divided by function will be reconstructed into a comprehensive platform integrating communication, evaluation, training, coordination and other modules. Single service units evolve into platforms that integrate communication, evaluation, training, and coordination across stakeholders.
3) **Data-Informed Policy Advocacy:** Through structured outcome evaluation and participatory feedback systems, design practice will generate credible and quantifiable data, which will become an important basis for promoting policy reforms. Service practices generate measurable outcomes and qualitative stories, which become levers for influencing policy and driving regulatory reforms.

The future of child hospice governance is not just about “doing more”, but about “doing more in a more coordinated, more consensus-building, and more trusting” way. System design provides methodological possibilities for this, and also provides emotional and logical support for the institutional future.

10. Conclusion and Future Outlook

10.1 Methodological Contribution: Theoretical significance for system design practice

Throughout the research process, I kept thinking about a question - how to make systemic design not only stay at the level of "improving services", but also truly participate in the evolution of the system? To this end, I tried to explore from the following three directions:

First, to build an integrated design framework. I connected the four levels of "emotional support", "process coordination", "public communication" and "system infrastructure construction" to form a strategic path logic. This makes service design rise from a single point of intervention to a structural tool in system governance. Design is no longer just about solving problems, but planning collaboration, restructuring trust and promoting cognitive renewal.

Second, to reconstruct the evaluation dimension with a result-oriented approach. I tried to transform the "results" of traditional design output into a "multi-scale impact path". In other words, the project does not end with "whether it is online", but with "whether it brings positive changes at the micro (individual), meso (organization) and macro (society) levels" as the evaluation criteria.

Third, to propose a design perspective around the evolution of governance. Many existing public welfare or care projects are often trapped in the logic of "starting and ending". I hope to prove that even a small system intervention, as long as the governance mechanism is well designed, can become the trigger for long-term institutional change.

10.2 Practical Implications: Potential for Service Innovation in China’s Welfare Institutions

From the practice of this welfare home in Changsha, I have seen many real challenges in China's children's hospice care system, and also seen the space for design intervention. Faced with problems such as resource constraints, low public awareness, and high pressure on caregivers, the four strategic paths (A-D) proposed in this study provide feasible coping methods Emotional support orientation, alleviating the adaptation anxiety of children and caregivers; Efficiency improvement orientation, reducing repeated human investment and management pressure; Communication and fundraising orientation, enhancing public connection and social recognition; Network support orientation, building a diversified collaborative service ecology.

These strategies are replicable and can be adjusted according to the actual capabilities of different regions. I believe they are not only applicable to Changsha, but can also provide inspiration for welfare institutions across the country.

10.3 Limitations: Site-Specific Constraints and Data Challnges

Although I tried my best to maintain the rigor and practical depth of the research process, there are still some limitations that cannot be avoided:

1) Site limitations:

   This project is based on a specific welfare institution in Changsha. Affected by geographical and management conditions, its design strategy may not be applicable to all types of welfare units, especially in areas with large differences in resource distribution.

2) Data constraints

   For ethical reasons, I cannot directly obtain psychological feedback from children, so a large amount of data can only rely on the observations of caregivers and psychological workers. This has affected the meticulousness of the evaluation to a certain extent.

3) Translatability of Cases

   Some intervention paths (especially those that rely on volunteer participation or have a ritual nature) may be difficult to implement in other cultural or institutional contexts, and more localized strategies are needed.

10.4 Future Research Directions:

Toward Scalable Systemic Innovation, if we want to make system design play a greater role in child care, I think future research should go in the following directions:

1) AI-Assisted Service Optimization

   Modules such as emotion monitoring, task scheduling and process visualization can all achieve higher levels of personalization and precision with the help of AI. This is not only a technological innovation, but also an amplifier of emotional connection.

2) Cross-Institutional Governance

   Welfare institutions, hospitals and non-governmental organizations need to move from temporary cooperation to institutionalized collaboration. Future research should focus on developing a sustainable co-management platform to promote the integration of resource flow, trust flow and knowledge flow

3) Expanding to Long-Term Care System Design

   Child care cannot only focus on the "end-of-life stage". From chronic disease management, emotional care to social integration, the support system throughout the life cycle deserves to be reconstructed. System design needs to change from "place filler" to "co-builder".

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