RETROSPECTIVE ANALYSIS OF THE CONSTRUCTION OF THE NATIONAL SYSTEM OF HOSPICE AND PALLIATIVE CARE IN GREAT BRITAIN

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ABSTRACT

Today, Great Britain has one of the best hospice care systems for palliative patients in the world, which leads to interest in the path of building a Hospice and Palliative Care (HPC) system in this country. The hospice care system is mainly financed by the volunteer sector, which indicates a significant development of the state-society partnership in the organization of HPC. The national HPC system consists of inpatient care, day palliative care, care in the community and emergency hospitals. 2004–2008 is considered the key moment in the formation of the country's HPC system, which will be the focus of this study. For specialist palliative care, the National Health Service of Great Britain allocated almost £50 million a year in those days until 2004. At the same time, volunteer support was about 4 times greater. More than 220 volunteer support groups for palliative patients operated in the country. The success of building a national HPC system is described in the Palliative Care White Paper. A number of interrelated national programs may be used as a standard of palliative care in 20 years by many other countries. The development of the HPC system has influenced the British homes for the elderly, the system of primary care, the attitude to the HPC problem of doctors, local communities and society as a whole, increased the quality and availability of palliative care. Palliative care since those years has been provided 24/7, managed by coordination centers located outside medical facilities and hospices. High national HPC standards and mechanisms for monitoring their compliance have been created. Narcotic analgesia for palliative patients with chronic pain, the necessary medical, psychological, social and spiritual care is mostly available. The public debates the question of a dignified death without restrictions. The value for money of HPC is recognized by British society as acceptable. Therefore, studying the British experience of HPC organization as one of the "best practices" is useful for other countries with less developed HPC systems.

Keywords: *"best practices", place of death, palliative care quality standards*.

INTRODUCTION

Great Britain is one of the countries in which Hospice and Palliative Care (HPC) is organized at a high level, which allows us to consider the organization of this type of medical and social care in this country as one of the "best practices" and makes it a subject of study in the health care organization [1]. The main needs of palliative patients in Great Britain are the same as in other countries [2], but the approaches to their satisfaction have an original meaning and history.

The country's hospice care system is mainly financed by the volunteer sector, which indicates a significant development of the state-society partnership in the organization of HPC. The national HPC system consists of inpatient care, day palliative care, community care and acute care hospitals. The period of 2004–2008 is considered the key moment in the formation of the country's HPC system, which will be the focus of this study. During this period of development of the HPC system, national programs were launched in the country, which changed approaches to the organization of this type of care, increased the coverage of palliative patients of various age groups, expanded the list of palliative diagnoses, influenced the attitude to palliative care of the government, communities and the whole society.

For specialist palliative care, the National Health Service (NHS) of Great Britain allocated

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almost £50 million a year in those days until 2004. At the same time, volunteer support was about 4 times greater. More than 220 volunteer support groups for palliative patients operated in the country [3]. The success of the development of the national HPC system is described in the Documents of the Council of Europe and the "White Book of Palliative Care" (2003–2010) [4–6].

The purpose of the study was to determine the problems of building a national system of palliative and hospice care in Great Britain for 40 years (1964–2004) and ways to overcome them.

Materials and Methods

The bibliographic, historical and systematic analysis methods were used in the research.

Results and Discussion

Of the half a million people who died each year, nearly two-thirds were over 75. 99.0% of the dead were adults aged 18 and over. 58.0% of deaths occurred in NHS hospitals; 18.0% of these patients died at home; 17.0% – in homes for the elderly; 4.0% – in hospices; and 3.0% – elsewhere. The distribution of deaths by place of death depended on region, age, and primary palliative diagnosis. For example, hospital mortality ranged from 52.7% in the South West to 64.7% in London, and hospice mortality ranged from 2.5% in the North West to 5.9% in the South East. The highest home mortality occurred among young (15–44 years) and middle-aged (45–64 years), the highest mortality in hospitals – among children (under 14 years) and the elderly (75–84 years), the highest mortality in hospices – for middle-aged people (45–64 years old). Patients with palliative oncological and respiratory diagnoses mostly died in hospitals (up to 50.0% and 67.0% of the total number of deaths, respectively). At the same time, the main causes of death were chronic diseases of the heart and respiratory tract, cancer, stroke, neurological diseases and dementia. If we compare this picture with the situation in 1900, then the majority (85.0%) of people died at home, and the main causes of death were infections. In addition, many more deaths occurred in childhood.

In 1950, only about 50.0% of people died at home. At the beginning of the twenty-first century, hospitals became the most common place of death. Subsequently, the problem of death and dying began to be discussed more often and openly in public, which contributed to the development of the system of care for dying patients. The improvement of her work was aimed at creating conditions for dying with dignity, without pain, surrounded by loved ones, with the choice to be at home, in a hospital or in a nursing home. Care for the dying among other vulnerable categories has become an indicator of the development of the health care and social assistance system. Gradually, the difference in attitude towards those who were dying (their age, gender, ethnic origin, religious beliefs, disability, sexual orientation, diagnosis, socio-economic deprivation, etc.) decreased. "Voluntary hospices" emerged (e.g. St Christopher's Hospice, founded in 1967 by Cecil Saunders).

The UK NHS Palliative Care Program (2004–2007) was the impetus for the development of other programs, including the Gold Standards Framework (GSF) [7], the Liverpool Care Pathway for the Dying Patient (LCP) [8] and Preferred Priorities for Care (PPC) [9; 10], Delivering Choice programs [11], etc. The NHS Palliative Care Program (2004–2007) included identification of people nearing the end of life, assessment of their needs, patient care and support for carers in the last years/days of life and after death. According to the results of its assessment, partnerships between communities and local authorities (interaction with schools, religious groups, funeral homes, homes for the elderly, hospices, medical and social non-government organizations, employers), local Departments of Health with the National Council were improved on issues of palliative care. It was possible to draw society's attention to the problems of treatment at the end of life, to change the attitude towards death and dying in society.

The programs took into account the difference in the needs of palliative patients depending on the region of residence and diagnosis. A lot of attention was paid to the conclusion of contracts and monitoring of the provision of medical and social services, training of personnel (on the issue of identifying palliative patients, determining the scope of optimal care, communication skills with patients and their relatives, care, emergency assistance (temporary life saving)), coordination of resources, creation regional registers of people approaching the end of life. At that time, the Marie Curie Cancer Care Delivering Choice Program was considered a good example of a centralized coordination mechanism of efforts [12]. The program demonstrated options for end-of-life choice, rapid access to 24/7 care, including hospices, nursing homes, assisted living facilities.

The development of the GSF, PPC and LCP programs had a synergistic effect: the experience of working with patients of one profile often spread to other categories. For example, an important result of the LCP program was the transfer of models developed initially for palliative cancer patients to palliative patients with other diseases. The principle of choosing the place of end of life, introduced by the programs, is an established practice of the UK health care system [13].

The development of educational programs for relatives of palliative patients took into account the fact that for many children, close friends and informal caregivers, preparing a relative for death was the first and quite traumatic experience in life. At the same time, the relatives of the palliative patient had not only to adapt to the situation themselves, but also to provide effective practical and emotional support to the dying person.

The education and continuous professional development of medical and social workers working with palliative patients included the provision of the necessary knowledge and skills in caring for seriously ill patients. Depending on the frequency of providing palliative care services to patients (on a permanent basis, often or occasionally), the "Skills for Care" and "Skills for Health" training programs of the Academy of Medical Royal Colleges [14] contained various competencies.

Numerical measurable indicators, necessary for ongoing monitoring of their implementation, were laid down in the programs. Some of these indicators were determined by self-assessment. Measurability has been useful to health and social workers, program managers, politicians, the media, and society. It was used to create standards for the quality of treatment and care, calculate the need for personnel and finance services. To evaluate the results of the programs, data from national statistics on the dead, data from surveys of relatives of the deceased, and their complaints were also used.

Calculating funding has always been a difficult task, given the uncertainty of when palliative care will begin for many critically ill patients. Funding was calculated for hospitalizations, maintenance of hospices and specialized palliative care services, community nursing services, nursing homes. Spending was measured in billions of pounds, but there was an understanding that the efficiency of using these funds could be increased. Part of the costs of palliative care remained unaccounted for: costs of other government departments (for example, for disability), costs of unpaid carers, etc. Since the beginning of financing the programs, expenditures have gradually increased. For example, £88 million was spent on palliative care from the state budget in 2009–2010, and £198 million in 2010–2011. But the quality and coverage of patients with help did not always increase proportionally. Optimizing the "costs/(quality+coverage)" ratio was associated with a reduction in the number of hospitalizations and the length of hospital stay while simultaneously increasing the standards of care. Naturally, as a result of such a policy, the number of deaths at home increased with stable total costs. Costs included 24/7 home care, administrative services of focal points, ambulance transport costs for home care. Attention to the problem of palliative care has increased the contributions of communities and philanthropists to nursing homes and community hospitals, and improved educational programs for staff, patients and their relatives.

The end-of-life care strategy for patients and their carers included the possibility of professional consultations. Each professional service knew its priorities and took into account the preferences of patients and their relatives where possible. Coordinated care and support followed the principles of the Gold Standards Framework (www.goldstandardsframework.nhs.uk). Coordination centers were established outside medical institutions and professional organizations that provided palliative care services to patients and their relatives. Patient registries increased the chances of responsiveness to patient preferences by service providers. 24-hour helplines have made access to home care services faster. The creation of specialized palliative care services allowed to raise the standards of care. Relatives and carers of palliative patients were given the opportunity to stay in hospitals together with patients.

Services were provided in accordance with quality standards, compliance with which was constantly monitored. The opinions and evaluations of the quality of services of relatives and caregivers of palliative patients based on the successful program "Views of Informal Carers – Evaluation of Services (VOICES) program" were also taken into account [15; 16]. Best practices were analyzed by a national team of experts and disseminated.

Great Britain considered the lack of open discussion of death and dying to be a problem in its society. Older people did not often discuss their own dying care preferences with close relatives or friends, so it was difficult to determine the extent to which their wishes were met. Health and social care staff often found it difficult to start a discussion with people about the fact that they were approaching the end of life. And by clinicians, death was often viewed as a professional failure. In order to change this situation, it was important to realize that only frank and timely discussion will allow identifying needs and planning care, improving coordination of services, allowing conscious choice of place of death (home, hospital, nursing home, hospice, etc.), providing care and support 24/7, not to carry out unnecessary hospitalizations, train medical and social workers to provide professional care, and, in fact, ensure maximum comfort, the necessary support of caregivers, reduce suffering and prepare a dignified death. It became clear that such training has a significant impact on the condition of carers.

The extent of the problems of inadequate organization of medical care for palliative patients throughout their improvement helped to assess the survey and analysis of complaints. Thus, in 2004–2006, the NHS analyzed more than 16,000 complaints. 54% of them were related to end-of-life care. Most of these complaints were related to poor communication, lack of basic comfort, violations of privacy, insufficient psychological care, late referral or lack of referral to specialized palliative care, inadequate invasive procedures before death. Relatives often said that they, and not the doctors, were the first to notice that the patient was dying. Inappropriate invasive procedures were often used even in the dying phase. The commission examined in detail and published 50 typical cases that demonstrated the main aspects of the problem.

The shortcomings of the existing system were eliminated step by step thanks to the performance of a number of tasks:

- increasing public awareness of HPC problems, broad discussion of death and dying, preferences of palliative patients regarding the place of death, analgesia and other types of symptomatic treatment, care and support;
- a dignified and respectful attitude towards the dying;
- provision of medical and psychological assistance, social and spiritual support;
- coordination of palliative care for its quick start and continuity;
- assistance to relatives providing care (their training and psychological rehabilitation after the death of the patient);
- special education for medical and social workers;
- implementation of palliative care quality standards and monitoring of their compliance;
- equal treatment of all patients, regardless of their religious and ethnic affiliation, social status;
- state and community support of hospices and homes for the elderly;
- objective control of cost and quality indicators of the HPC system;
- inclusion of HPC issues in medical reform programs;
- decentralization of financing and decision-making regarding the work of local institutions of the HPC system;
- preferential taxation;
- bringing services closer to patients by increasing the network of institutions that provide HPC.

Conclusions

The UK has had a long and difficult 60-year journey to a successful HPC system. Since the 2000s, palliative care has been provided on a 24/7 basis, managed by coordination centers located outside of hospitals and hospices. High national HPC standards and mechanisms for monitoring their compliance have been created. Narcotic analgesia for palliative patients with chronic pain, the necessary medical, psychological, social and spiritual care is mostly available. The public debates the question of a dignified death without restrictions. The value for money in HPC is recognized by British society as acceptable. Therefore, studying the British experience of HPC organization as one of the "best practices" is useful for other countries with less developed HPC systems, in particular, Ukraine. Taking into account the experience of Great Britain in the development of the national HPC can significantly improve the quality of management decisions in this area.

DECLARATIONS:

Disclosure Statement

The authors have no potential conflicts of interest to disclosure, including specific financial interests, relationships, and/or affiliations relevant to the subject matter or materials included.

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The data can be requested from the authors.

Statement of Ethics

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