



THE ROLE OF CAREGIVERS FOR CANCER PATIENTS ARE TREATED IN HOSPITAL (RESEARCH AT ONCOLOGY CENTER - THAI NGUYEN NATIONAL HOSPITAL)

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ABSTRACT

In Vietnam, up to now, cancer has become the number one cause of public health threats in the group of non-communicable diseases. In 2020, Vietnam ranked 91/185 in terms of new incidence and 50/185 in mortality rate per 100,000 people. Along with great advances in technology and cancer treatment regimens to slow, stop or eliminate a patient's cancer cells, those involved in patient care also have an important role to play. Improving patient health and quality of life. Caregivers have a very important role in observing changes in the patient's condition while caring for patients at home or in the hospital, can assist in the development of treatment plans, make decisions, and perform some part of the treatment. This article focuses on clarifying the role of caregivers for cancer patients being treated at the Oncology Center - Thai Nguyen Central Hospital, the difficulties they face, thereby proposing some recommendations. Solutions to improve the role of caregivers, towards improving the effectiveness of treatment for cancer patients. The data in this article are collected from primary and secondary sources.

KEYWORDS

Caregivers, the patient, cancer, the role of the caregivers, cancer treatment.

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1. INTRODUCTION

Cancer and cancer treatments can cause discomfort that greatly affects a person's life. Currently, medicine in the world as well as in Vietnam has been applying the Palliative Care model for cancer patients to improve the quality of life of patients and their families. The goal of palliative care according to the World Health Organization (WHO) is to apply measures to improve the quality of life for patients who are facing life-threatening illnesses and loved ones, through the prevention and alleviation of the burden they bear through early recognition, comprehensive assessment and treatment of pain and other physical, psychosocial and spiritual problems" Unlike direct treatments for cancer, which aim to slow, stop, or eliminate cancer, the goal of palliative care is to improve quality of life. Better quality of life during and after treatment.

To achieve this goal, patients are not only cared for with traditional physical treatments but also supported with psychological, social and spiritual issues. Participating in this model of care, in addition to the professional support of the medical teams and doctors who treat the disease directly, we must mention the role of those who care for patients daily at home and home. in hospitals during and after treatment. Clarifying the role of carers for patients is extremely necessary for hospitals to have solutions to strengthen the role of patient care teams, towards expanding care networks, and multidisciplinary coordination in care and intervention to reduce pressure on the health system or the patient's family, thereby aiming to improve the quality of life for cancer patients. Stemming from this fact, the author has conducted a study "The role of caregivers for cancer patients during treatment at the hospital". The study was carried out at the Oncology Center - Thai Nguyen Central Hospital to generalize the role and difficulties when performing the role of a caregiver for cancer patients, thereby proposing some solutions to enhance the role of carers for cancer patients.

2. RESEARCH OVERVIEW

2.1. Overview of the study area

Thai Nguyen Central Hospital was established in July 1951. Over 70 years of construction and development, the hospital has become a red address in medical examination and treatment of people in the province and neighboring areas, the results of inpatient and outpatient treatment annually increase from 105 - 120%, the scale of outpatient examination increased from 150 - 200%, the number of surgeries and special surgeries increased with the rate of medical examination. The main functions and tasks of the hospital are examination, treatment, prevention and rehabilitation for patients in the northeastern mountainous regions and cities. The hospital currently has a total of 1050 staff members working. The organizational structure includes 09 functional departments, 05 centers, 29 clinical departments and 09 paraclinical departments.

Oncology Center was established on February 14, 2011, based on transplantation from the Department of Oncology and the Department of Nuclear Medicine of Thai Nguyen Central Hospital. The center has been and is becoming a reliable address for anyone who needs medical examination and treatment for oncology. With the functions and tasks of a Regional Oncology Center, with a team of 61 specialized and experienced staff, including 23 doctors (02 doctors, 11 masters, 02 level-I specialists with many doctors), 36 nurses. With an average number of patients for cancer examination and treatment of 200 people per day, besides improving the quality of medical services and qualified human resources, the hospital also always focuses on the care of patients. Care and support for patients and their families both physically and mentally during treatment, palliative interventions, and quality of life improvement for cancer patients.

2.2. Research literature review

In the past time, there have been many studies on cancer in general and on cancer care in particular, including those related to patient caregivers. This is an issue that has attracted the attention of many researchers from different fields. Studies on the role of caregivers in cancer treatment, in general, have shown specific roles and effects of performing these roles on patients. Several other studies also point to the outlook for caregivers. Some other studies have assessed more specifically the knowledge (Emory University USA, 1995) and skills of caregivers (Memorial Sloan-Kettering Cancer Research Center, 2009); Evaluation, comparison of experience among caregivers (University of Amsterdam, 2000; Family involvement in pain management of cancer patients has shown the stress of patients and caregivers in the treatment of cancer). their families have to go through (Warner JE Study (1992)); The National Cancer Institute (2012) study on the potential development of the role of carer for cancer patients (2012) offered models describe the role of the caregiver in the treatment of the patient, however, the study does not analyze the role of the family caregiver, but only refers to the professional carer (who is hired or work in medical facilities); Memorial Sloan-Kettering Cancer Center study, New York (2009) explores the communication and communication skills of professional caregivers, in the organization of family meetings in palliative care Some studies of the American Weather Cancer Institute (2001) on the psycho-social of people Caregivers have generally shown symptoms of stress and depression in caregivers; challenges faced when patients are terminally ill, etc. Overall, these studies have achieved results that contribute significantly to the research field of cancer caregivers and their role, as well as their needs in the care of cancer patients in general.

Currently, in Vietnam, there are only studies on cancer and cancer patients, mainly in medicine. Carer support is also part of palliative care, but formal and large-scale studies have not been conducted. However, the palliative care model and caregivers of cancer patients are more or less mentioned in the book: "Guidelines for Palliative Care for People with Cancer and AIDS" (Dr. Nguyen Thi Thi). Xuyen Editor), Medicine Publishing House, 2006. The book is considered as a manual on how to practice patient care according to the palliative care model.

It is the above studies that are the basis for the author's research direction to evaluate the role of caregivers for cancer patients and to find solutions to improve the role of caregivers for patients. Cancer Center - Thai Nguyen Central Hospital.

3. RESULTS AND DISCUSSION

3.1. Situation of care for cancer patients at the Oncology Center - Thai Nguyen National Hospital

3.1.1. Overview of caregivers for cancer patients

Patient care in a hospital is a supportive activity that meets the basic needs of each patient to maintain respiration, circulation, body temperature, eating, excretion, posture, movement, and hygiene. Personal birth, sleep, vacation; psychological care; support treatment and avoid risks from the hospital environment for patients [4]. The caregiver is a broad concept and can be understood in many different ways, depending on the area of care. In the medical field, the concept of a carer for a patient is often understood as follows: A carer is an individual who is involved in assisting in the identification, prevention, or treatment of a patient population. . Carers include the patient's next of kin; professional caregiver employed by the patient's family; hospital staff and including doctors and nurses.

In this article, caregivers for cancer patients are those who directly care for patients about physical, mental, psycho-social problems, palliative interventions, and quality of life improvement.

for patients. Carers here include the patient's next of kin (also called family carer), service carers employed by the patient's family, a team of doctors, nurses, and staff. society. Caregivers can also be classified into two groups as follows:

+ *Non-professional carers include: patient's relatives, hired carers (Untrained)*

+ *Professional carers including medical staff, doctors, nurses, and social workers, hired service carers (Trained)*

Oncology Center - Thai Nguyen Central Hospital is always interested in comprehensive, patient-centered patient care, meeting the needs of treatment and daily activities to ensure safety and quality. quality and towards patient satisfaction according to Circular 07/2011/TT-BYT of the Ministry of Health of Vietnam. According to the survey, the number of patients treated at the Center is large, so the number of caregivers for the patient is also very large (corresponding to each patient being a family caregiver or a caregiver, along with medical staff, doctors, medical staff, social workers are always ready to help patients during treatment). With a large number of patients, every day it is estimated that more than 200 people are involved in the care of cancer patients with different roles.

3.1.2. Situation and role of caregivers for cancer patients in the study area

3.1.2.1. Carer's role as a patient's relative (Family Caregiver)

The survey shows that there are some basic and internal characteristics of family caregivers as follows: their age is mostly in the range of 25-55 years old, that is, the working-age actively increases their main income. More than 60% of them work in agriculture. Therefore, patient care also greatly affects their labor and income. Carers are mainly parents, spouses, or biological children of the patient, so they are closer and easier to share with the disease. More specifically, these caregivers are the ones who understand the patient, the patient's difficulties and barriers, and always accompany the patient in the journey to fight cancer. The remaining 12% of caregivers are loved ones, relatives in the extended family system, or close friends of the patient, but the frequency of care is very low, mainly taking turns for the family carer for a short time, not a constant accompaniment of the patient), only 6.7% were service providers employed by the patient's family.

Family caregivers and medical staff have an important role to play in improving the health and quality of life of cancer patients. Care includes assisting the patient with daily activities such as reminding the patient to take medication, eating, and have insurance issues. Care also includes emotional support such as helping the person deal with his or her emotions and make difficult decisions. Family caregivers have a very important role to play in observing changes in the patient's condition during long-term home care and can assist with treatment planning, decision making, and implementation. Do some part of the treatment. The caregiver's role may change as a patient's needs change during and after cancer treatment: At the time of diagnosis; during hospital treatment; During home treatment; After the treatment ends; At the end of life.

They perform roles such as: Finding information, managing insurance, paying bills, renewing prescriptions, exercising patients, reporting new symptoms or side effects, requesting reductions in symptoms, incorporate lifestyle changes, encourage adherence, and promote positive patient behavior. A caregiver's day-to-day life can change dramatically when caring for someone with cancer. These changes affect most aspects of life and continue to have an impact after treatment ends. In addition to communicating with medical staff, caregivers can also do the following: Be a companion to the patient in the treatment process, both physically and mentally; Remind the patient to take medicine and eat well; Make an appointment for an examination, transport patients to places of medical examination and treatment; Treatment in emergency cases; Discuss patient-related issues

with stakeholders. Family caregivers often begin to care for patients without training, with a lack of scientific knowledge about cancer, so the way they care for patients also plays a part. Some people have misconceptions about the disease, for example: do not give the patient a lot of nutrition because it will make the tumor grow; only give the patient a vegetarian diet without supplementing with other essential nutrients, or abstain from bathing the patient; cancer can be cured by herbal medicine...and some other concepts. On the other hand, family caregivers are less concerned with their quality of life and often put the patient's needs first. When caregivers feel unwell, this can also affect the health of the sick person. Supporting caregivers also contributes to a smoother patient's treatment.

3.1.2.2. The role of the service provider employed by the patient's family

For families with cancer patients who need hospital care but family members do not have time or are busy working, they can rely on patient care services through service packages at the hospital. Outside the hospital, or search and connect yourself to rent. Currently, several large hospitals in Hanoi and Ho Chi Minh City have provided and deployed prestigious packages of care for patients and the elderly at home, at the hospital by the hour, or for a long time.

In Thai Nguyen, public hospitals have not yet implemented and provided patient care service packages. The hiring of caregivers for this service is often hired by patient families through self-connecting and searching. These caregivers are often not trained in knowledge and skills to care for cancer patients. This group of caregivers accounted for 6.7%. They only perform some care roles such as: Looking after, monitoring patients; Clean the patient's body and change the patient's clothes; Cleaning around the patient's treatment area; Take care of meals, clean up; Travel, walk when required; Massage tired, sore body areas; Turning patients around to prevent ulcers, etc. Mental support and psycho-social care for patients are less often done, partly because they have not been trained and trained, mainly based on the experience of physical care for patients, the lack of skills and knowledge about the psychology of cancer patients, partly due to not fully understanding the patient's condition and the patient's family situation.

3.1.2.3. The role of doctors and nurses

Doctors who directly treat cancer patients play a very important role in the process of cancer examination, diagnosis and treatment. In addition, doctors also have the following duties: Work closely with nurses at the oncology center in the assessment and decentralization of care for cancer patients with different conditions, and coordinate in the planning of cancer patients. plan and implement care plans for each patient; Coordinate with nurses and technicians in performing surgery, procedures, guidance and health education for patients; Check the implementation of indications for treatment, monitoring and patient care by nurses, students and technicians.

Along with great advances in cancer treatment techniques and protocols, oncology nursing is also constantly developing and making rapid progress, meeting the requirements of comprehensive health care, improving quality. life of cancer patients. The role of the oncology nurse no longer stops at infusion, dressing change, temperature measurement, etc., according to the doctor's orders, they have been trained at a higher level, more in-depth, significantly contributing to the improvement of their health. Improve treatment efficiency and meet the needs of patients and families. The nurse is the person that patients most often see, and possibly the people who most often care for cancer patients with their loved ones. They combine in-depth knowledge of the human body, disease, and mental and emotional care and support. From there, they view each patient in their specific cultural,

religious, lifestyle and family circumstances, as well as their medical condition and treatment. These nurses are experts in chemotherapy, radiation therapy, side effects management, pain management, and cancer care during and after hospital discharge.

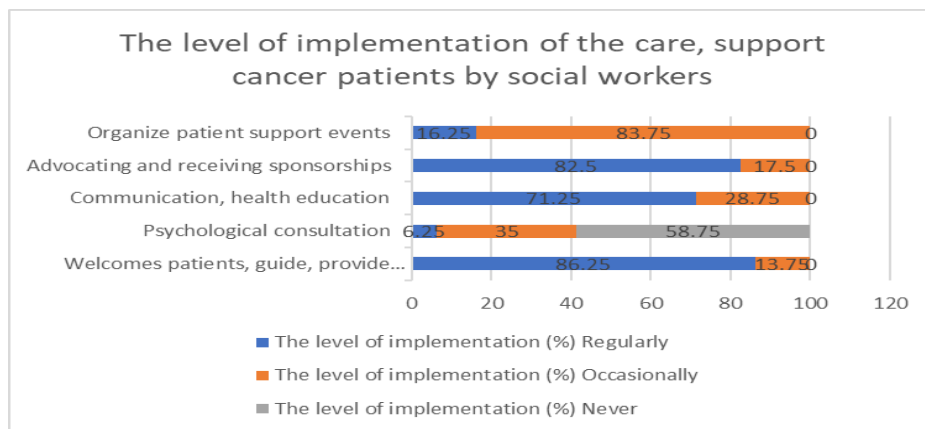
The nursing care role at the Oncology Center - Thai Nguyen Central Hospital is performed through activities such as: Receiving patients; Perform nursing techniques; Use drugs and monitor drug use for patients; Monitor and evaluate patients; Ensuring safety and preventing professional and technical errors inpatient care; Record medical records; Caring for the dying and dying patients; Rehabilitation care; Taking care of patients with indications for surgery and procedures; Nutritional care; Take care of personal hygiene for the patient; Mental care; Counseling, health education guidance, patient and family self-care, monitoring, disease prevention during the hospital stay and after discharge.

Among these activities, according to the assessment of the patient and the patient's family, the activity that is evaluated as best/completely performed is Reception of the patient; Perform nursing techniques; Use drugs and monitor drug use for patients; Monitor and evaluate patients; Ensuring safety and preventing professional and technical errors inpatient care; Record medical records; Caring for patients with indications for surgery and procedures. The activities of monitoring the patient's medication use, taking care of personal hygiene for the patient, taking care of the patient's nutrition, counseling, guiding, and health education are also performed by nurses, but not often. often, inadequately, mostly because family caregivers monitor drug use: "The nurse came to give medicine and infusion to my husband, but then I was the one to monitor the infusion process, if there is anything abnormal or the medicine runs out, I will report it to her" (In-depth interview with relatives of stage IV lung cancer patients), except in the case of severe patients in the intensive care units who will be nursed. care and follow-up. Mental care activities are also interested by nurses, but the level of support is not regular.

3.1.2.4. The role of social workers in supporting and caring for cancer patients

The hospital's Department of Social Work and Community Health Care was established in 2015, consisting of 14 social workers. The care and support role of social workers is carried out in many different forms and activities, but all aim to create satisfaction, improve the quality of life for patients, and support patients with peace of mind, trust in the examination and treatment process at the Center.

The survey shows that the level of performance of care and support activities for cancer patients by social workers is as follows:



(Source: Survey by questionnaire)

Looking at the data table, it can be seen that the most frequently performed activity is the role of welcoming, instructing and providing information to patients (86.25%), followed by advocacy, receiving resources. Support and communication, health education for patients and their families during and after treatment. Patients rated these activities very well: *"Every time I come for medical examination and treatment, I receive a warm welcome, guidance and full and dedicated information from social workers. I find this activity very necessary for the patients, and I feel very satisfied"* (Interview, 39-year-old male patient). With this activity, daily social workers welcome, guide, provide information, introduce the center's medical examination and treatment services to patients; Support the patient without family, relatives, helpless patients with legal procedures, find relatives for the patient; Regularly guide patients through procedures to receive support from the "Bright Tomorrow" cancer patient fund, the poor patient fund of Thai Nguyen province and the hospital's fund for poor patients with special difficulties. Central Thai Nguyen; Regularly consult on the rights, legitimate interests and obligations of the patient, programs, social policies and health insurance, social allowances in medical examination and treatment.

Cancer patients face a lot of psychological difficulties and need psychological counseling from social workers. However, this activity is rarely done (only 6.25%). This can be explained as follows: Thai Nguyen Central Hospital is a general hospital, the number of patients coming for examination and treatment is very dynamic, the operating model of social work is a vertical model with 14 social workers, the staff is too thin, so it is not possible to meet individual psychological counseling activities or group counseling for patients in departments and centers, but only in a few schools. In case there are signs of a serious crisis are notified.

Advocacy and reception activities play a very important role, creating resources to help patients with extremely difficult circumstances have the opportunity to receive treatment. In 2020, the Department of Social Work and Community Health Care has mobilized and raised funds with the amount of 3.1 billion VND. The organization of events on the occasion of holidays and New Year has attracted a large number of cancer patients to participate in bringing material and spiritual values to patients during treatment and improving mental health. for patients, dispelling the pain of illness, fatigue and pressure in life, bringing satisfaction to patients.

3.2. Some challenges of caregivers for cancer patients

Based on understanding the role of caregivers of cancer patients and the activities achieved, this survey also points out some difficulties and challenges for caregivers. Specifically:

Family caregivers have a great role in taking care of and supporting the patient both mentally and physically to maintain the patient's treatment process. However, the family caregivers themselves also face many difficulties such as The family caregivers themselves face psychological difficulties due to having a relative with cancer - a disease with a fatal prognosis and medical expenses. the economy is very high in Vietnam but has not yet received support; Psychological pressure when caring for patients; Pressure when performing dual roles (some people have to earn money, take care of small children, and take care of patients,...); Financial pressure and financial planning balance to ensure family life and cover medical expenses; loss of income due to reduced working hours, interruption of work or even quitting to spend time taking care of patients; Lack of knowledge about pathology and knowledge and skills to care for cancer patients in different pathological forms and stages. They are people with diverse professions: business, agriculture, etc. Their knowledge of medicine is very limited, so the issue of fostering and improving patient care knowledge for family members is also urgent; They lack the knowledge and skills to provide psychological support to the

patient when there are signs of crisis,... Therefore, to fulfill the roles of caring and accompanying the patient, family caregivers are very important. need the support of comprehensive care services in the hospital, the support of medical staff, social workers to help them reduce the socio-economic - psychological - social burdens caused by the care process. care for cancer patients.

- The team of doctors and nurses also face many difficulties such as High work pressure because their work is related to the health and life of others, so when working, they must be very focused and must always be careful. keep up the spirit. Therefore, encountering pressure and stress, fatigue is inevitable; Difficulty in communication – language. Especially when many patients are ethnic minorities. The language barrier makes it difficult for much medical staff in the process of disease exploitation and communication and support; In addition to professional knowledge, medical staff also have limited knowledge and skills to provide psychological support to patients in crisis cases.

- The hospital's social staff is thin, so it is difficult to carry out regular care activities, lack initiative in taking care of patients and their families. On the other hand, they lack specialized knowledge about cancer, so care and support are still limited; In addition, the hospital lacks close coordination among members of the cancer care team, lacks training programs on healthcare knowledge for patients. The hospital also has not yet built up services to provide carers at the hospital and home.

4. CONCLUSIONS AND RECOMMENDATIONS

Through research, the author found that the care for cancer patients being treated at the Oncology Center - Thai Nguyen Central Hospital is being performed by the patient's relatives (family caregivers), caregivers of services employed by the family with the care of the hospital's medical and social staff. Each component in this care system has a different role in the process of caring for the patient, they have performed quite well in the role of care, support, towards patient satisfaction, health promotion. physical and mental health for patients, helping patients improve their quality of life during treatment. However, they still face many barriers when performing the role of caring for cancer patients. Therefore, there should be solutions to overcome these difficulties to promote the role of care for cancer patients during hospital treatment. On that basis, the author proposes the following solutions:

- The Department of Social Work and Community Health Care needs to carry out a program to survey the care needs of patients and caregivers to develop appropriate plans to meet the needs of patients. provide care and establish social services to meet the professional care needs of patients such as individual counseling services, group consultations, building a model of a cancer patient support club, expanding patient care network. It also provides support services to the direct carers of cancer patients.

- In addition, the Department of Social Work and Community Health Care needs to implement training programs for family carers and service providers so that they know how to support patients, such as Nutrition programs for cancer patients, massage, exercises, psychological relief...

- Hospitals need to build comprehensive professional care models and services to meet the care needs of patients at the hospital and home.

- Hospitals need to further promote palliative care for cancer patients. Combining cancer treatments with palliative care increases the quality of life for both patients and their loved ones and

caregivers. Palliative care must be performed directly and regularly by a team of doctors and nurses at the hospital.

The synchronous implementation of the above solutions and strengthening the coordination between components in the care system for cancer patients is essential to enhance the role of caregivers, improve treatment efficiency and improve patient outcomes quality of life for cancer patients.

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