

WERONIKA KAMINSKA 

University of Gdansk

SUPRIYA CHITTAJALLU 

Indiana University School of Medicine-Fort Wayne

TIFFINI DAVIS

Indiana University-Purdue University Indianapolis

## THE SOCIAL STIGMA OF HOSPICE CARE IN THE CONTEXT OF CANCER

### Abstract

Hospice care is designed to help individuals with pain, physical and psychological, that arises during the advanced stage of a disease so that the patient can face their impending death with dignity. Through the hospice lens, the patient is viewed as an entity that needs both medical and non-medical care, which differentiates hospices from other forms of care available. However, despite hospice care having been integrated into the medical sphere and its widespread availability to patients, it has begun to be met with social reluctance and fear. This article is a review of theories, concepts, and research in the context of the social construct of cancer, palliative treatment, and hospice care. The texts analyzed in this article have been selected to show both the time-changing approach to the issues discussed, as well as the indication of threads that are characteristic of the USA and Europe, including Poland.

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Weronika Kaminska, MA, Department of Sociology, University of Gdansk, Department of Sociology, Indiana University-Purdue University Indianapolis; email: [wekami@iu.edu](mailto:wekami@iu.edu); <https://orcid.org/0000-0002-5148-2324>

Supriya Chittajallu, MBA, Indiana University School of Medicine-Fort Wayne; email: [supchitt@iu.edu](mailto:supchitt@iu.edu); <https://orcid.org/0000-0001-6132-6571>

Tiffini Davis, Department of Sociology, Indiana University-Purdue University Indianapolis, email: [davistif@iu.edu](mailto:davistif@iu.edu)

The aim of the article is to reflect on the social stigmatization of hospice care, changes in the identity of patients, especially the transition from oncological treatment to palliative and hospice care, and thus draw attention to the patient experience before the impending death.

**Keywords:** hospice care, stigmatization, cancer, transition, identity, dying

## INTRODUCTION

The concept of hospice care was created to relieve physical and mental suffering among patients with advanced disease [Neimeyer et al. 2011]. It was designed to help those facing imminent death situations maintain an adequate quality of life and move through the dying process with dignity. Since the establishment of the first hospice in London, hospice care has met with great enthusiasm in many places around the world, as reflected in the increase in places offering this type of care [Parker-Oliver, Bronstein, Kurzejeski 2005]. Although the concept was appreciated by the medical community, other institutions, and society, another phenomenon has started to develop in recent decades in many places around the world (for example, in the USA and Europe), i.e., reluctance and fear of hospice care, which is perceived as a place of death for patients (or that it even causes death), thus generating fear and reluctance to seek help in hospice.

On the other hand, when individuals agree to be in a hospice, sometimes they themselves, and their relatives, avoid using the word “hospice” [Gentry 2008; Buss, Lichodziejewska-Niemierko 2008], generating even more escalating stereotypes about hospice care. There are many social campaigns to change the social hospice stigma, such as “Hospicjum to też życie” (Hospice is also a life) and “Umierać po ludzku” (Die humanly) in Poland, or “#happFacesOfCaring” in the USA [Modlinska et al. 2008; National Hospice and Palliative Care Organization 2020]. However, the stigma of the hospice is still socially common. One of the main factors that increase the stigmatization of hospice care is the social construct of cancer, according to which the individual must, in a way, do everything they can to recover [Donovan 2005; McPhee Arcand, MacDonald 1979]. Going through the process from diagnosis to cure, people dealing with cancer can count on support and positive thinking from relatives, foundations, and medical care. Thus, they are expected to be able to be reintegrated into society. Consequently, the possibility that medical therapy will fail, and that the individual should consider hospice care, is often not allowed to be mentioned.

El-Jawarhi et al. [2017: 759] showed that a lack of information about hospice care and how this care can help patients with advanced cancer often means that patients' relatives, and the patients themselves, see this care as being applicable only in "hypothetical scenarios of others for whom hospice would be more relevant." The societal pressure to be a success story, a survivor, drives the narrative that to not fight is to die. In this paradigm, there is no room to access knowledge about hospices until it is forced upon the individual.

This article considers the reasons for the stigmatization of hospice care by relating this situation to the social construct of cancer, including the identity of a cancer patient. The article presents the concept of a patient's identity transitioning from an oncological patient to a patient under hospice care from the perspective of both the difficulties with identity change and the potential benefits for the patient. Finally, it examines how the stigma of hospice care affects patients, patient families, and hospice staff.

### **THE INFLUENCE OF THE SOCIAL CONSTRUCT AND STIGMA OF CANCER**

According to the American Cancer Society, in 2021 in the USA, there were 1.9 million new cases of people with cancer and over 608,000 deaths [Cancer Facts & Figures 2021]. In Europe, there were about 4 million new cases and 1.9 million deaths [World Health Organization – Europe 2022]. Despite the growing morbidity statistics, there is also positive information about people who have been considered cured of cancer, i.e., people who have survived over five years after receiving information about the cure – 17 million cancer survivors in the USA and 12.5 million in Europe [Cancer Facts & Figures 2021; European Academy of Cancer Sciences, Cancer Survivorship].

Cancer has caused widespread social fear for over a century. However, it was also documented in ancient times, through the Persian queen Atossa's ulcerative tumor in her breast, which she carefully concealed from the eyes of the public [Mukherjee 2010; Sontag 2001], and Hippocrates' descriptions of a mysterious disease that resembled cancer [Iavazzo et al. 2009]. However, depending on the source, the first recorded information describing cancer dates back to between 1500 and 2500 BC (Edwin Smith Papyrus). Interestingly, both descriptions (Atossa and the Edwin Smith Papyrus) refer to breast cancer and tumor resection as a means of fighting the disease [Mukherjee 2010; Kane, Petrosyan, Ameerally 2019]. Although many discoveries regarding cancer per se have been made during these hundred years, which can be seen through the development of the system

of diagnosis as well as prevention and therapy, the disease continues, causing increased cases of sickness and deaths all over the world [Umar et al. 2018].

The level of development of cancer care and treatment in the USA is recognized as the best in the world. For patients outside the USA seeking treatment, money is sometimes collected by various charity organizations and foundations because there is a doctor or therapy there that may give a (last) chance to cure cancer. This creates a picture of the USA as an idyl for people with cancer, a place where a much-desired cure can be obtained, even when there seems to be no hope left. According to some publications, modern drugs for certain types of cancer are available in the USA much faster than for patients in Europe [Uyl-de Groot et al. 2020]. Although treatment in both Europe and the USA is advanced, the United States remains the leader in terms of novel therapies, which prompts reflection on the differences in the approach to cancer and its social construction, as well as individuals coping with the disease and acceptance of the impending death there when the disease has reached an incurable stage. It begs the question of whether or not the United States affords patients a greater number of interventions simply because there is less acceptance of being diagnosed and eventually dying, among both patients and providers.

Society recognizes most types of cancer as a disease that occurs through no fault of the patient, though there are a few exceptions where specific cancer types are stigmatized by society. Uterine and lung cancer are stigmatized because they are perceived to be the result of poor lifestyle choices [Cataldo et al. 2011]. So far, there are only recommendations about factors that are likely to contribute to decreasing the risk of cancer [Key et al. 2002; Avgerinos et al. 2019]. The picture is vague and, in fact, when analyzing the available literature on prevention and factors, one can get the impression that so many things affect the risk of generating cancer cells in your body – from exposure to everyday stressors, polluted environments, processed food, to genes and family history of cancer that they generate the perception in society that we are powerless against cancer [Trichopoulos, Li, Hunter 1996; Parkin, Boyd, Walker 2011; Weigl et al. 2018].

This helplessness is also connected with the fact that we were often unaware that, up to this point, we have been exposed to carcinogenic factors (e.g., air pollution or contaminated drinking water). Due to all the potential threats that surround us, upon receiving a cancer diagnosis, the affected individual is often unable to indicate what, when, or how different factors contributed to their condition. Also, when meeting a patient, doctors can only rely on the information collected from the patient and the data from research on the specific type of cancer for which the patient has just been diagnosed. Individuals are also unable to

recognize the early symptoms of cancer by themselves, and (most often) cannot physically feel that the disease is shrinking/cancer cells are being removed from the body. Thus, cancer takes the form of a strong, unpredictable, out-of-control disease [Weinberg 1996].

### **THE TRANSITION OF ONCOLOGICAL, PALLIATIVE, AND HOSPICE CARE PATIENT**

Cancer makes individuals deal not only with the symptoms of the disease or treatment but also with a new social role, which may affect their identity during the course of the disease. From the moment they receive the diagnosis, the patient feels the influence of “the Big C” on their own reality [Stergiou-Kita, Pritlove, Kirsch 2016]. A person with cancer often tries to reconcile the current situation with other social roles and duties that are important for them. The role of the oncological patient is associated with additional tasks such as medical visits, taking medication, therapies, following an appropriate diet, and adapting their daily life to the situation [Zebrack 2000]. The individual must also get used to the new situation, give it meaning and define their attitude towards the disease [Chekryn 1984]. According to the European Cancer Patient Coalition, “having a cancerous disease is a unique, time-based experience that is different for each person and their loved ones” [European Society for Medical Oncology 2017: 2].

Oncological care is comprehensive. It includes many components aimed not only at curing the patient but also at ensuring an adequate level of quality of life when dealing with cancer, including diagnostics, treatment, rehabilitation, psychological and pastoral support, and access to painkillers [Ministry of Health 2020; Yabroff et al. 2021]. This care is commonly equated with oncological treatment, which is only a component. Oncological treatment focuses on causal treatment, which aims to completely eliminate neoplastic cells [Mukherjee 2010]. Due to the constant progress of medicine and the pursuit of the most effective therapies, there are currently many forms of treatment depending on the type of cancer. The most common include the surgical removal of neoplastic lesions, chemotherapy, radiotherapy, hormone therapy, immunotherapy, and targeted therapy [Miller et al. 2019; Abbas, Rehman 2018].

For some patients, however, oncological treatment may be one of several transitions – sometimes over a relatively brief period. When the disease progresses to an advanced stage, and the possibilities of causal treatment have been (or inevitably become) exhausted, palliative treatment is started. Then, out of hope

for a cure, plans for life after the disease, the adopted attitude and the re-evaluation of life, the individual has to face another, even more difficult diagnosis.

Due to the constant need to adapt medical care to the expectations and situation of the patient, the definition of care is also changing [Dzierżanowski 2021]. Palliative care is defined as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness” [World Health Organization 2020]. Until now, palliative treatment has had a negative connotation, which makes it even more difficult for the patient to deal with the current condition [Onyeka 2010; Formagini 2022]. Often (when causal treatment is discontinued), the individual becomes a palliative patient. After receiving information about the benefits of symptomatic treatment, the patient rebuilds their world, their reality. In this type of care, some patients may still live a few extra years. Palliative care is introduced during the advancement of neoplastic disease and is often combined with other causal treatments that the patient is taking. The main principle of palliative treatment is to counteract pain caused by cancer. It is a symptomatic treatment aimed at counteracting the effects of the disease [Łuczak, Kotlińska-Lemieszek 2011; Van Mechelen et al. 2013]. Palliative treatment, like hospice care, is part of a broader issue, which is palliative care. It covers not only physical pain symptoms but also psychological and spiritual support for the patient and their family [Yennurajalingam, Bruera 2012]. The social construct of neoplastic disease and the pressure of fighting for health and life to the end mean that, despite the positive impact of palliative care on the quality of life, it is stigmatized and, therefore, sometimes included in patients’ treatment relatively late, e.g., when they require care from a hospice [Shen, Wellman 2019].

When the disease continues to worsen, wreaking havoc on the body, palliative treatment may unexpectedly not work, which sometimes results in the patient being referred to hospice care. These changes cause many emotions, dilemmas, and hesitations, from counting on the possibility of recovery, as patients take in information on all treatment options and waiting for a real extension of life in palliative treatment, to the state of hospice care, in which the patient’s time is “counted” for the next six months of their life [Saunders 1978]. The patient may also find out about the disease too late and is referred directly to palliative or even hospice treatment.

Harrold and von Gunter [2016: 232] state that “hospice care is palliative care at the end of life”. Hospice care is included when “the most important goals are comfort and symptom management” [Oxford American Handbook of Hospice Care 2016:234]. It is holistic care that covers all aspects needed to

provide patients with the best possible comfort and sense of dignity as they face imminent death [Currow, Agar, Phillips 2020]. Hospice care can be provided at the “patient’s home, a nursing home, an inpatient hospice unit, or a hospital” [Harrold, Von Gunter 2016:233]. As they rightly point out, “although a hospice provides end-of-life care, referral to hospice care does not shorten life expectancy. For some diagnoses, admission to hospice is associated with longer survival” [Harrold, Von Gunter 2016: 233].

Even though the non-medical care in each of the above-mentioned types of care is the same, how it is administered is different. They also require a different approach and skills when the specialists are dealing with the patient. Helping an oncological patient to learn about their new situation, develop a new attitude to face their disease, and find strength for treatment will look different than the care provided to a patient who has received information about their transition to palliative treatment and who will likely be unable to attempt further causal treatment. The approach is yet again different with hospice patients when they must prepare to close all matters and “make the final transition” [Kalish 2019].

### **CHANGES IN INDIVIDUAL IDENTITY DURING CANCER AND THE TRANSITION TO AN ADVANCED STAGE OF CANCER**

Living through cancer creates new identities that can influence individuals’ personal well-being and relationships with care providers, but little is known about these post-cancer identities. Even less is known about the identities that are formed by those that will die from their cancer. The experience of developing a life-threatening illness means that a patient is sometimes forced to reevaluate their emotional, social, and existential needs, each of which is a strong influencer of personal identity, while often under considerable distress [Campbell-Enns et al. 2015]. There are two primary narratives that detail the identity changes of this population: (1) the cancer patient who pursues oncological treatment, which is then followed by hospice care, and (2) the individual that is unaware of their cancer until it is at a terminal stage, for which hospice care is their only remaining option.

The progression of cancer and the uncertainty of the success of treatment result in varying changes in patient identity throughout the treatment process. The first narrative, in which the patient discovers their cancer early enough for treatment, involves two shifts in identity, as the patient (1) moves from their non-oncological to oncological treatment identity and (2) from their oncological treatment to hospice identity. This second identity shift can occur quite quickly

after the first, depending on various factors such as how early on the cancer is detected, the type of cancer, and its metastatic rate. This potentially rapid change in self-perception can create an additional layer of vulnerability for this patient population.

Referring to the experiences of cancer survivors, who have been studied to a greater degree, there are four primary identity constructs, as established by Park et al. [2009]: “cancer survivor”, “person who has had cancer”, “patient”, and “victim”. Of these, survivor identity correlated with better psychological well-being and post-traumatic growth, as well as a higher likelihood of being involved with cancer-related advocacy [Park et al. 2009]. However, for the narratives examined here, the end stage is hospice care, so the survivor identity is not realized. The other three constructs are still valid for this population, however. The medical community must remain aware of not only the physical effects of cancer and oncological treatment, but also the psychosocial impacts. These identities guide how these patients receive their care, recover, and engage with their world. Recognizing and meeting patients where they are in this identity shift is vital to the health of this population.

The term “survivor” has been actively promoted and used with the goal of creating a sense of empowerment for those with cancer. This survivorship represents living after a cancer diagnosis, regardless of how long the person lives, and it is typically used for those who beat their cancer or who are in remission. However, what do those with end-stage cancer or who are seeking palliative care become due to these existing identities and constructs? Are they simply patients or victims, despite these terms holding connotations that have the potential to negatively affect their health and behaviors? While first-time oncological patients may have a more direct path navigating between these two identities, it can be a more difficult path for those experiencing additional cancers. For oncological patients experiencing terminal cancer after having attained the survivor identity through remission or being deemed cancer free from a previous cancer, do they still identify as survivors because of their previous success? Does this knowledge that they survived cancer before allow for an easier transition and acceptance of their identity as a hospice patient? Or does it make the return of cancer more devastating?

Choosing to enroll in hospice care represents a critical developmental stage in the oncological patient experience [Waldrop et al. 2016]. This choice, inherent in the two narratives described, also marks a cognitive and identity shift, as it is a major transition on the cancer trajectory. It marks an end to the fight. A common trope within cancer medicine is the push to have patients “fight” their disease.



If they are fighting, they are viewed favorably as oncological patients, as they are participating in the identity by pursuing active treatment. Hospice patients can be afforded greater dignity by trying to move away from this trope as it stigmatizes hospices and how these individuals can transition their perception of self.

Waldrop et al. lay out the hospice enrollment decision process as a flowchart. What unites the experience of hospice and non-hospice participants is the beginning stage, which starts with recognizing that their advanced cancer is a problem that needs a decision. Arguably, this is the beginning of the shift from the oncological patient identity to a more hospice-oriented identity. After they recognize their disease, these individuals become more aware of how their decline is life-changing, which leads them to the alternative generation stage. For those that fall within the two narratives addressed here, they either lack treatment options or they are undesired. This leads to the final evaluation that hospice care is a decision that allows for the cognitive shift that results in an identity transformation [Waldrop et al. 2016]. For those in this terminal stage, in which treatment of the disease is stopped, the “patient”, “person who has cancer”, and “victim” identities are the most likely to be adopted and maintained, irrespective of whether the patient has previously identified as a survivor.

The patient identity could be appropriate for those engaging in treatment even though it is not active treatment meant to cure their cancer. Unfortunately, when treatment has stopped, but the patient identity continues, there can be an implied “sick role”. For a person with cancer who discovers their cancer at the terminal stage, there is often no time for treatment, let alone recovery, so they are most likely to identify as victims. The victim identity reflects the person’s lack of control, the unfairness of their situation, and their powerlessness [Park et al. 2009]. “The person who has cancer” identity can exist alongside these two identities or by itself, but is neutral, as it has no positive or negative connotations. It simply identifies the person as a member of this disease community.

As they receive care to treat their cancer, and later as they transition to a passive patient while receiving palliative and hospice-care-related treatment, the patient identity is likely to allow greater self-healing as he or she explores these different identities, from their non-oncological to oncological patient identity. Their continued role as a patient helps ease the burden of the re-evaluation of self, though the nature of this role evolves. How the patient adapts to the new social role (the hospice patient) and how he or she experiences the changed life situation (changing from the disease stage to the terminal stage, under the care of a hospice) may be influenced by the stigmatization of hospice care. This may delay their decision to start hospice care until they can only be provided with

pain control support; thus, there is a lack of support for the patient regarding non-medical needs [Myers 2002]. The stigma of hospice care also influences how a new identity is built or denies the existence of a new identity (when the patient is not informed by the doctor or family that he is under the care of a hospice).

### **COPING WITH HOSPICE CARE – PATIENT, FAMILY AND CAREGIVERS**

The purpose of hospice care is to maintain a patient's quality of life until the end. In hospice care, a patient can be under home care, depending on the country's hospice system. For example, in Poland, home care is primarily provided at the patient's home, while in the US, it is also provided at other locations where the patient is staying, including nursing homes or other long-term care facilities. With inpatient care, however, regardless of the country, the patient is in a facility specifically for patients whose death is likely to occur within the next six months [Hyunh, Aleksandr, Rich 2008]. The goal of the place where a patient stays is to provide care with a level of comfort and enable relatives to participate in the care.

The context and goals of hospice care, such as hospitality or caring for a sick or dying person, have remained the same from its inception [West et al. 2019]. However, the manner in which support is delivered to a patient may differ depending on the hospice and the country. For example, in hospices in Poland, a psychologist is responsible for non-medical needs, and sometimes also a Roman Catholic priest. These people are part of the hospice team in most hospices in Poland. The position of a priest in hospices in Poland is related to the dominance of Catholicism in Poland. In the United States, on the other hand, most hospices have a spiritual counselor to help patients with their spiritual needs, regardless of their faith. The patient may also ask for a priest's visit, but he is not part of the hospice team. Previously, hospices had much more religious connotations, but nowadays, in some places (such as in the USA), a declaration of professing a particular religion is not a necessary condition for a patient to be admitted to a hospice [West et al. 2019]. A spiritual counselor (or chaplain) is an important part of a hospice team in the USA [Ita 1995; Neimeyer et al. 2011]. They help individuals find meaning in the current situation and guide patients by talking to them, listening to their fears, and offering advice to make it as easy as possible for patients to go through the dying process. Some studies show that patients who reported greater spirituality had less death anxiety than those who described themselves as less spiritual [Ita 1995; Neimeyer et al. 2011]. However, some hospice patients are not aware of their impending death or even that they are

under the care of a hospice. In this case, helping the patient to cope with emotions is exceedingly difficult or even impossible. Hospice care for patients who are aware of the advanced stage of the disease and their impending death may give them a chance to say goodbye to loved ones, close their affairs and duties, and leave this world with dignity and preparation.

There are many hospice programs available all over the world, but hospice services are underused. Novitskie [1993] pointed out that despite the rapid growth of hospice programs in the United States, “the number of patient deaths that occur in the acute hospital are much greater than the number of patient deaths that occur in hospice” [Becker 2004: 1]. It may be related to stereotypes about hospice care, which is associated with death and suffering. In Poland, however, patient occupancy is too high, and there are still too few hospices, resulting in long waiting times to get a place in a home or residential care [Ciałkowska-Rysz 2009]. The lack of places in hospices also affects the quality of services provided to patients [Ciałkowska-Rysz 2009].

Hospices are also touched by social stigma, which may impact the decision of whether the patient will be under hospice care and also impact the patient’s perception of the new reality while receiving hospice care. Erving Goffman [1963] began to analyze stigma in the context of patients in the 1960s. He showed that stigmatization is associated with specific social expectations toward the stigmatized person and makes that person feel discriminated against or even excluded (partially, temporarily, or completely) from social life [Goffman 1963]. Although decades have passed since Goffman’s theory was first proposed, it undeniably influenced the perception of how individuals in society are stigmatized, which is an important subject of social research.

Stigmatization in the context of a hospice can manifest itself in three main dimensions: patients, relatives, and the hospice team. Patients are the center of hospice care. They must face the advanced stages of a disease, as well as physical and mental suffering and their impending death. The transition to hospice care is associated with an irreversible change in the patient’s status, e.g., with cancer, they go from being defined as an oncological patient to a palliative patient under the care of a hospice [Bass, Labus 1985]. For the patient, the word hospice in this context means that this is their final medical status and that there are no further causal treatment options. Patients then associate the hospice with the final destination, which ultimately means the end of their life journey. When the patient was receiving treatment, there was the possibility that he or she would get well and be able to go home. However, when the treatment stopped, it took away all hope of that.

Depending on the type of cancer and the stage at which it is detected, the outcome of the disease, and the patient's experience, can be altered. The moment of diagnosis signals the patient's awareness of the cancer that is spreading through their body. With deadlier cancers, such as lung or pancreatic cancer, the fast spread coupled with later detection can make the disease incurable. The limited time afforded to the patient in this event may not allow them to prepare for the dying process and death; thus, these individuals often cannot cope with such a course of events. The individual becomes vulnerable, left without hope, and feels abandoned by doctors, who now seem like they do not want to continue to fight for the patient's health and life [Broom, Kirby 2013].

In addition, patients must also deal with leaving their life and their relatives, whom they will no longer have a chance to see again. These aspects can cause suffering, especially when the person is aware that it is impossible to oppose the non-existence that will come soon. Schütze [1997: 21] presented an interesting approach to understanding the tragedy of suffering. He compared individually experienced states to the process of the suffering trajectory, not only in the context of the stages through which the patient goes through [see Corbin, Strauss 1992, 1994], but as "influencing the identity of people affected by suffering" [Schütze 1997: 21]. He describes how a difficult life situation brings with it a series of human activities and attitudes, leading to the feeling of fatalism. As a consequence, the individual becomes "in his life orientations more and more depressed, and in his life activities – more and more passive" [Schütze 1997: 22]. Schütze's characteristics may also refer to suffering as the opposition to growth, especially the lack of finding meaning, which is considered in the context of irreversible events, e.g., the diagnosis of an incurable stage of the disease or information about the impending death.

No longer able to participate in social and family life, a patient's favorite activities can also cause suffering [Solomon, Hansen, Baggs 2018]. During the last moments of their life, the vast majority of patients would prefer to be at home, with relatives [Tang 2003; Cohen et al. 2010]. However, some may not be able to choose home hospice care because their advanced stage of disease requires constant, close monitoring. In the event that the patient's condition worsens, doctors also recommend staying in a hospice facility. Another reason may be the need to administer intravenous drugs and fluids to the patient continuously or every few hours, which is only possible in an inpatient hospice. Some patients choose a hospice facility out of care for their relatives. Home care would require them to give up their jobs and devote their time to caring for the patient [Broom, Kirby 2013]. The second reason patients choose a hospice facility is that their

family will not see their physical and emotional suffering or their changing appearance due to the progressive disease. Sometimes patients also do not want their relatives to see the dying process or their death, to save them from suffering [Broom, Kirby 2013].

Patients' relatives may have difficulties accepting that a hospice is the next stage for their loved ones with an advanced stage of the disease. Some may see the end of treatment as more detrimental to the patient. Enrollment in hospice can be a difficult decision for patients and their family members, representing an acknowledgment of the limited time that remains [Powers et al. 2011; William et al. 2015], which can be extremely hard for family members. It is especially difficult for those who may live in another state or country, as there is no guarantee that they can get to the patient before he/she passes away. Admission to hospice care also implies that family members take on a new set of roles that obligate them to provide care or help for the patient, especially in the context of hospice home care [Butterfield-Picard, Magno 1982; Bass, Labus 1985]. Depending on the patient's condition, he/she may or may not be able to make decisions for him/herself. All medical decisions would then be the responsibility of a family member. However, there are some patients who may not have any family members or who may not be close to their family members. In that case, most of the care for the patient would happen at a hospice facility.

A change, especially a sudden one, from an oncological to a hospice patient, may result in the relatives being unable to handle the patient's current health status and impending death. Everyone manages or copes with change in different ways. However, a family caregiver may not have much time to cope with all the changes that are happening in a short period. Family caregivers can experience psychological, social, and spiritual distress at levels that equal or exceed those of the hospice patient [Choi et al. 2013; William et al. 2015]. Despite this, home care hospice can be a valuable experience for the patient and the family members. Relatives can consciously spend as much of the time left as possible before the patient's death, whereas they would have less time if the patient were in hospital. Home hospice allows patients to continue going about their daily life. The family members can help and be there for the patient, sometimes simply being around the patient, even if it means just sitting and listening. Hospice care provides support not only to the patient but also to the family.

Hospice teams can help a patient's relatives through the grief process. According to Wright et al. [2010], family caregivers in a hospice had better emotional well-being in bereavement than caregivers of those who died in hospitals, with less complicated grief, post-traumatic distress [Wright et al. 2010],

and depression [Bradley et al. 2004; Solomon, Hansen, Baggs 2018]. Sometimes the reason a patient goes to a hospice facility instead of home care is that the family members cannot be around all the time to help take care of the patient. Sometimes, the only person who can look after the patient is the spouse, who is often elderly. The spouse may not be strong enough to help care for the patient. Thus, it is critical that hospice programs provide adequate in-home assistance to all patients, regardless of family members' availability [Kumar et al. 2020]. Having a nurse come to help the family is a huge part of helping the home hospice to succeed, as it allows patients to live their remaining time in their own home.

Hospice stigma also affects the hospice team. This is a particularly interesting dimension of stigmatization around the hospice, as it can affect all members of the interdisciplinary team, including nurses, social workers, doctors, and volunteers, generating many stressful situations from the perspective of caring for a dying patient [Trylińska-Tekielska 2019; McPhee, Arcand, MacDonald 1979]. All of these healthcare professionals help maintain the quality of life for hospice patients. Solid collaborative interdisciplinary teamwork has been found to affect patient care in positive ways [Parker-Oliver, Bronstein, Kurzejeski 2005]. The hospice team oversees both the medical aspects of patient care (including pain control and monitoring) and the non-medical needs (e.g., psychological, social, and spiritual) [Bass, Labus 1985]. Working in a hospice requires that the interdisciplinary team support the patients and their families in everyday challenges and observe the individual's death. Thus, the hospice team must take care of their own emotions. Difficulties resulting from working in such a demanding work environment may lead to burnout and depression, thereby negatively impacting the quality of patient care [Trylińska-Tekielska 2019]. The social stigma of hospice care also affects the hospice team itself, as working in a hospice is perceived as taboo [Ashforth, Kreiner 2014]. Perceiving social stigma in the context of working in a hospice means that the profession is seen as inappropriate, forbidden, or something bad. This may generate many ambivalent emotions among hospice team members, making them question the rightness of working in a hospice and the idea of holistic patient support.

### **RESEARCH ON THE QUALITY OF LIFE DURING PALLIATIVE/HOSPICE CARE**

A quality of life that is comparable to the time before the disease, especially during oncological treatment, has become as important as the treatment itself. As noted by Lepper et al. [2014:18], quality of life is difficult to define unequivocally, as it

pertains to subjective feelings, “largely determined by individual needs, beliefs, values and attitudes, and moreover, it is a value that changes over time”. It can be assumed, following WHO, that it is “the perception of an individual’s position in life, in the context of the value systems and culture in which they live, and in relation to their goals, expectations and interests” [Leppert et al. 2014, after: World Health Organization 1995]. Moreover, quality of life has become an essential element of care provided to the patient at every stage of the disease. Recognizing and incorporating measures to improve the quality of life in cancer disease has become a significant turning point in patient care since the 1970s [Cella, Tulsky 1993]. In addition to goals such as “survival and treatment toxicity [...], in the next 20 years, concern for the psychosocial needs of patients increased” [Cella, Tulsky 1993: 328].

Interest in the quality of life in neoplastic diseases occurred much later than with other disease entities. According to Cell and Tulsky [1993], the situation changed when, in many cases, cancer became a curable disease and the survival time of people with neoplasms increased. Since then, through increasingly better, promising cancer therapies, research into the quality of life in people with cancer has gained importance. Those studies, in order to precisely analyze the quality of life of cancer patients, often refer to some types of cancer that are associated with a specific feature that determines the importance of certain aspects of quality of life over others.

A study of patients with laryngeal cancer revealed that after completing therapy, patients faced many psycho-social problems, including difficult verbal communication with those around them, a sense of rejection, and, ultimately, social isolation [Biu et al. 2018]. As a result, research is being conducted on more advanced prostheses, as well as on vocal rehabilitation methods [Souza et al. 2020]. Other studies noted that among breast cancer patients who had had a mastectomy, patients started to have lower self-esteem, identity problems (e.g., what it means to be a woman, attractiveness) and depression [Carver et al. 1998; Begovic-Juhant et al. 2012]. Therefore, to increase the quality of life, work began on enabling patients to undergo surgical breast reconstruction [Rowland et al. 2000].

The measurement and impact on the quality of life differ between palliative and hospice patients, who have mostly completed or will soon end causal treatment and are under symptomatic treatment. In this case, improving the quality of life is primarily aimed at relieving pain (palliative treatment) and helping meet their psychological, social, and spiritual needs [Steele et al. 2005]. It is important to ensure the patient’s sense of dignity, respect their rights, involve them in their care and in making decisions at a level that is adapted to their abilities [Xiao et al. 2019].

However, it should be noted that in the era of the Covid-19 pandemic, support of a patient by the hospice's interdisciplinary team has changed. Especially the form of patient's visitations by their relatives during social isolation. Wysocka et al. [2021] noted that the need for closeness was severely reduced, making the patients' quality of life significantly lower.

## CONCLUSION AND DISCUSSION

Hospice care helps patients to control and minimize the intense physical pain associated with their disease. It also supports the individual and their relatives in the context of non-medical needs, including psychological, social, and spiritual support. This type of care is aimed at individuals whose disease advancement will cause death in the next few months. Hospice care sees death as a natural stage that everyone will have to face at some point in their life. It is also the main goal of hospice care to help the individual go through the final stage of their life journey with dignity. Despite the idea of holistic support for an individual, many stereotypes have arisen around the hospice, and this type of care is affected by social stigma, which may concern the patients and their relatives, as well as the first interdisciplinary team of the hospice.

The social construct of cancer, including the support of individuals, positive thinking, and the pressure of overcoming cancer, made it unacceptable for patients, their relatives and society to think about any other situation than recovery. In this context, continuing to search for additional treatment options in the face of advanced, incurable cancer may generate hope in the patient that perhaps there is something else that could help him/her. On the other hand, however, it raises the question of whether it simply makes it seem like they can deceive death, preventing the individual from being able to consciously face their own transition and prepare for their impending death. It is important to look for a solution to change the perception of hospice care solely in the context of death and suffering. Hospice care does not cause death; rather, it aims to bring relief from physical, spiritual, and emotional suffering. The negative image of hospices makes individuals delay the decision to include hospice care until only help in minimizing physical pain is possible, and holistic patient care is no longer possible, which can only confirm social beliefs that hospices are related only to suffering and dying.



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Weronika Kaminska

Supriya Chittajallu

Tiffini Davis

## SPÓŁECZNA STYGMATYZACJA OPIEKI HOSPICYJNEJ W KONTEKŚCIE CHOROBY NOWOTWOROWEJ

### Streszczenie

Opieka hospicyjna ma za zadanie pomóc jednostkom w bólu – fizycznym i psychicznym pojawiającym się podczas zaawansowanego stadium choroby tak, aby z godnością mogły zmierzyć się z nadchodzącą śmiercią. Hospicjum postrzega pacjenta jako całość, jako jednostkę, która potrzebuje zarówno opieki medycznej jak i zaspokojenia poza-medycznych potrzeb, co zdecydowanie wyróżnia ten rodzaj opieki od innych dostępnych. Jednakże, tak jak opieka hospicyjna została włączona do obszaru opieki medycznej i jest obecnie szeroko dostępna dla pacjentów, zaczęła spotykać się ze społeczną niechęcią, strachem. Artykuł stanowi przegląd teorii, koncepcji i badań w kontekście społecznej konstrukcji choroby nowotworowej, leczenia paliatywnego i opieki hospicyjnej. Analizowane w ramach niniejszego artykułu teksty zostały dobrane tak, aby pokazać zarówno zmieniające się w czasie podejście do omawianej problematyki, jak również wskazanie wątków charakterystycznych dla USA oraz Europy, w tym Polski. Celem artykułu było przedstawienie refleksji na temat społecznego napiętnowania opieki hospicyjnej, zmian tożsamości pacjentów i przejścia od leczenia onkologicznego do opieki paliatywnej i hospicyjnej, a tym samym zwrócenie uwagi na mechanizmy, których doświadcza pacjent przed zbliżającą się śmiercią.

**Słowa kluczowe:** opieka hospicyjna, stygmatyzacja, choroba nowotworowa, tranzycja, tożsamość, umieranie