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Defining "Dignified Death": A Qualitative Study of Perspectives of Palliative Care Patients in Mexico

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Abstract

Background: In Mexico, the rise of chronic diseases such as cancer has driven the advancement of palliative care in public health institutions such as the National Cancer Institute (INCan) in Mexico City. While we know that palliative care improves quality of life and helps with decision-making at the end of life among cancer patients, this study investigates how terminally ill palliative care patients at the INCan understand and define a dignified death.

Objectives: To analyze how cancer patients receiving palliative care at INCan define dignified death, as well as to identify the main elements they consider important for a death with dignity.

Methods: A qualitative study was conducted involving in-depth interviews and ethnographic observation on the INCan palliative care ward. A semi-structured interview guide was developed, and 48 patients were interviewed, including 32 women and 16 men. The interpretive framework used was Glaser's or classical grounded theory. Coding and code extraction were used for the analysis.

Results: Upon analyzing palliative care patients' concepts of dignified death, five central elements emerged as defining features: 1) avoiding pain and suffering, 2) the presence of religious beliefs including a belief in God, 3) the desire to fall asleep and never wake up, 4) the legal option of euthanasia, and 5) settling unfinished matters.

Conclusions: Cancer patients receiving palliative care at the INCan define a death with dignity as one without pain or suffering, which includes elements such as religion, the resolution of unfinished business, and the legal option of euthanasia. Findings provide insights into patients' needs and desires and can lead to the enhancement of palliative care and greater respect for patient autonomy. The study showed that INCan patients need more information about end-of-life decisions, including advance directives.

Ethics Approval and Consent to Participate: Ethics approval for this study was granted by the ethics committee at the study hospital site: Instituto Nacional de Cancerología (INCan). Approval number is: (023/043/CPI) (CEI028/24). Ethics approval was also granted by the IRB of the home institution of the PI (second author), Southern Methodist University, approval number: (24-139). All participants provided informed consented to participate in the study. The research was conducted in accordance with Declaration of Helsinki.

Data Availability: The data that support the findings of this study are available from the study Remaking Mexican Death, but restrictions apply to the availability of these data, which are highly sensitive given that the study deals with medical patients and so are not publicly available. The data are, however, available from the authors upon reasonable request. Email the study PI, Elyse Singer at esinger@smu.edu, for data requests.

Keywords

Advanced cancer, palliative care, dignified death, end-of-life decisions, euthanasia, Mexico.

Introduction

Since its emergence in the UK and the US in the 1960s, palliative care has become central to efforts to accomplish “dignified death” across the globe [1, 2]. Palliative care is designed to increase quality of life in individuals with chronic and terminal illness by mitigating physical, psychological, social, and existential suffering. In Mexico, palliative care emerged in 1980 in response to an increase in life expectancy and rising rates of chronic degenerative diseases [3, 4]. One of the leading health institutions where palliative care has advanced in Mexico is the National Cancer Institute (INCan)—initially as a "Cancer Pain Relief" program, which subsequently evolved into comprehensive palliative care for patients and their families [5].

Researchers in other contexts have determined that the provision of early palliative care helps support doctor-patient communication by providing patients with information about the progression of the disease and enabling them and their families to make decisions, ultimately resulting in a better quality of life and a reduction in physical and psychological symptoms [8, 9]. The early introduction of palliative care, moreover, reduces the use of intensive medical care at the end of life, saving health systems money and potentially saving patients and families duress. While the benefits of palliative care are myriad, less is known about what palliative care patients desire at the end of life or how they define a dignified death, particularly in non-Euro-American contexts where most of the research is based [10]. To answer these questions, we conducted a qualitative study in the palliative care ward of Mexico’s National Cancer Institute (INCan), including interviews and ethnographic observations.

Philosophies of care at the INCan include promoting awareness of death such that patients feel prepared to face this final stage [11, 12]. At the INCan, palliative care providers generally introduce the topic of death in conversations with patients once the disease has progressed significantly. Talking about death can be challenging, and even more so when patients are in the terminal phase of an illness and must confront their imminent mortality [13, 14]. While research indicates that clinicians and patients generally avoid talking about death, some studies have found that patients and caregivers are willing to engage these hard topics. A study in Italy found that talking about death is not taboo, either for patients receiving palliative care or for their caregivers. The word “death” is mentioned very frequently in the Italian context, demonstrating that, for patients and caregivers, talking about death can be considered a common practice [15].

Social scientists have also begun to explore how patients define a dignified death. In the Swedish context, research shows that terminally ill patients perceive a good death as a process rather than a discreet event. A dignified death, for these patients, was associated with having time to plan and prepare for death, and dying comfortably, quickly, independently, with minimal suffering, and with one’s social relationships intact. Some patients felt comforted by the belief that death is predetermined, while others felt uncomfortable considering death as the end of existence. Past experiences with the death of others influenced the participants' perception of a good death [16].

In the United States, Kuczmarski and Odejide [17] reported three key elements as central to achieving a dignified death among patients with hematological malignancies: conversations about the goals of care, avoiding overuse of medical care near the end of life, and the timely use of palliative care. In another US study [18] focused on lung cancer patients' perceptions of what constitutes a good death,

one hundred lung cancer patients answered open-ended questions regarding the concept of a good death. Content analysis revealed four themes describing a good death: occurring during sleep, without pain, peacefully, and quickly. Another mixed methods study [19] involving patients at the end of life identified themes such as pain and symptom management, clear decision-making, preparation for death, affirmation of personhood, and a sense of fulfillment in life or closure. In a literature review conducted by Proulx and Jacelon [20], the definition of dignity in dying acknowledges not only an intrinsic and unconditional quality of human worth but also external aspects such as physical comfort, autonomy, a sense of meaning and usefulness, preparation, and interpersonal connection. Other studies show that the experience of dying with dignity depends on the individual knowing that loved ones, caregivers, and strangers perceive them as a complete human being, regardless of their frailty [21].

Research in China [22] found that terminally ill patients and their families conceive of death with dignity as follows: preparing for and accepting death without fear, living without pain or discomfort, not prolonging the dying process, not being a burden to others and feeling supported by loved ones and professionals, maintaining human dignity, finding value and meaning in life, and satisfying spiritual needs. According to another study [23] in Chinese society the attributes of a good death may include physical comfort without pain and bodily integrity, psychological and spiritual peace, the well-being of family members, and their companionship with patients. In other research conducted in China, patients expressed that a “good death” entailed dying without pain or physical suffering [29, 30].

Research from United States, Korea, and Tanzania indicates that definitions of “good death” vary according to ethnicity and social class. [24, 25, 26, 27] The definition of dignified death depends on the specific situation of each patient, their beliefs, and values. In a study conducted in Brazil [28] found that terminal patients perceived dignity as an important dimension of experience at the end of life. Among the wishes of patients at the end of life are symptom management, dignity and spiritual peace, and not being alone or abandoned by family. Moreover, in a study in Ghana [31], nurses mentioned “physical and psychological comfort” as one of the central elements of a good death. In a study by Ribeiro et al. [32], when applying the Go Wish[1] [33] card game to palliative care patients in Brazil, the authors found that patients most frequently chose card 19, “I want my family and friends to be close to me.”

Regarding the place of death, in a study in Colombia [34] found patients with advanced cancer preferred to die at home, although some expressed their desire to die in a hospital to have better control of symptoms. In addition, Malhotra et al. [35] reported in their study using data from a cohort study of patients with advanced cancer in Singapore, that the financial burden could motivate people to choose to die at home rather than die in a hospital.

One study in Mexico [36] with patients, family caregivers, and physicians on the perception of death with dignity indicate that a good death is "a dignified and peaceful death," perceived as a multidimensional process that requires attention not only to biomedical needs but also to the

[1] The Go Wish tool consists of cards that are used as a game, with professional design and printing. It is widely applicable and economical, helping people to talk about end-of-life care. The cards focus conversations, provide important vocabulary to express patients' needs and concerns, and offer a means of sharing those ideas.

existential and relational aspects within the family. Other studies in Mexico have focused on opinion polls on the legalization of euthanasia or medically assisted suicide, generally showing public support for the practice [37, 38].

As can be seen, the issues of death, end-of-life decisions, a good death, and dignity have been studied in some countries, reflecting divergences and convergences in research results due to social, economic, and cultural factors. However, research in Mexio is limited. Investigating these issues in the Mexican context can yield information that allows practitioners to find better ways to care for ailing patients at the end of life in accordance with their wishes.

Methods

A qualitative study was conducted involving in-depth interviews and ethnographic observation of cancer patients and providers on the palliative care ward. The interpretive framework used was Glaser's or classical grounded theory. The basic approach of this framework in social science research is that social theory is developed inductively, emerging from the data obtained in the research and not the other way around, meaning that the data obtained are the essential element for the development of theories. According to this approach, research focuses on how individuals interact with the phenomenon under study and allows for the prediction or explanation of the subject of study. Qualitative interview data were coded for emergent themes [39].

Objective

This research aims to analyze how cancer patients treated in the palliative care unit of the INCan define a death with dignity. Findings from this study can help establish strategies in palliative care to assist terminal patients in transitioning through the end of life in ways that better meet their needs.

Design

We conducted a qualitative study in the palliative care ward of the INCan from August 2023 to August 2024. The study included hospital ethnography as well as forty-eight in-depth interviews with cancer patients, most of whom were terminally ill and came from different states of the country. We used an interview guide that authors one and two created specifically for this study [see supplementary files].

Setting

This research was conducted at the INCan, a tertiary care hospital that forms part of the Mexican Ministry of Health, which treats approximately 7,500 new patients each year [41]. The INCan provides specialized medical care to cancer patients and serves as a referral center and governing body for cancer care in Mexico. The hospital is also a center for medical education and research, including in palliative care, and services range from treatment and rehabilitation to follow-up care [40]. The INCan was created to provide cancer care for people without social security arriving from various parts of the country, and today the hospital offers specialized training in several specialties, including palliative care.

The INCan Palliative Care Service (SCP) was inaugurated in 2011 and has become a pioneer program in the country, treating more than 1,000 new patients a year and constantly expanding and evolving its approach.[2] Innovative strategies for integration with oncologists include a support team for patients with advanced cancer in clinical trials, a palliative care geriatric team, and research activity among clinicians [42] The SCP provides care to both patients and their families with a multidisciplinary team composed of palliative care physicians, nurses, psychologists, psychiatrists, social workers, volunteers, administrators, nutritionists, and dentists, whose goal is to improve quality of life and guarantee a dignified death [5]. Care is provided through outpatient services, hospitalization, an emergency department, a day hospital, telephone support, and at home. The multidisciplinary palliative care team works to address the physical, social, and psychological symptoms of cancer and cancer treatment among patients in advanced stages of the disease [6, 7]. The palliative care ward consists of four clinics, each providing care to patients in a different room according to type of cancer as shown in Table 3[5].

Participants

Forty-eight patients were interviewed for this study (Tables 1 and 2), of whom 32 were women and 16 were men, arriving from different states of the Mexican Republic. The age range of the patients in our sample was 30 to 84 years.

Table 1. Interviews conducted with female patients

[2] The SCP was inaugurated in 2011, independently of the Pain Clinic Service [6R], but both services, with different clinical activities and philosophies, aim to improve patient quality of life.

Participant	Age	Residence	Diagnosis
1	64	Ciudad de México	Recurrent ovarian cancer
2	53	Chiapas	Uterine cancer
3	35	Estado de México	Cervical cancer
4	48	Estado de México	Cervical cancer
5	56	Ciudad de México	Cervical and breast cancer
6	48	Estado de México	Ovarian cancer
7	55	Estado de México	Endometrial cancer
8	54	Pechuga Hidalgo	Endometrial cancer
9	57	Estado de México	Cervical cancer
10	58	Estado de México	Breast cancer with bone metastasis
11	43	Estado de México	Breast cancer with bone, rib, and brain metastasis
12	44	Guerrero	Breast cancer, bone, liver, and possibly brain metastasis
13	60	Estado de México	Breast cancer with bone and blood metastasis
14	54	Estado de México	Breast cancer, lung, liver, and spinal metastasis
15	47	Ciudad de México	Cancer metastasis to bones and liver
16	46	Hidalgo	Uterine cancer
17	58	San Salvador Atenco (Texcoco)	Liver cancer
18	52	Tehuacán, Puebla	Breast cancer with metastasis
19	66	Estado de México	Breast cancer with metastasis
20	68	Santiago Zapotitlán	Breast cancer
21	68	Puebla	Breast cancer with metastasis
22	46	Puebla, Tlacotepec	Breast cancer, metastasis in bones and liver
23	49	Hidalgo	Rectal cancer
24	51	Estado de México	Liver cancer
25	67	Estado de México	Gallbladder cancer
26	33	Varacruz	Kidney cancer and under a rib
27	42	Puebla	Cancer in the lymph nodes
28	46	Huehuetoca, Edo. México	Cancer in the esophagus, lungs, bone
29	76	Huixquilucan, Edo. de México	Multiple myeloma
30	83	Hidalgo	Breast cancer
31	78	Azcapotzalco	Lung cancer
32	71	Estado de México	Lymphoma

Note: Descriptive Data of all Female participants. Table prepared by the authors based on data from interviews conducted.

Table 2. Interviews conducted with male patients

Participant	Age	Residence	Diagnosis
1	50	Toluca	Prostate cancer
2	52	Quintana Roo	Prostate cancer
3	30	Michoacán	Osteosarcoma
4	31	Morelos	Knee sarcoma
5	61	Ciudad de México	Pancreatic cancer
6	62	Veracruz	Stomach cancer
7	72	Chalco	Liver and rib cancer
8	68	Oaxaca	Stomach and esophageal cancer with liver metastasis
9	69	Guerrero	Peritoneal cancer
10	78	Ciudad de México	Prostate cancer
11	84	Estado de México	Stomach lymphoma
12	73	Ciudad de México	Pancreatic cancer
13	74	Oaxaca	Prostate cancer
14	71	Ciudad de México	Cancer in the ampulla of Vater, stage four with metastasis to the neck and shoulder
15	77	Puebla	Colon cancer
16	78	Estado de México	Throat cancer

Note: Descriptive data of all male participants. Table prepared by the authors based on data from interviews.

The authors developed an interview guide to explore three dimensions of patient experience. The first dimension addressed the personal sphere, with the aim of learning about the patient's personal circumstances and their experience of the illness. Dimension two, palliative care and dignified death, examined the opinions of sick people regarding definitions of dignified death and whether patients are able to achieve a dignified death based on the provisions of the Ley de Voluntad Anticipada[3] (LVA), and the third dimension, medical care and end-of-life decisions, explored the care provided in the hospital as well as respect for end-of-life decision-making. For the purposes of this article, data from the third dimension of end-of-life experience is analyzed.

Data analysis

The authors read and coded each interview for salient thematic categories. Once the codes were obtained, excerpts were extracted from the codes and information related to the topic of interest, in this case definitions of dignified death, was identified. The authors used Dedoose software for coding. Moreover, information from ethnographic observation was used to analyze the code “to settle unfinished matters,” which was not found in the interviews but emerged during observations on the ward. This information was obtained from field notes taken during observation.

Procedure

Once the research project was approved by INCan ethics committee, ethnographic observation was carried out in the palliative care ward for approximately 47 weeks from July 2023 to June 2024. The project team, consisting of the PI (Author Two) and a Postdoctoral Research Associate (Author One),

[3] The Ley de Voluntad Anticipada (LVA) was passed on January 7, 2008, and enables terminally ill Mexico City residents to make free and informed decisions about whether to continue or withdraw curative measures, while also ensuring that they have access to palliative care services.

rotated between each consultation room to observe each clinical environment and to identify and invite patients to participate. The selection of patients was made according to what was observed in the consultation rooms according to the inclusion criteria listed below:

• Patients diagnosed with advanced cancer who are receiving palliative care at the INCan.

• Patients who are aware of their terminal diagnosis.

• Patients of both sexes.

• Patients over 18 years of age.

• Patients who understand and sign the informed consent form to participate in the study.

If patients agreed to participate in an interview, the investigators explained the study objectives and performed a process of informed consent indicating that the interview would be audio recorded. This study does not use the participants' names or pseudonyms; instead, the participant number is presented. A private space outside the palliative care ward was assigned for the interviews, although on some occasions interviews were conducted in the waiting room of the palliative care area due to lack of space. Once the recordings were available, the transcriptions and corresponding analysis were carried out.

This research was submitted to the INCAN ethics committee and was approved. The approval number is (023/043/CPI) (CEI028/24). All participants provided informed consent before participating in the study.

Results

As mentioned, at the INCan, the palliative care area consists of four clinics: Consultation room 1. Palliative care clinic for gynecological/urological tumors; Consultation room 2. Palliative care clinic for breast/lung cancer/sarcomas; Consultation room 3. Palliative care clinic for gastrointestinal tumors/hematological neoplasms/head and neck tumors; Consultation room 4. Palliative geriatric clinic. Ethnographic observation and patient interviews were conducted in each consulting room. A total of 48 patients from different states of the Mexican Republic were interviewed. Table 3 shows the number of patients interviewed per consulting room:

Table 3. Patients interviewed by clinic

Consulting room /clinic	Women	Men	Total	Main diagnoses
Consulting room 1. Palliative care clinic for gynecological/urological tumors	9	2	11	Cervical, ovarian, endometrial, and prostate cancer.
Consulting room 2. Palliative care clinic for breast/lung cancer/sarcomas	13	2	15	Breast cancer with metastasis, lung cancer.
Consulting room 3. Palliative care clinic for gastrointestinal tumors/hematological neoplasms/head and neck tumors	6	5	11	Rectal, liver, pancreatic, gallbladder, kidney, lymph node, stomach, esophageal, and peritoneal cancer.
Consulting room 4. Palliative geriatric clinic	4	7	11	Prostate cancer, lymphoma in the stomach, pancreas, ampulla of Vater, colon, multiple myeloma, throat, breast, lung.
Total	32	16	48	

Note: Patients in research sample per palliative care consultation room. Table prepared by the authors based on data from interviews conducted.

As can be seen, the participants are diverse in terms of diagnosis, gender, and state of origin, which allowed us to obtain information about how a diverse segment of palliative care patients define dignified death.

For the development of this study, the project team analyzed the code "concept of dignified death." When analyzing the code, five elements that are central to death with dignity were observed, including avoiding pain and suffering, belief in Good, the desire to fall asleep, settling unfinished matters, and euthanasia.

According to palliative care patients, dignified death entails avoiding pain and suffering. Many patients associated their illness with a great deal of suffering and expressed that they did not want their deaths to be marked by suffering in the same way. The following vignettes show some of the fragments of what patients said about suffering and pain in relation to their vision of a dignified death:

...because I want no suffering, no pain... Patient 9 (man, 69 years old, peritoneal cancer).

Well, maybe without suffering; a death that doesn't cause you too many problems... Patient 8 (man, 68 years old, cancer of the stomach, esophagus, and metastasis to the liver).

Well, I say that it is dignified not to suffer, not to be in pain. You see, then you are suffering terribly, and a dignified death is when you are not suffering, when suddenly there is nothing else... Patient 6 (man, 62 years old, stomach cancer).

That I don't suffer when I die. Patient 1 (woman, 64 years old, recurrent ovarian cancer).

Participants also mention learning to live with pain and fear of what might happen in the disease process.

Well, in these cases, I think that it will happen to all of us, right? But this is the most... it's something more painful, isn't it? Because you're suffering. It's something you're living with every day, your pain,

your fear. Yes, but you have to learn to live with that pain and that fear. Patient 1 (man, 50 years old, prostate cancer).

In some cases, from the perspective of palliative care patients, death is understood to be beautiful precisely because it promises an end to the enduring suffering that has defined their illness process.

It's good, good... Well, it's also so beautiful because all suffering ends there. Patient 2 (woman, 53 years old, uterine cancer).

Patients express that a good death entails not only the absence of suffering, but also the ability to shield of loved ones from their suffering.

Oh, well, maybe what I'm doing. I mean, coming here, controlling my symptoms, well, yes. Maybe what I'm doing, right? Well, yes, I'm not suffering in a bed; that my children, above all, don't see me, let's say, suffering and at the same time suffering themselves because of it. Maybe that would be... [a dignified death]. Patient 28 (woman, 46 years old, cancer of the esophagus, lungs, bone).

Another central concern for patients is to be cognitively well and without physical pain.

Eh, well, without ailments, without pain, without this.... To be well. I mean, now it's about being well at the moment of your death, avoiding pain, severe pain, I don't know. This is new to me too. Patient 2 (man, 52 years old, prostate cancer).

Participants state that to achieve a dignified death, it is important to be free from pain and suffering, and they are clear that palliative care plays an important role in controlling the symptoms they associate with suffering. Their discourse reveals an extreme fear of experiencing physical pain; indeed, several patients attend palliative care specifically for pain control. Moreover, some patients state that part of a dignified death includes avoiding additional problems for their relatives, as many already feel like a burden due to the constant care they require from family members as well as the financial costs their treatment entails. Suffering, for these patients, is broader than physical pain and discomfort; it includes emotional duress due to the perceived toll patients exact from family members in the end-of-life process. As the following statements demonstrate, the experience of pain and suffering at the end of life is intersubjective and unfolds in the relationship between patients and their loved ones.

Without feeling [too much], I think that would be a dignified death. But we would all suffer, wouldn't we? Both my family and I, as I say goodbye. Patient 9 (man, 61 years old, pancreatic cancer).

Well, maybe without suffering; a death that doesn't cause you too many problems... Well, it's more for the family, so that they are aware that this has to happen. Patient 8 (man, 68, stomach and esophageal cancer with liver metastasis).

A dignified death? Oh, well, knowing that it has to happen someday; that it's something very normal; that, well, there's no need to be shocked or make life difficult for my family. On the contrary, being reasonable and know that, well, sooner or later it has to happen. Patient 17 (woman, 60 years old, breast cancer with metastasis to the bones and blood).

Patients' religious beliefs also play an important role in how they imagine a dignified death. Some patients believe that God is the only one who can decide when and how death will occur. These participants were unable to express more on the topic of dignified death, even though they understood that they were suffering from a terminal illness, perhaps due to a fear of talking about death or because of their deep convictions and beliefs about life and death and the limited agency of humans in this process. Patients expressed the following perspectives:

No, if God says so, then that's it, if it's no longer possible, then it's no longer possible, but that's the way it is, and you have to accept it. Patient 9 (man, 69 years old, peritoneal cancer).

Well, as I was saying a little while ago, in my last moments, I would give anything to be able to walk, to be able to do my own things, to be able to work part-time... if God gave me that opportunity. Patient 17 (woman, 58 years old, liver cancer).

Well, I think only God knows that, right? Because God, God is the only one. He gave us life and he will know how we are going to die, if I am going to die of a heart attack, if I am going to die of pain, of the pain I feel. Patient 2 (woman, 53 years old, uterine cancer).

Patients' beliefs are rooted in their faith that death is something inexplicable that can only happen when God wills it. Their acceptance of death and resignation to its unpredictability, including when and how it will happen, is evident in their responses. Acceptance of death and the presence of religious beliefs provide strength when facing the end of their lives, even if pain and suffering are present.

In addition, some participants describe their version of a dignified death as falling asleep and never waking up, freeing them of any pain and suffering that may occur at the moment of death. While perhaps most people would desire a death that includes falling asleep without feeling anything, this is especially true for cancer patients who have experienced a disease process with constant and enduring pain.

[A dignified death would be] *to fall asleep and never wake up again. That's it. For me, that would be a very beautiful death. Patient 1 (woman, 64 years old, recurrent ovarian cancer).*

I would like to say that maybe I would like to fall asleep and never wake up again. Patient 3 (woman, 35 years old, cervical cancer).

...fall asleep, cardiac arrest, and that's it. Without feeling anything, I think it would be a dignified death. Patient 5 (man, 61 years old, pancreatic cancer).

A dignified death, well, I imagine it when they sleep peacefully and dawn breaks, and that's it, right? Patient 25 (woman, 67 years old, gallbladder cancer).

Other participants' definitions of dignified death included having the legal option of euthanasia, though importantly, patients never raised this spontaneously and only mentioned it when asked directly. Nevertheless, in their spontaneous narratives of what defines a dignified death, many patients indicated that they would prefer to die before the disease progresses and they suffer intense pain, and ethnographic observations of clinical consultations revealed that several patients asked the clinician directly about euthanasia. Patients' observations of the enormous physical pain of other patients with

more advances stages of cancer in the palliative care waiting room, in addition to their own pain, help contextualize their stated desire to hasten death through euthanasia. It is possible that the refusal of patients to spontaneously mention euthanasia unless asked directly stems from discomfort or lack of familiarity with euthanasia, which is currently illegal in Mexico.

[A dignified death would be] not feeling this pain, despair, anguish, or whatever it is, is like sleeping and resting, and in fact, I told my husband, and he laughed because I said that if there was so much pain, why didn't they give them the injection they give here, what's that injection called that they give? ... Patient 3 (woman, 35 years old, cervical cancer).

Well, I would say [euthanasia] would be fine, wouldn't it? Because I have the right to express my opinion about myself... and if I already feel uncomfortable or there is nothing more that can be done, come on... they are just delaying what is going to happen someday... And if they were to propose that to me, I would say that would be fine. Patient 17 (woman, 58 years old, liver cancer).

[This participant is not referring to euthanasia, but rather to respecting her advance directives] So, for me, a dignified death is precisely when you reach that point where there is no more treatment and everything, eh, I think I mentioned it to the doctor at some point, but if it happened somehow that I, because I also talked about an advance directive. Patient 11(woman, 43 years old, breast cancer with metastasis in bones, ribs, and brain).

Patients' perspectives on what defines a dignified death include the option of hastening death by lethal injection, not delaying death, and respecting advance directives to refuse or withdraw life-sustaining treatment. These perspectives lead us to believe that patients have considered that euthanasia can be used to achieve a dignified death. Although most interviewed patients do not know much about euthanasia, they are aware that it exists and the idea that they might be able to use it makes them feel more protected and at peace in their suffering. Our findings highlight the need to provide patients with information about the various legal options they do currently have at the end of life, including palliative sedation, which is legal in Mexico and available at health centers such as the INCan, and to avoid its conflation with euthanasia.

One feature of patients' understandings of "dignified death" that emerged in ethnographic observation more so than in interviews was the importance of settling unfinished matters. In conversations with palliative care clinicians, patients regularly explained that to die peacefully they needed to resolve outstanding interpersonal disputes and problems or else achieve personal goals before it was too late. One patient with cervical cancer, for instance, expressed her longstanding desire to get married to her partner before she passed away.

Doctor: It is the process of the disease; it is progressing and affecting the organs. Right now, the lung is filled with water, but that water cannot be removed because it will most likely fill up with water again. We are at a point where death can occur suddenly; the disease is already very advanced. Do you have any fears? Any concerns? What do you think about what I just told you?

Patient 3 (woman, 35 years old, cervical cancer): (cries a little) All I want is for God to allow me to get married before I die. My wedding is on Saturday. It's the only thing I want...

Another observation made in the field notes was that of patient 3 (man, 30 years old, osteosarcoma) who decided not to continue treatment and to look for his son to apologize for a past wrong that he did not disclose:

Patient 3, a palliative care patient, arrived at the INCan emergency room, where a palliative care resident, was making his rounds. Patient 3 was sitting on a hospital bed, hunched over and staring at the floor. A mass the size of a melon protruded from his shoulder: a life-threatening osteosarcoma. Patient 3 could not survive long without the oxygen tank connected to his mouth. Since his cancer was no longer responding to chemotherapy, his oncologists had referred him to palliative care.

Patient 3 rejected the palliative care service. When Dr. encouraged him, he responded with a question: "Are you a father, doctor?" The patient didn't have much time, he explained. He couldn't ignore the weight of the tumor that bent his upper body down like a hook and crushed his lungs. He wasn't interested in comfort measures. Before he died, he said, he needed to find his son and apologize. Dr. ten years younger than Patient 3, seemed to understand and respect his decision. Instead of establishing a palliative care plan, he worked quickly to locate a portable oxygen tank so the man could find his son before it was too late.

Beyond the more salient definitions of dignified death already discussed, a few idiosyncratic ideas emerged in the interviews, including the understanding, presented by one patient, of leading a life with integrity and managing one's emotions appropriately during life:

A death with dignity? Having done what I had to do... if I made mistakes, I corrected them; I always stood up; if I fall, I get up; if the news makes me sad, I transform it. Hey, don't give up, then. That's a dignified death. Patient 8 (woman, 54 years old, endometrial cancer).

Certain absences in the data are also instructive. Only one patient in the sample spoke about donating their organs or body to science. It is clear that the vast majority of people in this context do not consider this option or associate it with a dignified death, likely because there is very little information available to the public about the usefulness of organ donation and whole-body donation. Only one in our sample patient expressed:

Yes, yes. We have been very clear on the subject. For example, I have told [my family]: the day it happens... well, in fact, I asked here if there was organ donation and if I could still do it. They told me yes, that there is research here and at the UNAM (Universidad National Autónoma de México), so that's my idea. And I told them: "Look, when the day comes, when I die, I would really like whatever is possible to be donated for research. And they accepted it very well. So I've talked to them about it, yes. Patient 28 (woman, 46 years old, cancer of the esophagus, lungs, bone).

In short, the data reveal that the Mexican public could benefit from more information on controversial options such as palliative sedation, euthanasia, organ donation, and whole-body donation, which, when shrouded in secrecy, can lead people to stigmatize or reject these options. It is important to disseminate information within the healthcare system regarding the options currently available for a dignified death. A movement has recently emerged in Mexico that is advocating for and promoting the legalization of euthanasia as part of a dignified death.

Discussion

Patients in palliative care at the INCan are generally aware of the progression of their disease and are conscious of their morality. Nevertheless, it is difficult both for them and the interviewer to talk about the end of life. In this study, based on the information provided by patients as well as ethnographic observation, a dignified death can be defined as one without pain or suffering, broadly conceived. Participants were clear that the experience of tremendous physical pain throughout the course of the disease, as well as regular exposure to patients in the final stages of their illness in the hospital waiting room, made them acutely aware of the symptoms they may experience as they moved toward the end of their lives, and avoiding this was paramount for them. Thus, in this study, most participants agree that a dignified death will be achieved only if the sick can avoid increased pain or suffering in the dying process.

This finding echoes those of existing studies conducted in Mexico and in other parts of the world. In one study conducted in Mexico [38], people with chronic illnesses expressed that a dignified death would be painless, peaceful, and would happen at home without fear or suffering. Studies from elsewhere around the globe have also found that patients define a dignified death as one in which people die without pain or suffering; [29, 30, 43, 23, 28, 44, 45, 46, 47] reflecting what we determined in the current study. According to our findings, patients are clear that seeing a waiting room full of people with advanced disease in wheelchairs, on stretchers, worn out physically, throwing up or crying from pain, makes them scared of suffering at the end of their lives. The patients interviewed express their desire to die before they are in this situation of extreme suffering.

One of the primary concerns that patients in our study expressed is being a burden to their families, a finding also consistent with studies in other contexts [48, 49, 27, 50, 28, 51]. Patients who consider themselves to be a burden to their families may opt to die away from home so as not to further inconvenience their family members with their care, even when they would prefer to die at home.

Moreover, patients' religion and belief system also influence the way they think about death. In the current study, patients generally understand that God decides when death occurs and that human agency is limited in this regard. Ko et al. [52] reported that for Mexican-American Catholic patients, religiosity and spirituality is thought to lead to a good death. Hattori and Ishida [53], moreover, point out that according to the beliefs of the sick elderly Japanese Americans in Hawaii, God determines the moment of death, and many disapprove of medical interventions at the end of life. Another study [54] found that death with dignity in the Lebanese context is reinforced by faith and loyalty to God. Lebanese participants expressed that their faith in God provided comfort and dignity at the end of life, as God “listens to those who suffer.” These findings coincide with what patients in this study express about their faith in God, which gives them the strength to face illness and the end of life.

In our study, another element of the code of dignified death was the desire to fall asleep and never wake up. This is consistent with what Payne, Langley, and Hiller [55] indicate in their qualitative study when they report that for patients, a good death could occur under the following circumstances: dying while asleep, dying peacefully, with dignity, being pain-free, and dying suddenly. Studies by Ancy et al. in the US involving patients who believed in God [56], by Saderson et al. in Australia—who conducted an online course on "Dying to Learn" attended mostly by women and healthcare professionals [57]—and by Kalnina and Skulte in Latvia—who surveyed the general population

[58]—also found that for patients the best way to die is while asleep. Around the world, many people consider that a dignified death entails avoiding physical or mental suffering and is defined by peacefulness and calmness. In the current study, patients' desire to fall asleep may be the result of rejecting agency over the dying process instead of planning or "choreographing" their own death as is desirable in other contexts such as in the United States [59]. Believers consider that God is the arbiter of death, leading them to a degree of resignation to illness, pain, and eventual death.

Many of the patients in this study also consider that to achieve a dignified death it is necessary to have the legal option of euthanasia. Although they do not mention the term as such, they have heard of it and agree with hastening death to end suffering when the disease progresses, a finding that echoes that of other studies in which both sick patients and the general population defend euthanasia to accomplish a good death and avoid suffering [60, 61, 62, 63].

Finally, the patients in our study emphasize the importance of settling unfinished matters, such as getting married or apologizing to family members with whom they have longstanding conflict. Another study [23] points out that the absence of unresolved business or interpersonal disputes was identified as an additional characteristic of a good death.

Finally, it is important to highlight a piece of information related to the wishes or desires of a patient regarding organ donation after death, though we do not explore this topic in depth in this paper. Marinelli et al. [64] and Silva et al. [65] point out that patients with a chronic illness who experience unbearable suffering that causes them disability may be motivated to contribute socially, and the only possible way to do so is to donate organs that can help other patients continue living.

According to the theory resulting from the interpretative framework of this study, the following propositions can be made: 1) managing the disease and observing sicker patients in the hospital setting leads participants to fear experiencing a death with pain and suffering. The progression of the disease can cause increased psychological suffering, as patients must depend on care from their families which makes them feel like a financial and emotional burden; 2) the sick do not have a clear concept of euthanasia, but they seem to desire the legal option of assisted death before their suffering becomes unbearable. Making plans such as getting married or apologizing to family members, among other things, can help the sick reach their goals in life before they die and achieve a dignified death; 3) most patients do not discuss the option of organ donation because there is limited awareness of this option among the general Mexican public.

The information obtained in this study deepens understandings of how dying patients at the most important public cancer hospital in Mexico conceptualize dignified death, providing insights on their desires and fears, as well as gaps in information, such that patients, families, and palliative care providers can make the best decisions at the end of life and, ultimately, guarantee that more patients are able to achieve a dignified death.

Conclusions

In Mexico, advances in palliative care in hospitals such as the INCan have provided patients with more options at the end of life with the hopes that they are better able to achieve a dignified death. Nevertheless, little is known about what patients in this context desire for their own deaths. This study focused on identifying the various elements related to patients' perceptions of dignified death such

that their perspectives can inform the delivery of more culturally sensitive palliative care. The patients interviewed emphasize several elements as essential to dignified death: dying without pain or suffering; faith in God; the desire to fall asleep and never wake up; the ability to settle unfinished matters; and the legal option of euthanasia. Existing literature in and beyond Mexico suggests that the main desires of patients at the end of life are focused on avoiding pain and suffering, both physical and psychological, which can lead to the decision to hasten death when this option is available and accessible. In the interviews and ethnographic observation of the current study, we found that avoiding suffering is paramount for patients. For these patients, suffering is conceptually broad and includes physical pain, as well as being a burden to their families. Being a burden causes patients psychological suffering, since the illness, by incapacitating the patient, forces them to be dependent and causes their family to suffer from providing the care and attention patients need. In a Catholic majority country such as Mexico, religion also plays an important in shaping how patients think about death. The patients in our study sample generally agree that God determines who can give or take life, and they hold fast to their beliefs in the final stages of life. Nevertheless, patients in this population express support for euthanasia, perhaps because the degree and urgency of their suffering outweigh Catholic prohibitions on the procedure.

The information obtained in this study demonstrates that to deliver a dignified death to ailing patients in Mexico according to their own definitions, end of life care should focus on managing physical pain; providing more support or respite to families who are responsible for caregiving and opening dialogues between patients and their family members about caregiving tasks to reduce patient guilt about being a burden; offering more information about advance directives and controversial end of life options; and opening a national dialogue with various specialists on euthanasia and medically assisted suicide, which remain illegal in the country. As mentioned, advances in palliative care have provided more end-of-life options to patients in Mexico; however, there are cases in which achieving pain control becomes impossible. Therefore, it is necessary to investigate this issue further to propose better care alternatives and respect the decisions of patients who are facing the end of their lives.

Declarations

Ethics approval and consent to participate: Ethics approval for this study was granted by the ethics committee at the study hospital site: Instituto Nacional de Cancerología (INCan), approval number: (023/043/CPI) (CEI028/24) as well as by the IRB of the home institution of the PI (second author), Southern Methodist University, approval number: (24-139). All participants provided informed consent to participate in the study. The research was conducted in accordance with Declaration of Helsinki.

Data Availability: The data that support the findings of this study are available from the study Remaking Mexican Death, but restrictions apply to the availability of these data, which are highly sensitive given that the study deals with medical patients and so are not publicly available. The data are, however, available from the authors upon reasonable request. Email the study PI, Elyse Singer at esinger@smu.edu, for data requests.

- Consent for publication: Not applicable

- Availability of data and materials: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

- Competing interests: The authors declare no competing interests.

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- Authors' contributions: E.O.S. is the study PI and Norma N.A.O.V. is a Research Associate on the project. E.O.S. and N.A.O.V. collected and analyzed the data from which this paper are drawn. N.A.O.V. took the lead on writing the manuscript and E.O.S. provided help with conceptualization and editing. S.R.A.P. helped with study design, logistics, and access, and provided editorial support for the manuscript.

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