

Report of Qualitative Findings: Palliative Care Exploratory Study

August, 2019



INDEX

Background, Methodology and Objective	3	
Qualitative Sample	4	
1. Environment of Interviewees	6	
2. Sensitization and Exploration of Palliative Care	16	
3. Mexico's Present Situation	23	
4. Palliative Care Legal and Regulatory Framework	44	
5. Real and Potential Formation and Training	50	
6. Final Considerations and Recommendations	55	

BACKGROUND, METHODOLOGY AND OBJETIVES OF THE STUDY



Background and Methodology:

- At the request of Dr. Amparo Espinosa Rugarcía and the DMD Mexico Foundation, Factum Mercadotécnico conducted 6 interviews **with geriatricians**, **1 interview with a palliative pediatrician**, **6 interviews with caregivers / relatives of seriously ill patients**, **1 Focus Group with general practitioners** and **1 Focus Group with nurses**.
- Interviews and focus groups took place in Mexico City. They were audio-recorded with the prior consent of the participants to guarantee the confidentiality of their ideas and contributions.

General Objective:

- To obtain detailed information on Palliative Care in Mexico: its current status and availability, its progress, challenges / obstacles and possible evolution.



QUALITATIVE SAMPLE: SPECIALIST PHYSICIANS INTERVIEWS



GENDER	AGE AND YEARS OF EXPERIENCE	SPECIALTY
1. Masculine	34 years old 6 years of experience at the Mexican Social Security Institute (IMSS) and Médica Sur	Internist and Geriatrician
2. Masculine	45 years old 12 years of experience at the IMSS, the London Clinic, the Spanish Hospital and private medical practice.	Internist and Geriatrician
3. Masculine	Age not mentioned 10 years of experience at the IMSS and private medical practice.	Internist and Geriatrician
4. Masculine	37 years old 6 years of experience at the National Institute of Geriatrics and private medical practice	Internist and Geriatrician
5. Feminine	31 years old 2 years of experience at the General Hospital, the November 20 Medical Center and the Dalinde Hospital.	Geriatrician and Palliative Care
6. Feminine	36 years old 5 years of experience at the General Hospital, the ABC Hospital and the San Angel Inn Hospital.	Internist and Geriatrician
7. Feminine	36 years old 7 years of experience in Pediatrics and 4 years in Palliative Care at the National Institute of Pediatrics.	Pediatrician, Pediatric Palliative Care and Pediatric Pain Medicine

QUALITATIVE SAMPLE: CAREGIVERS INTERVIEWS



GENDER	AGE AND KINSHIP WITH THE PATIENT	ILLNESS OF RELATIVE
1. Feminine	52 years old. She took care of her father who was diagnosed in 2012. He died at the beginning of 2019, when he was 95 years old.	Alzheimer
2. Feminine	59 years old. She took care of her husband during 3 years: diagnosed in 2015 and died in January 2019 when he was 58 years old.	Amyotrophic Lateral Sclerosis (ALS)
3. Feminine	66 years old. She has been taking care of her husband for the last three years. He is still alive.	Metastatic cancer that started in the prostate and has already spread to the bones
4. Feminine	67 years old. She took care of her 74 years old brother who was diagnosed in 2015 and died in 2017.	Chronic kidney disease
5. Feminine	54 years old. She took care of her younger sister who died in March 2019.	Multiple sclerosis
6. Masculine	38 years old. He took care of her 68 years old mother with the help of his father, brother, aunt and two 24 x 24 hours nurses. The mother was diagnosed in December 2017 and died in March 2019.	Brain cancer tumor that caused a motor disability (so she could not move), but without pain

CHAPTER 1. ENVIRONMENT OF INTERVIEWEES



AILMENTS THAT DOCTORS AND NURSES FACE



Interviewees of both segments face daily ailments such as:



Cognitive and memory deterioration (dementias): Alzheimer's, Parkinson's, senile dementia, mixed dementia. Those were mentioned especially by geriatricians.



Advanced / terminal cancer, mostly breast, cervical-uterine and prostate cancer, as well as leukemia in pediatric patients.



Pluri-pathologies or complications caused by chronic degenerative diseases: Diabetes mellitus, hypertension / heart diseases, vascular disease, chronic kidney disease, metabolic syndrome, COPD.



Musculoskeletal conditions: Osteoarthritis, osteoporosis, hip fractures, degenerative joint diseases with chronic pain. In the case of children, congenital malformations.

The high prevalence of these diseases coincides with the diagnoses referred by the interviewed caregivers and are also the diseases that most require palliative care, according to the medical perspective.



- Geriatricians and palliative caregivers had mainly emotional motivations to choose their specialty, because they believe that aging can be active and healthy:
 - Some of them were brought up by **long-lived grandparents**.
 - Others had **grandparents who got sick** and lacked the necessary care services.
 - Others had mentoring geriatricians ("*the father of my best friend*"), discovering their human side and their **genuine concern** for older adults.
- In the case of the nurses, they chose their career because of **family tradition, the influence of friends / companions, or having a sick family member at home**.
- They do not tend to specialize in older adults, but they consider themselves qualified to treat any kind of pathology, from psychiatric diseases (which are increasing among the young population), to fractures, epilepsy, asthmatic crises, emphysema and cardiopathies, among others chronic-degenerative and terminal diseases.



CHALLENGES OF PATIENTS WHEN REACHING OLD AGE FROM THE DOCTORS' VIEWPOINT.



Physical Level Challenges



- Stay functional and autonomous, seeking that their independence is respected.
 - In case of suffering from a chronic disease, be responsible for monitoring their treatment if their condition so allows them.

"Everyone loves children; they are always surrounded by love. Not so the old age persons."
(Geriatrician, 36 years old)

"The entire population will age. The population pyramid turns around. They are forgotten and vulnerable patients."
(Geriatrician, 31 years old)

Emotional Level Challenges



- Accept, assume and try to enjoy old age, securing their own dignity.
 - Face the loss of health, family (children), and functionality.
 - Understand that life habits in early adulthood have impacted at the end of life.

"They feel they are no longer useful, that they are a burden, and their family corroborates them so." (General practitioner)

Their frequent abandonment and the rejection of family and society causes them depression and anxiety.



CHALLENGES OF CAREGIVERS WHEN TAKING CARE OF A RELATIVE



Emotional Level Challenges



- Understand when the disease is progressive and has no cure, facing a "cold" diagnosis whose only outcome is to go home and wait for death.
- Respect the patient decisions concerning his body (such as refusing dialysis, chemo or radiotherapy, tomography, and so on.)
- Keep the emotional strength without cracking in front of the patient: smile, cry secretly, stay optimistic and positive.
- Take full responsibility of the patient when facing the reluctance or irresponsibility of other family members (in some cases), or coordinate the rotation of other caregivers. Likewise, face family conflicts when opinions differ and the family "gets fractured" because its members drift apart.
- In patients with dementia, face obsessive-compulsive disorders, paranoia, delirium, anxiety crises, etc.

"The hardest part was to see him die slowly while being still alive. He was like a baby: he lost swallowing, he used diapers, he forgot how to walk, he didn't express anything."

(Female caregiver, 52 years old)

"My husband refuses any help. He doesn't want a stranger at home."

(Female caregiver, 66 years old)

"My dad was saying goodbye to my mom, who was his couple for 50 years."

(Caregiver, 38 years old)

This implies to work a mourning for the family member who has stopped being active, productive; who is no longer as he was before and who seems to be absent in life.



CHALLENGES OF CAREGIVERS WHEN TAKING CARE OF A RELATIVE



Physical Level Challenges



- Keep the patient clean, feed him, handle him / carry him, shave him, moisturize his skin to avoid bedsores, administer medications, etc.
- It is common for the patient to lose weight, to suffer from anemia and to be fed through a nasogastric tube, or that he only accepts porridge, liquids or a polymeric diet.
- Face exhaustion due to only few hours of sleep and sporadic rest over the months or years.
- On the other hand, gender differences also influence: a caregiver requires great physical strength - which they usually do not have - to move a male patient and, therefore, falls are frequent. Likewise, the cleaning and care of the sexual organs requires breaking with taboos and socially established rules.

“My dad refused to wear a diaper because he said he was not an old man. He defecated when he bathed, he dirtied himself with excrement. He didn't let me wash his anus or penis.”
(Female caregiver, 52 years old)

“Here shyness comes into play: my brother was a man; he didn't want me to bathe him. He preferred for me to ask my other brother for help.”
(Female caregiver, 67 years old)

As they have to rely on the caregiver, the patients gradually lose their privacy, their individuality and often feel that the presence of nurses and family members is an invasion of their living space.



CHALLENGES OF CAREGIVERS WHEN TAKING CARE OF A RELATIVE



Economic Level Challenges



- While some caregivers received financial help from their relatives, or their patients had a robust medical insurance to meet their needs, the expenses seem endless and growing day after day.
- Medical expense insurances do not cover several rare or progressive diseases, such as ALS.
- Hiring nurses is an additional expense that is often prohibitive.

"In public hospitals there are no chairs to sit on. I needed a support, but that support has a cost."

(Female caregiver, 54 years old)

"Every Friday I checked the bills with my dad, I asked for refunds, I paid the nurses: it was an additional task for me."

(Caregiver, 38 years old)

Most caregivers agree that their exhaustion is more emotional than physical, since they usually give up their life project: their family, their work, their social life, and everything revolves around the patient.



CHALLENGES OF CAREGIVERS WHEN TAKING CARE OF A RELATIVE



Additional Challenges

- Solve the shortage of trained and qualified professionals to address certain diseases (such as ALS). In those cases, the caregiver will have to train the nurses.
- Adapt the house spaces with special fixtures that contribute to the patient comfort: a settee, a compression mattress, a wheelchair, a shower chair, respirators, gas cylinders, etc.
- Remember that for the same disease, each patient has different symptoms and there are no solutions that can be generalized.
- On a social level, some caregivers tried to include and integrate the patient into family events (weddings, baptisms) in order to make them feel an important part of the family nucleus regardless of their condition.
- Another great challenge is to learn new communication styles through signs, gestures and glances when the patient can no longer verbalize.

"Despite the multiple sclerosis, his brain functioned and he was aware of things, so his suffering was more spiritual than that of his body"

(Female caregiver, 54 years old)

"You feel emotionally devastated, but you have to draw strength to keep going."

(Female caregiver, 59 years old)

The caregiver usually learns and adopts new roles he never exercised before. For instance, a traditional family father learns to take care of the home when his spouse is seriously ill.



DIFFERENCES BETWEEN THE KINDS OF CAREGIVERS



Patients with professional caregivers and/or assisting nurses

- The additional support of a professional caregiver or nurse allows the primary caregiver to rest, sleep, eat and even to keep working. In other words, it represents “a bastion” that enables and facilitates the work:

“The nurses not only took care of my mom, but were also very kind with my father. They made up my mom, put her wig on her because she liked to look pretty.”
(Caregiver, 38 years old).

Caregivers without additional assistance

- Some female caregivers who counted on institutions such as the **Pain Clinic** or **geriatric advice**, appreciate the medication, advices and physical therapy that they received in those places.
- Others would have liked to have the support of a foundation or association that would provide them with some guidance and emotional support.
- Due to the stress, two of the female caregivers currently suffer from breast cancer and fibromyalgia. That is, they consider that the accumulated emotional load, fear and stress, today show up through their own body.

Female caregivers reveal a greater degree of involvement. They tend to assume that, for being women, they have the inherent obligation to take care of their relative, especially if they are retired or single.



THE LIFE OF A CAREGIVER: HOW IT HAS CHANGED?



The experience of caring has strengthened them: they feel capable of making important decisions and closing cycles



They notice how they (and other relatives) have gone through the stages of grief: denial, anger, acceptance.

They have learned to be more patient, tolerant and they value their life and their family more than before.

Three of the interviewed caregivers already had experience with other relatives, but still, the task is equally complex.



They have feelings of guilt because some consider that they didn't do enough.

After the death of their relative, their life becomes meaningless and they don't know what to do. They even reveal that they feel an internal emptiness they don't know how to handle

Caregivers say to have lived "enslaved" to the patient who was like "a piece of furniture" or "a sack of potatoes", but nevertheless, they express that loving care is the basic pillar of this relationship.

CHAPTER 2. SENSITIZATION & EXPLORATION OF PALLIATIVE CARE



CAREGIVERS

- Provide the means for a better **quality of life** to terminally ill patients or **who have no cure**.
- **Remove discomfort without removing the illness**.
- Medical care so that the patient **doesn't suffer while his death arrives**, avoiding him unnecessary additional pain or suffering.
- Make **feel well, clean and fed** a patient who will not get ahead.
- Stay alive until **God decides otherwise, with the strength He gives us. His plans are perfect**.
- Make **his life beautiful** the **last minutes**.
- **Only one female interviewee doesn't know the word**.

How did they learn about Palliative Care?

- Through previous experience taking care of a relative (mother, child) or through practice.
- In hospitals, as the XXI Century.
- *"My husband had contact with laboratories and that's how I knew it."*

NURSES

- **Palliative is not curative: it is an option to take care and improve the patients and their families**.
- Administer them medicines, change their position, keep them lean and dry, with tubes, drains, lubrication, submit them to restraint to maintain under **control their pain and aggression**, etc.
- It is an **extra to the basic treatment**.
- Palliating is providing **quality of life and a dignified death to a chronic or terminal illness**.
- **It is handling pain, including its emotional and psychological part**.

In certain cases people think that Palliative Care is given to all patients, including the curable ones, to seek their reintegration into society. Therefore, **there is some confusion among nurses, even the most experienced**.

GENERAL PRACTITIONERS

- **Multidisciplinary treatment** based on **empathy**, **focused on the patients, their relatives and caregivers**.
- It is not only the administration of medicines, but it also includes the **spiritual part, the religiosity, the psychologic and thanatologic part**, etc.
- It is to **avoid the collapse of the caregiver**.
- Being surrounded by what the patient **likes and provides him comfort**.

GERIATRICIANS/PALLIATIVISTS

- **It is an art: it is a turn back** to humanization and empathy with the patient. It is a branch of the new Medicine, an area of opportunity for the doctor through **coexistence and warmth** (Palliative Pediatrician).
- **Set of strategies** aimed at ensuring the **well-being of the person diagnosed with an incurable, progressive, chronic and/or terminal disease**.
- It is all the attention to **the patient and their relatives** concerning the **physical, emotional and psycho-cognitive symptoms**: a support to the social and family network. It also covers **nutritional and rehabilitation measures**.
- **It is the integral handling of the last symptoms: it is an accompaniment, not a cure**.

OBJECTIVES OF PALLIATIVE CARE

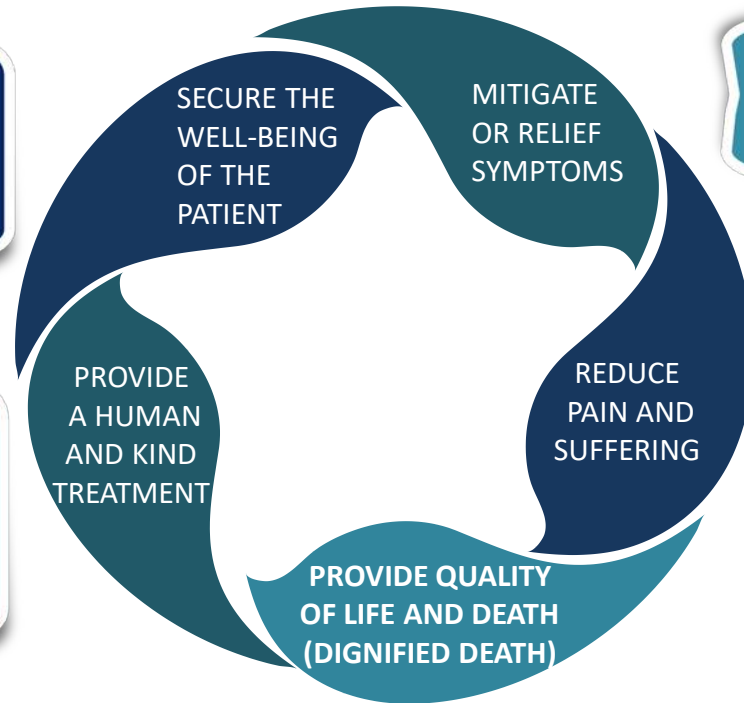


"The objective is to make transition not so difficult: that the patient and the caregiver accept that he will soon transcend."

Female caregiver, 59 years old

"In Medicine we have been absorbed by technology, money, haste and we have neglected the respectful and dignified part of the human being."

Palliative Pediatrician, 36 years old)



"Manage nausea, insomnia, depression and lack of appetite."

Geriatrician, 31 years old

- It is common for **traditional doctors to show less dedication to incurable patients** and devote their efforts to those who have a better prognosis, or the prioritize those who are in critical / emergency condition, **especially in public institutions having high demand.**

General practitioners, geriatricians and nurses agree that their patients automatically link palliative care with a prompt and imminent death, thus causing fear and even rejection against that expression. This makes clear the lack of information about the subject.

HOW AND WHERE PALLIATIVE CARE CAN BE PROVIDED?



In an ideal scenario, such approach should happen in the following spaces:



Help at hospitals or medical offices

- Some private and public institutions give **outpatient consultation** appointments to keep the patient under surveillance.
- In private consultation, some geriatricians and palliative caregivers advise the relatives on how to handle **symptoms and the pharmacological treatment**.
- Hospitalized patients should also have access to palliative care, although usually it's only provided in **Third Level Hospitals**.



Home support & telephone attention

- Given the distances or the limiting conditions of the patient, especially with foreign or bedridden patients, both pediatric and adult, a telephone follow-up is advised.



Through foundations or non-profit associations

- Some specialized foundations provide **emotional and psychological support through individual, group or family therapy**, as well as **nutritional counseling and bibliography review**.

In both pediatric patients and the elderly, Palliative Care should be implemented as soon as an incurable or terminal pathology is diagnosed, but this early intervention is rarely achieved in First Level of Care Hospitals.

WHO CAN PROVIDE PALLIATIVE CARE?



Doctors and nurses claim that this is a multidisciplinary team consisting of:



GENERAL PRACTITIONERS OR FAMILY DOCTORS are sometimes those who detect and diagnose serious, terminal or chronic degenerative diseases. They are responsible for referring them to palliative care.



PAIN SPECIALISTS (algologists), palliative care givers (pediatric or oncologic), geriatricians, internists, cardiologists, nephrologists, etc.



NURSES, who are the operative part of the team, because they are instructed how to use the medication and palliative sedation.



PSYCHOLOGISTS AND TANATOLOGISTS provide emotional support, mainly to help the family deal with the grief.
SOCIAL WORKERS can reinforce this task.

“This team comforts the family. If the doctor's explanation is too technical, the nurse or social worker can clarify the terms.”
(Geriatrician)

“I always tell them: touch, hug your relative, nothing will happen to you”
(Nurse)

The General Health Law stipulates that every health professional must know how to refer a patient to palliative care, but chronic degenerative and rare diseases have overwhelmed the doctors / nurses who must update themselves to deal with them adequately.

WHO CAN PROVIDE PALLIATIVE CARE?

In everyday life it is the caregiver who – there and then - looks for tools to alleviate the pain and symptoms of his relative. Among which we find:



ALTERNATIVE MEDICINE:

Acupuncture, aromatherapy, music therapy, Chinese medicine, magneto-therapy, stem cell treatments, natural remedies, vitamins and nutritional supplements (they consider all of this to be a palliative handling).

The geriatricians claim that this search is due to the weariness caused by the side effects of the traditional medicine, as well as by the *“faith of a magical worldview”*.

ATTENTIONS, COMPANY SPACES, LISTENING AND UNDERSTANDING:

Show movies, music videos, pictures to exercise the memory of Alzheimer's patients; offer the patients their favorite food or grant them their whims, favoring their requests more than the medical indications; make sure that the patients' friends visit them at home, etc.

- Nurses confirm that occupational therapy (pottery, handicraft) makes hospital stay more enjoyable.

CANNABIS:

It helps improve breathing, limb mobility and whets the appetite, even in patients without physical pain (for example, ALS and brain cancerous tumors).

“The different types of care are hand-picked based on common sense.”

(Female caregiver, 67 years old)

“I gave my sister chocolates although it was forbidden. I put on her beautiful nightgowns and stockings.”

(Female caregiver, 54 years old)

Some general practitioners and geriatricians consider these alternatives to be part of quackery or a placebo effect. Others visualize them as a complement to the treatment with scientific evidence, because in palliative care *“one has to resort to everything”*.



CHAPTER 3. MEXICO'S PRESENT SITUATION



PERCEPTIONS ON PALLIATIVE CARE IN MEXICO



Infrastructure is still deficient in terms of specialists, thanatologists, training, awareness and coverage, but there seems to be an increasing interest.

With the Advance Directive Act, dignified death has been upgraded to a human right and that opens a forum for palliative care.

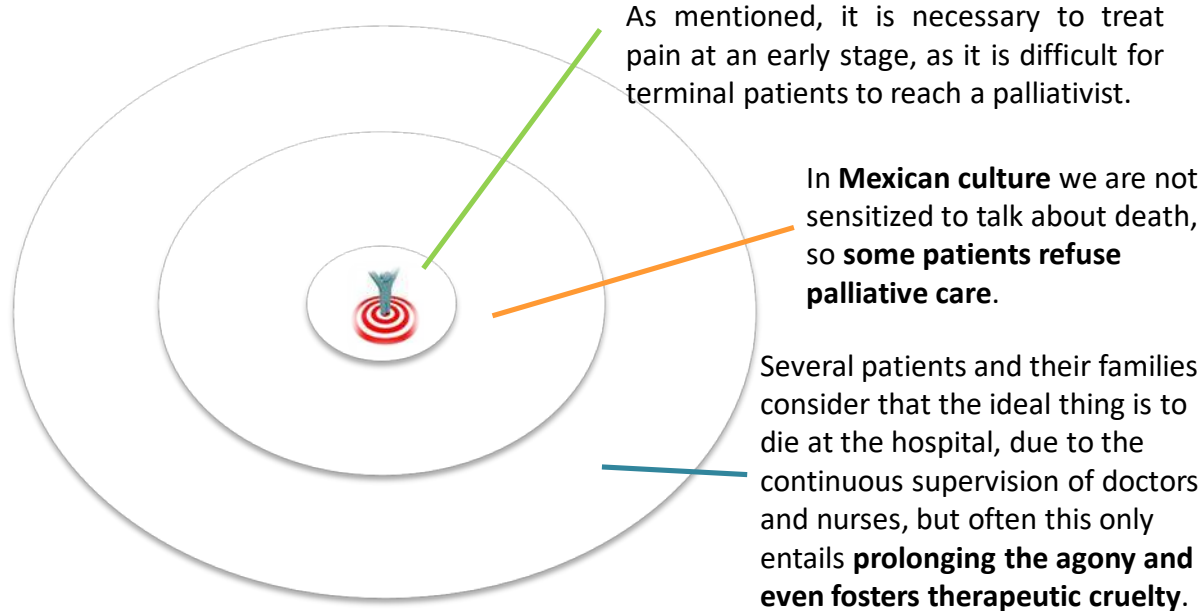
The youngest geriatricians and palliative care givers assert that the new generations of doctors (nephrologists, cardiologists, intensivists) already take palliative care more into account: the topic is already discussed and discussed more than 10 years ago. They all seek to break the taboo.

Doctors, as well as nurses and caregivers, agree that palliative care is still in an incipient, "primitive" state of vagueness and riddled with confusion.

HANDLING OF PAIN AND SUFFERING



Physical and emotional pain is daily in geriatrics and pediatric oncology.



“Elderly persons suffer a lot of somatic and neuropathic pain, so we resort to palliative care when neuromodulators no longer help.”

(Geriatrician, 34 years old)

“We recommend to die at home with your family, your odors, your food, your pillows.”

(Geriatrician)

Geriatricians are the most open to recognize that palliative care has limitations and is insufficient. In those cases, the most dignified way to die is through euthanasia and physician-assisted death, although in Mexico these are not common.

AVAILABILITY OF MEDICINES AND PROFESSIONALS TO TREAT PAIN



In Mexico there are few geriatricians, few psychiatrists and **much less trained expert palliativists**. This results in a low capacity to handle delusions, anxiety, psychomotor agitation and depression, so common in the elderly population.

Most general practitioners and specialists agree that **the private sector does have human resources and supplies to alleviate pain**, while the **public sector has more shortcomings**, since their use is restrained to high specialty hospitals (for example, psychotropic and controlled medications).

Although there are medications in Mexico, they are very expensive. Compared to other countries, such as the United States or South American countries where morphine and opioids have affordable prices, in Mexico it seems that there are distribution, bureaucratic, logistics, and even profit obstacles.

“At the Medical Center there is a palliative care formal area, but their work overwhelms them!”
(Geriatrician, 34 years old)

“I already learned how long it takes for morphine to have the expected results. Without that drug, it is impossible, because bone cancer is one of the most painful.”
(Female caregiver, 66 years old)

Beyond staff and medications, a palliative care culture is needed. Therefore, it is not assigned the relevance it deserves and is underdeveloped.

AVAILABILITY OF MEDICINES AND PROFESSIONALS TO TREAT PAIN



To the extent that a disease, such as cancer, has been studied in greater detail and depth, there is a wider range of medications, foundations and professionals available to the patient and his family.

For neurodegenerative diseases, resources are more limited.

In addition to the illness, there are large differences in the public and private sectors. Since IMSS and ISSSTE usually do not provide palliative care, it must be obtained by the family member or its caregiver.

Even Third Level Attention hospitals (such as the National Institute of Pediatrics) require support from AMANC or the Casa de la Amistad because they lack supplies and medical, psychological and nursing personnel.

"Social Security has its palliative care clinic, but it only has one internist, one nurse and one social worker. They cannot satisfy the demands of their population!"
(Female caregiver, 59 years old)

"With money, in the private sector you can get all the analgesics you want, but that the doctor knows them is another limitation."
(Geriatrician)

"Maybe the ISSSTE has the medicines, but you have to go and lose 6 to 7 hours to get the prescription, go to the pharmacy, and see if they give it to you."
(Female caregiver, 67 years old)

Palliative care should always go hand in hand with Pain Medicine, but algology is a new field, where much remains to be investigated.



SUPPLY

- Supply depends on demand: if a population requiring palliative care and medication is not identified, no resources will be allocated (Geriatricians).
- According to geriatricians, in general there is a good access to medicines such as Buprenorphine and Tramadol, but the availability of other stronger drugs for emergencies must be increased.
- Nurses consider that the supply will depend on the economy of the patient and his family, as they usually “send a relative” to buy painkillers, because there is not enough budget in the public health sector.

SHORTAGE

- About controlled painkillers, caregivers express that they are restricted due to the misuse (abuse) they are given.
- It is often not a matter of shortage, but rather that they are only prescribed by anesthesiologists and some specialists, because general practitioners do not dare to do so.

Caregivers whose relatives were treated in both public and private institutions confirm an important shortage of painkillers (including chemotherapies), which forced them to look for generic drugs.

MORPHINE AND OPIOIDS

- In general, they are hardly available: they are usually scarce in pharmacies because few pharmaceutical companies produce and distribute them.
- Its supply varies according to the city and the time of the year: they are usually scarce at the beginning of the year (Geriatrician).
- At the IMSS, it is not common for morphine or oxycodone to be prescribed because the trade lacks training to do so.
- A special COFEPRIS prescription is required to prescribe them.

CANNABINOIDS

- Although their use is not regulated in Mexico, some caregivers have sought this option in the United States, if their economic condition allows them.
- They help to control pain, nausea and anxiety.
- There is more and more openness and diffusion, as they slowly began to be dissociated from the issue of addictions.

"We use morphine patches when my husband gets mad with pain. Marijuana is not approved, but a doctor gave me a contact for some sublingual drops."

(Caregiver, 66 years old)

"My mother was an old-fashioned woman and took morphine as a joke. I was not against it, but I don't know the subject."

(Caregiver, 38 years old)

Geriatricians and palliativists assert that morphine is a noble medicine, and is even the cornerstone of palliative care and symptoms difficult to control, but it is demonized and underutilized because it is stigmatized as "dangerous" for health, or even addictive.

Two important phenomena are perceived:



- Many general practitioners and specialists **ignore how easy and useful** they are.
- They even **ignore that there's a recipe book or Physician's Desk Reference** to prescribe morphine and its byproducts.

- For being linked to morphine and its byproducts, it causes **"dread"** among some physicians due to the big responsibility it implies.
- Others **fear to register at the COFEPRIS and be checked by the SEDENA.**

- Several interviewed geriatricians do not use the recipe book, but they rely on palliativists or anesthesiologists for this purpose.
- Others know that it can be electronically requested to the COFEPRIS with an official ID. It is downloaded online, has a barcode and has 100 to 200 prescriptions that are issued in triplicate (for the doctor, the pharmacy and the patient) and thus helps prevent the abuse of controlled substances.
- The doctor is notified **through e-mail when the patient has filled the prescription.**
- The general practitioners interviewed reject the recipe book due to the **"loopholes in the legal system"** and the **"side effects of morphine"**.

Morphine is one of the medications with the highest scientific evidence of safety in pediatric and adult patients. It is even used with neonates in intensive care, but - once again - parents fear that children develop an addiction.

PALLIATIVE CARE DEVELOPMENT: EVOLUTION OR STAGNATION?



EVOLUTION

In the last 3 to 5 years, nurses, social workers and medical personnel are more aware of its importance.

Gradually, the multidisciplinary vision is being understood as a key element for palliative care.

In addition, the care strategy no longer focuses on dying patients, but on this multidisciplinary team.

STAGNATION

Health budget cuts are a strong threat to palliative care (geriatricians, general practitioners and nurses).

The premise of saving lives at all costs does not allow to open to it either.

The stagnation or delay depends on each doctor and nurse: on their training, experience and criteria.

“Resistance to change stops us: the mission is to heal and they don't teach us that we can be useful in the death process.”
(Geriatrician)

*“Palliative care is **good, nice and cheap**: its very sustainable and cost less than intensive therapy, but they still see us as hospital hippies.”*
(Pediatrician Palliativist, 36 years)

Doctors learn and emulate what they see in experienced doctors (their teachers). Therefore, it is important to sow the seed of palliative care among doctors in training.

PSYCHOSOCIAL AND SPIRITUAL SUPPORT OFFERED (ACCORDING TO DOCTORS AND NURSES)



"Many patients ask, as their last wish, to go to La Villa or eat a tamale sandwich. One has to be flexible."

(General Practitioner)

- High Specialty Hospitals (as the National Institute of Nutrition) have volunteers in their psychology and thanatology area, although it is not a service not normally provided.
- The Pain Clinic of the National Institute of Pediatrics also has master's interns in Game Therapy and Cognitive Behavioral Therapy.



- Most geriatricians explore the religion or worldview of patients.
- They even take advantage of their home visits to understand such environment (images of saints, virgins, etc.)
- They suggest them a sacrament or a ritual according to their religion, as they understand that the Jews, the Catholics and the atheists have a different concept of death.

"We have had talks with Buddhists at the ISSSTE. That broadens our vision, because spirituality is not necessarily religiosity."
(Geriatrician, 31 years old)

"How many times we give grandpa a painkiller for a headache without knowing that the pain is because he is depressed or anxious?"
(General Practitioner)

Psychologic and thanatologic support cannot be imposed: the patient and his family must request and accept it. In Mexico, many people still believe that going to the psychologist is synonymous with being mad.



PSYCHOSOCIAL AND SPIRITUAL SUPPORT THAT CAREGIVERS WOULD HAVE WANTED

"In my sister, her pain was of the soul: she was angry with life, she wanted to study Psychology, take dance classes. She couldn't understand why she had sclerosis."

(Female Caregiver, 54 years old)

"At the Alzheimer's Foundation they told me to take my dad away because he didn't get along with the other inmates. I got very angry because I paid for it: it wasn't free. That was a crookedness!"

(Female Caregiver, 52 years old)



Coexistence with relatives of other patients in public institutions who share their experiences and form an organic support network.



A telephone service line ("as Locatel") to provide guidance according to the illness and direct him to specialized clinics or foundations.



Family and group therapy, film debates, yoga sessions, meditation and bioenergetic therapy to cope with emotions.



Low-cost equipment rental, such as wheelchairs, oxygen tanks, respirators, etc.



Psychologists, thanatologists and "healers" to assimilate the illness process.

The need exists: caregivers expect personalized palliative care campaigns tailored to the needs of each patient, as far as possible.

HANDLING THE GRIEF

It's not just a matter of losing life, but also the functions of life.

50% of children with cancer recover, so grief must only be handled when their quality of life gets limited or the danger of life appears.

In older adults, this gradual and inevitable deterioration must also be assumed, since grief is a process and not a stage of the illness.

Sometimes the psychologic and thanatologic support is unreachable.

In some institutions, certain caregivers of cancer patients have requested the guidance of volunteer thanatologists, but taking care of their relatives is so demanding that time and distance don't allow it.

Other caregivers don't know where to look for such support.

*"I was the punching bag of everyone for being the most objective and detached: my dad lived in denial, my furious brother somatizing with gastritis and headaches."
(Caregiver, 38 years old)*

Handling the duel, both in advance and afterwards, is an essential complement to palliative care. Strictly speaking, it should end when the family finally assimilates the grief and is able to regain its balance. This prevents a pathological duel from being established.

THE LAST MONTHS OF LIFE (THE TERMINAL STAGE)

Both pediatricians and geriatricians explore what weapons (social, academic, economic and cultural) has the family to face the battle implicit in the disease.

In addition to handling physical and emotional symptoms, the last months are used to clear up legal procedures, such as wills.



While some patients ask for euthanasia, thanks to palliative care and symptom control, their outlook changes and they deeply appreciate it.

Some geriatricians suggest the option of palliative sedation when their patients ask for a dignified death: this is a relief at the end of life, since it implies sleeping without pain, but without causing death.

General practitioners and nurses deny that their patients have openly requested them euthanasia, but geriatricians and palliativists claim that it is common, although it is not yet feasible in Mexico as it is considered a crime.

“Some foundations lend oxygen tanks to patients, but they reach their inland villages and... there is not even light!”

(Pediatrician Palliativist,
36 years old)

OBSTACLES

- In rural areas, the idea that the evolution of the patient will be “what God commands,” or “while God gives him strength” prevails, so palliative care has little room.
- In fact, they are not even conceived, as there are **no qualified personnel**.
- Palliative care could not be provided at home, as many medications are for hospital use only.
- In low social strata, relatives don’t ask about palliative care: in addition to ignorance, for "grief or fear."

GEOGRAPHIC DISTANCE

- Telephone follow up is not viable in isolated places where there is no signal or cell phone network.
- Opioid-based painkillers can only be obtained in **Mexico City, Guadalajara and Monterrey...** which forces family members to travel long distances to get them.

As in many other issues, income and education are usually two factors that determine inequality in access to palliative care and health services. However, some relatives of limited material resources exhibit a remarkable wisdom to understand and apply this health care almost naturally.

AGE OF THE PATIENT

"They look for an alternative medicine and - in their magical worldview - if the child smiles, they think it worked."
(Pediatrician Palliativist, 36 years old)

"I explain the parents that difficult times are coming and that we all will have to do our best efforts."
(Pediatrician Palliativist, 36 years old)

THE PEDIATRIC PATIENT

- Nurses explain that an older adult understands and accepts an oncological diagnosis more easily than a teenager, a young adult or a child, since they represent life and hope.
- However, once they accept the diagnosis, they commit themselves and accept even more easily such care.
- Refusal in parents is more common if the patient is young.

ACCES TO PALLIATIVE CARE

- There are strong limitations: only certain Third Level Hospitals in large cities have this service.
- The advantage is that they have more diffusion, more progress and, historically, there is more interest in protecting the child than the elderly (although both have the same right).

Although high-specialty hospitals - especially pediatric ones - have palliative care services, there is no guarantee that they can be offered to the entire population.

CASES REFERRED BY PHYSICIANS: SUCCESS STORIES IN PALLIATIVE CARE



65 year old male patient.

Diagnosis: advanced COPD, pneumonia, urinary tract infection.

Palliative approach: Treatment of poly-psychiatric symptoms, physical rehabilitation.

Confer with Palliativist to administer inhaled and subcutaneous morphine.

Patient died in peace thanks to palliative sedation.

Case referred by: Geriatrician.



Male patient

Diagnosis: Terminal metastatic prostate cancer. Bedridden for a year.

Approach: The family hid him his diagnosis, arguing that it was only a urinary tract infection. When the geriatrician explains him that he has a tumor, the patient stops clinging to life, is treated with morphine and buprenorphine and dies with less pain.

Case referred by: Geriatrician.

Male patient

Diagnosis: Advanced Dementia

Approach: The family has taboos concerning the use of morphine. They ask if it causes addiction or accelerates death. The doctor explains them the advantages of its use. The family accepts it and the pain gets drastically reduced.

Case referred by: Geriatrician.

Female patient

Diagnosis: Terminal ovarian cancer.

Approach: The patient gets blue scorpion venom. The doctor understands her faith, her hope, respects her ideology, but continues with palliative care until she dies.

Case referred by: Geriatrician.

CASES REFERRED BY PHYSICIANS: SUCCESS STORIES IN PALLIATIVE CARE



The Palliative Care Clinic was implemented at the 20 de Noviembre Hospital.

Initially, patients with breast, prostate, renal, and other types of cancer arrived.

Greater diffusion was given to those services and gradually non-cancer patients also came, with Parkinson's, multiple sclerosis, liver failure, among others.

The benefits have been remarkable.

Case referred by: Geriatrician



Pediatric patients

Diagnosis: Cancer

Approach: Support for parents, siblings and the sick child from diagnosis on helps all of them stick more to the treatment and improves the evolution of the disease, as they feel accompanied and safer.

Case referred by: Pediatrician Palliativist

Male patient

Diagnosis: Type 2 Diabetes with amputations.

Approach: He isolated himself in the Gerontologic Hospital; he only listened to the radio. The doctor approached, started to talk to him, and gradually the man began to interact with the staff.

Case referred by: General Practitioner

Retirement home for 4 to 5 women between 90 and 100 years old.

Various diagnoses.

Approach: The caregivers (not nurses) fed them, helped them exercise, injected them. On Sundays they were visited by a priest and "their well-being was surprising."

Case referred by: General Practitioner

CASES REFERRED BY PHYSICIANS: SUCCESS STORIES IN PALLIATIVE CARE



Pediatric patient, age not mentioned.

Diagnosis: Terminal Cancer

Approach: The National Institute of Pediatrics provided oxygen supplies for the patient living in Veracruz.

The patient's father returned to Mexico City TO explain that his daughter was calm, “she got tired”, but she ate, played with her cousins, watched television together. The girl asked the father to bring her toys to her bed.

She asked her mother and brothers to hug her, told them she loved them.

“Her heart went out, she fell asleep in my arms. It was the biggest gift I could have had.”

Case referred by: Pediatrician Palliativist.



70 year old male patient

Diagnosis: Pulmonary fibrosis

Approach: Morphine reduced dyspnea, anxiety and he lived his last 2 weeks without suffering.

Case referred by: General Practitioner



Pediatric cancer patients.

They know their treatment step by step, they know how to dialyze them, they force their parents to take courses and they are extremely responsible with their treatment.

Case referred by: Nurses

CASES REFERRED BY PHYSICIANS: WRONG HANDLING



Female patient

Diagnosis: Kidney and cervical cancer.

Approach: In a committal, doctors tell the patient's daughter that "her mother will die because of her" if she does not sign the authorization to provide her intensive care.

Doctors disclaim all responsibility.

Case referred by: Geriatrician.

90 year old male patient

Diagnosis: Dementia

Approach: Although the diagnosis is long-standing, his children have never talked to him about death and every day it will be more complex to do so.

Case referred by: Geriatrician.



Male patient

Diagnosis: Unknown

Approach: The geriatrician intended to sedate him with Midazolam (barbiturate that induces sleep), but it was impossible to get it. The patient died with pain.

Case referred by: Geriatrician.

4 year old male patient

Diagnosis: Facial osteosarcoma

Approach: His condition was extremely painful and aggressive: "it was unworthy to live in those conditions."

He lived in the state of Guerrero mountains and could not have access to CP or euthanasia.

Case referred by: Palliative Pediatrician

The "Doctor in your home" social program brought doctors, nurses, social workers and psychologists at home for disabled patients. The program was suspended at the end of Mancera's Mexico City Government (it was not given continuity).

CASES REFERRED BY CAREGIVERS: WRONG HANDLING



Female patient

Diagnosis: Multiple sclerosis

Approach: *"Social Security left me with a very bitter taste: a kind detail from a doctor or a nurse can help both the caregiver and the sick person."*



10 year old male patient

Diagnosis: Encephalitis caused by vaccine in poor condition / expired.

Approach: *"The doctors were hiding for fear of a lawsuit or the cancellation of their professional ID."*
The boy remained in a vegetative state for 9 years until he died.

Female patient

Diagnosis: Amyotrophic Lateral Sclerosis (ALS)

Approach: *"You ask for an appointment with a specialist, such as a pulmonologist, and if you say that the patient has ALS, they refuse to see him." The caregiver was forced to form a medical team with her acquaintances to respond to emergencies."*

Male patient

Diagnosis: Chronic kidney disease.

Approach: *"The ISSSTE doctors check the file, talk to the students, rarely talk to the relative, and leave. In the Social Work area there is no one, only a guard. Some nurses were friendly, but didn't involve themselves. I had to go after the doctors to get an explanation about what was happening. It was terrible!"*



Nurses show anger, disgust and boredom saying that *"patients spend their time pressing the button of the rescue pump to get morphine", "relatives are upsetting with so many questions and don't understand that they should talk about that with the doctor, not with us", "relatives never get trained in palliative care, their patients relapse and they always come back."*

A greater fatigue is noticed among nurses: the more experience they have, the more automation they must handle and, in certain cases, palliative care is an additional workload for them.

CHAPTER 4. PALLIATIVE CARE: LEGAL AND REGULATORY FRAMEWORK

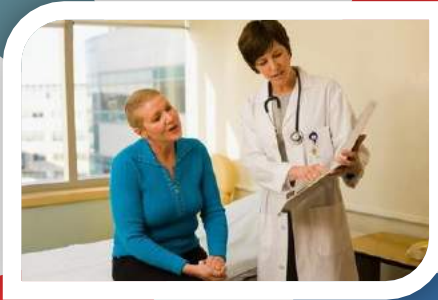


PATIENT AUTONOMY AND HIS INTERVENTION IN THE TREATMENT



General practitioners, specialists, nurses and caregivers agree that autonomy consists in the ability to make decisions about our body and even our death.

The patients' intervention in their treatment should be absolute, provided that their cognitive and neurological conditions allow it. Functionality scales in geriatrics help determine this possibility in each patient.



The biggest dilemma comes up among pediatric palliatives, who question how much autonomy a child can have and how far he can decide for himself.

The medical team, the patient and the family member form a virtuous triangle that, ideally, must find a balance and appropriate communication channels to decide on the treatment.

LAWS



- Palliative care was mentioned in the Official Mexican Standard since 1994 and a amendment was made in 2004 (General practitioner and geriatricians).
- **Article 166 of the General Health Law and the amendment to Article 4 of the Constitution** refer to rights and obligations when handling terminal illnesses, as well as pain and dignified death in advanced stages (Palliative Pediatrician).
- Between June and July 2019, dignified death legislation was presented before Congress and palliative care before the Chamber of Deputies (Geriatricians).

“It was implicit, but now that it is more limited, it open more doors.”
(Palliative Pediatrician, 36 years old)

REALITY



- This topic is only discussed in geriatrics, but not in general medicine.
- Although laws stipulate that all hospitals must have a palliative care area, most don't know that (General Practitioners).
- It is possible to request it, or sue if it is not provided, but this doesn't happen yet, since the patient's rights are unknown.
- Institutions don't inform on the Advance Directive document because it would imply additional work.
- Patients don't request it because its cost is high (about \$ 1,500) and it implies a notarial procedure (Nurses).

**This is a topic that is only known in an isolated and superficial way.
Geriatricians and palliativists know more about it than general practitioners and caregivers.**

"I was at a working table in the Senate and we sought to incorporate this care universally. All votes were in favor."

(Geriatrician, 31 years old)

"We must toot our own trumpet. Nobody talks about palliative sedation."

(Geriatrician, 34 years old)

"Palliative care is part of good practices, but no rule obliges to exercise them."

(Geriatrician, 37 years old)

"No law says that the doctor must go to your house if you can no longer walk. An initiative is needed and it should come from the Foundations."

(Female Caregiver, 59 years old)

REALITY



- **All caregivers don't know** if there is any kind of law protecting their relatives or supporting them to have access to palliative care.
- Some geriatricians explain to their patients the **importance of the Advance Directive Document** and increasingly take it into consideration. However, it is **not yet approved throughout the country**.
- In public institutions **there are no medications for palliative care in their Basic List**.
- **The topic is not thoroughly touched in medical congresses**, or it is only addressed in Geriatrics or Neurology congresses.

OPEN THE DEBATE

- Working groups between doctors, thanatologists, psychologists, social workers and nurses, including testimonies and members of society.
- Create medical commissions or committees to develop palliative care seminars.**

DISSEMINATION

- Inform that there is palliative care in almost all health institutions.
- Likewise, communicate clearly its benefits and motivate the patients to demand it.

TRAINING

- Compulsory training in all health-related careers: formally train certified personnel and change the mentality of the emergency doctor who only sticks to save lives.**
- Palliativist teams available to support specialist colleagues.**

MEDICINE SUPPLY

- Improve the supply of intravenous and subcutaneous morphine, which are the most effective.
- Trust and legislate in favor of cannabinoids.**

REPLICATE THE MESSAGE

- Create an itinerant home care system.
- Provide workshops to caregivers, simple and graphic bibliography, informative brochures for family members, videos in waiting rooms, as well as create informative capsules on open television, mass media and social networks.

GO FORWARD

- Strengthen the legislation and dissemination of the Advance Directive Document, as well as legislate on euthanasia and non-resuscitation orders.

VAGUENESS OF TERMS

- Euthanasia is still considered suicide or homicide, without understanding that it is an important part of palliative care (according to caregivers).
- There is a generalized misinformation.

LACK OF EMPATHY

- As long as the legislators remain as external observers and do not come to know these testimonies, they will award minimal importance to the topic.
- Health professionals also need to be sensitized and get prepared to guide family members explicitly and respectfully.

THE SYSTEM

- The lack of budget and the bureaucracy are also the great enemies threatening palliative care in Mexico (Caregivers and Nurses).

THE IDEOLOGY

- In many cases, faith, religiosity and fear of death hamper access to optimal palliative care. For example, nursing homes run by nuns do not adhere to medical precepts, but to the beliefs of the nuns (General practitioners and nurses).
- Radical groups will surely oppose this new initiatives and campaigns.

“From the beginning, my husband was told about the magnitude of his cancer, but he was told in a very inappropriate way and he has been very depressed since then.” (Caregiver, 66 years old)

CHAPTER 5. REAL AND POTENCIAL FORMATION AND TRAINING



CAREGIVERS

- In general, they did not receive training, but it would have been useful for them, especially in daily activities such as bathing, mobilizing and feeding the patient with more confidence.
- In isolated cases, the geriatricians counseled them, which was an invaluable support.

ADVICES TO OTHER CAREGIVERS

- According to their experience, training begins with the basic principles of patience, respect and a loving behavior towards the patient.



- Subsequently, look for support networks, as an in solo caregiver tends to collapse.
- Even the caregiver needs to learn to manage his *dead times* and not neglect his personal life.

"If the nurse trains me and I am 24 hours a day with my relative, it is a chain and I even help her facilitate her work."

(Female caregiver, 67 years old)

"You leave the hospital screaming, desperate by your pain, you don't even know what the fuck. As time goes by you feel more lost ..."

(Female caregiver, 52 years old)

"As a caregiver you have a good attitude and disposition, but without knowledge."

(Female caregiver, 59 years old)

"Life trained me. I never thought I'd be a caregiver twice: with my son and my husband."

(Caregiver, 66 years old)

At the public level:

- The IMSS has already started the first generation of the Palliative Care specialty with a duration of 4 years. Before, it was only a postgraduate with a high specialty in algology and a duration of two years (for example, in specialty institutions such as the Dr. Gea González Hospital, General Hospital, Medical Center, National Institute of Nutrition, etc.).
- The **IMSS** also teaches three Palliative Care courses per year for nurses.
- The **ISSSTE** (at the López Mateos Hospital for instance) offers free courses for nurses.
- The **INCan** (Institute of Cancerology) has High Specialty graduates and postgraduates courses.
- The **National Institute of Geriatrics** and the **University of Guadalajara** offer online courses.



"I applied for the course, but I wasn't accepted. Only 3 to 5 having some pull are selected."
(Nurse)

"I was trained at the National Institute of Pediatrics and the quality was good."
(Palliativist Pediatrician, 36 years old)

"They invite to the courses in the morning, but that's when I am working"
(Nurse)

"Just as they teach vaccines at the university, they should teach the use of morphine."
(Palliativist Pediatrician, 36 years old)

General practitioners, specialists and nurses agree that it is necessary to include the Palliative Care subject (not just as a theme, but as a formal subject) in the curricular map of both careers, with a theoretical-practical focus.



In private hospitals such as the **Spanish Hospital, Médica Sur, foundations** and **thanatology schools**. It is also possible to get training on your own in congresses, workshops and courses.

- It is intended to train general practitioners and nurses expressly dedicated to palliative care (First Level of Care).
- A 4-year specialty is being planned in conjunction with the UNAM.
- Although there are face-to-face and online courses, their quality standards and certification must be attested.

In spite of these efforts, the courses tend to be insufficient and scarcely disseminated, since it is not yet possible to recognize which patients need this care and how to send the trained team to facilitate the timely access to it.

"Pain Medicine was an optional subject in the career and I think it is fundamental."
(Geriatrician, 31 years old)

"It is a subject requiring skills and competencies difficult to develop."
(Geriatrician, 37 years old)

Several specialists learned about the subject until they took turns in the Geriatrics area where the patients and their families received a privileged attention, while the Internal Medicine mission is to take care of all the pathologies to abate them.



England, Ireland, France and Germany are spearheads on the subject, but we have only emulated few of their examples, as we must adapt them to Mexican culture. (Palliativist Pediatrician and Geriatricians).



In Mexico there is access to literature from Spain and its clinics specialized in palliative care. (General Practitioners)



In the United States there is more morphine and more access to rescue bombs, as well as to nurses trained in body mechanics. (Nurses).
Likewise, accompanied death is done at home. That accompaniment has already started in Mexico with home care. (Geriatrician)

*"Every three years we get the NANDA updates , which is the diagnosis book for the nurses."
(Nurse)*

*"At the INCan there are psychiatrists, oncologists and nutritionists who brought a European hospital model."
(Geriatrician , 36 years old)*

CHAPTER 6. FINAL CONSIDERATIONS AND RECOMMENDATIONS





Successes and Achievements

- **Affection, and psychological, thanatological and spiritual support.**
- **Technology and medical developments: updates** in material handling.
- **Administration of drugs to control pain.**
- **Hygiene measures to prevent side effects and complications** (bedsores, ulcerations, infections).
- **Gradual acceptance of the terminal phase.**
- **Associations and foundations** interested in supporting terminal patients and their families.
- **Appropriate diet** for each condition.
- The comfort of being able to stay at home.
- **Advance Directive Document Law, wills and funeral packages being gradually published.**
- Nurses are being empowered as agents of change.



Failures and Weaknesses

SOCIO-CULTURAL AND IDEOLOGICAL OBSTACLES:

- For several patients, Palliative care is a death **sentence**, so **they refuse to receive it**. For many others it something totally **unknown or hardly comprehensive**.
- **The refusal of the patient or the family ("*there is still something that can be done*")** hinders access to Palliative Care.
- **There's a lack of education, clear information and dissemination** (for example, a handbook for the patient and his family).
- **There is no interest** in incurable patients.
- The population with serious diseases is on the rise: **there is no culture of prevention for a healthy old age**.
- The most orthodox doctors perceive that the palliativist has a **holistic or philosophical approach**, ignoring that his work is based on **medical evidence**.



Failures and Weaknesses

"When the specializations started, they used to say: I only see livers, only wombs, only kidneys.

They started to focus on one thing! "

(General Practitioner)

HEALTH SYSTEM FAILURES:

- The **Basic List of Medicines is limited**: not all hospitals have access to those medicines.
- Palliative Care require human resources, personnel training and assignment of specialized staff: **there's a lack of ethical, certified and committed personnel**.
- **Palliativists are scarce** and concentrated in **few cities**
- For many specialized doctors, palliative care **confirms "the defeat" of their efforts**.
- **There's a lack of economic / budget resources** ("*government failures*").
- There is a **shortage of medicines** (according to nurses) due to "*shoplifting*", "*mafias and leaks*".
- The **hyperspecialization of doctors has led to a reductionist, limited vision**. Especially at the end of life, it is necessary to see the patient as a whole, together with his family.



Failures and Weaknesses

LEGAL FAILURES:

- **Legal loopholes and gaps in institutional policies** have prevented the implementation of palliative care unanimously: the IMSS, the ISSSTE and the Ministry of Health have different strategies, but do not seem to complement each other.

PALLIATIVE CARE HANDLING FAILURES:

- Handling the grief requires a perspective more experiential than theoretical.
- Occasionally, nurses are inflexible in their protocols and do not allow palliative care to be established according to the needs of each patient.
- The subject has been excluded from the **Medicine and Nursing curriculum** .
- There are **few courses** or, perhaps, limited diffusion of them.

PALLIATIVE CARE POTENTIAL EVOLUTION:

- As we can see, the areas of opportunity are more numerous than the achievements so far achieved.
- The caregivers are those who see a slower progress in this matter, given that the health authorities confer primacy to the prevention of pathologies and not to their terminal phases, or even to the attention of medical emergencies.
- Geriatricians and palliativists show more optimism: they expect to see a growing trend of humanization and respect towards the serious/terminal patient. In addition, they perceive that this kind of care is an increasingly relevant focus of attention in Mexico.
- They also trust that there will be more palliative care units in hospitals over the next decade.

Recommendations:

The present study shows the need to close the gap between caregivers and health professionals: caregivers must be trained in a brief, simple, operational and practical way to be prepared to repel the disease attacks, but they also need sensitive, patient, doctors and nurses willing to accompany them in critical moments.

- Therefore, it is suggested to the DMD Foundation to reinforce its efforts towards the design of **workshops for caregivers**, as well as **webinars and podcasts** so that they can see or hear during the spaces when they need to take a break (or as they call it, in their “dead times”), or have the desire to learn, something about the ailment of their relative.
- Likewise, in these materials it is recommended to include a section of Frequently Asked Questions divided by illness, because caregivers confirm that each disease is unique and implies a special challenge. It is proposed to place a special **emphasis on rare or poorly investigated diseases** (dementias, ALS), as cancer is one of the most studied.
- On the other hand, it is recommended to **train volunteers** who could operate as **support cells** in public and private hospitals, not only in Mexico City but in **other cities** and even in **isolated/rural areas**.
- In order to reach remote areas, it is proposed to create a **free telephone helpline** for patients and caregivers who need to clear their doubts.

Recommendations:

- It is also recommended to collaborate with **Thanatology Schools teaching some palliative care subjects.**
- It is extremely necessary to increase the availability of **home palliative care**, for which a **directory** of doctors and nurses who provide this service could be created or, in turn, **recruit a network of professionals** willing to do so.
- It is also recommended to create or join a **campaign** in synergy with other foundations to publicize palliative care, its objectives, its benefits, its scope.
 - This campaign would have to rely on **testimonials** and share **anecdotes from doctors** convinced of its relevance and credibility.
 - It is even suggested to look for a warm and close "**spokesperson**" **able to connect with the audience** with a **persuasive** tone and manner.
 - In this campaign it is suggested to place special emphasis on **palliative sedation** as a key tool that to date is little known.

Recommendations:

- In order to approach the population with lesser economic and cultural resources, the Foundation can design a **Basic Guide of Palliative Care** (with little text, but clear images) **for its distribution in first-contact institutions or First Level of Attention** - for instance, clinics and health centers.
- This kind of materials—flyers, brochures—could even be distributed by **laboratory representatives** to medical offices to also have a reach in the private sector.
- There is a great need to obtain support through **family therapy and group therapy (support groups)**. Here also, the Foundation could generate a **directory of clinical associations** to guide family members during the disease process, or even open their own area of psychotherapy.
- Likewise, **the elaboration of the mourning** is usually a pending issue when the patient dies. It is recommended to promote this objective and, when death arrives, to design an **Attention Program** to look after the caregiver, helping him to resume his life plan, his activities and to recover his balance.

THANKS!

