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## Chapter

# The Challenges Facing Palliative Care Advocacy: What Is in a Name?

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## Abstract

The need for Palliative Care (PC) continues to grow throughout the world, requiring continuous development, true to its “ethos.” As awareness grows so does the expectation for timely response and policies to potentiate its delivery. The scientific dimension of its philosophy, underpinned by research and scientific practice, looks to explain its nature, origin and concepts, models and theories within which it is delivered. The concept *palliation* is widely used; yet, it is understudied by academics and clinicians. Interestingly, it is increasingly questioned by society and other specialists, calling for it to “be debated and essentially contested”. Our aim is to contribute to society’s understanding of palliative care so that they can have a clear and truthful awareness of the complex implications of its mission. We approach the different concepts, scientific theories and structures can be achieved by following different pathways, including defining its “ethos”: personality or nature, manifest in the very formulae by which PC places itself before those who need it. What a fascinating topic it is to research and write on!, phenomenological in its base, it shows how different translations of the Anglo-Saxon PC influence its understanding and much needed expansion. Semiotics are at the base of the essence of how palliative care might be assumed and promoted. PC is, for sure, one of the most important, existential spheres to apply our knowledge today and a novel promising methodology to apply the semiotic and phenomenological approaches learning of different aspects of cultural transfer processes.

**Keywords:** palliative care, scientific conceptualization, linguistics, advocacy, ethos, spirituality

## 1. Introduction

The extension and transferability of what has come to be known as PC [1, 2] has become stalled in some countries [3]. Many believe it to be a consequence of inadequate funding or even political indifference [4]; others question whether it might be due to lack of conceptual intelligibility and transferability across languages and call for a fresh PC [5, 6] definition that incorporates its philosophy and ethos while being fully transferable across countries and cultures.

But what can be said to constitute, identify and define the *Palliative Care Ethos*? With the patient at its centre, PC looks for direction in their own and their loved ones’ narratives:

*'You can tell them all that it was all right', was the unpretentious and comforting message Cicely Saunders was asked to pass on to a lady's relatives once she had died. It was important for that patient to let her loved ones know that she had not gone through a strange, dramatic, or just unlucky experience, ( ... ) written up as such without sentimentality or sensationalism, but a common experience ordinary people have always faced, writes D. Clark [7]. A good example of the rich exchanges full of meaning and depth that can take place within the ordinary delivery of PC. So beautifully common in many ways; and yet, so elusive to capture in a defining snapshot to apprehend its uniqueness.*

*'The joy, purpose and meaning of medicine has been codified, sterilized, protocolised, industrialized and regimented' says Dr. Eric Levi [8]: a stark reminder of the reality in ever-advancing health systems which seem to have forgotten the more artistic aspects of medicine which allows compassion to highlight our common humanity, a fundamental aspect of PC.*

## **2. The purpose of medicine**

Medicine is as old as humankind itself [9]. At first it was mythological, the causes of diseases were attributed to the gods or spirits, subsequently acquiring a more scientific character as it was recognized that diseases had physical or environmental causes.

Hippocrates has been considered the father of scientific medicine. The Hippocratic Corpus [10], with its 53 books, has philosophical and ethical writings such as the Hippocratic Oath and Aphorisms, as well as others of medical order consisting of 7 books on Epidemics, 4 on the Regime, 4 on Diseases, 2 on Predictions, 2 on Women Diseases, Instruments of reduction of Joints and Fractures. Writings used by doctors to learn for centuries. One of these texts, the Hippocratic Oath, remains valid- It concisely points out the duties of doctors, duties that were not imposed on them by the authority of the moment but rather, somewhat self-imposed after assessing the value and importance of their own work. This Oath is a model of professional behavior not only for doctors but for all professions.

Medicine is finite, limited. People will die. Diseases will change, but it always comprises great respect for human weakness. Sometimes we will have patients with acute problems, sometimes chronic conditions, some patients will be conscious and sometimes unconscious, sometimes it will be curable diseases and sometimes incurable, sometimes we will have friendly patients, sometimes we will have patients with diseases that we like to treat and sometimes with pathologies that for the doctor are unpleasant, but they are all our patients, all expect us to treat them with respect, they want to feel taken care of, they want humanitarian treatment.

Our medicalised modern cultures tend to render reason and mystery mutually exclusive, defining "death by disease" as failure, and dying as disgraceful. Providers and policymakers alike marginalize aging and dying individuals, while formulating largely ineffective strategies to prevent deaths from violence or epidemics, terrorism, and famines. Policies to nurture care and support the elderly, those with long terms conditions and children [11–13] born with congenital medical conditions, malformations or different capacities, are too often inadequate and departed from reality. They tend to be declarations of intentions lacking in budgetary provision.

## **3. Palliative care**

### **3.1 Meaning and fullness of worth within the health and social contexts**

It is palliative care mission to demonstrate that each life is morally significant to its natural end, restoring patients' and families' quality of life where possible, and attending meticulously to the dying period when necessary [3, 4].

PC changes the perspective from which the world sees health and social care, since its philosophy gives standing to the multiplicity of beliefs and communication patterns manifest in the collective of suffering patients. This motivates the articulation of a good enough ethic.

Contemporary literature [3] shows researchers' acknowledgement of historically relevant milestones in PC roots from bygone days and subsequent evolution, including Palliative Medicine being recognized in some countries as a specialized field of training and work. There is also explicit acknowledgment of the difficulties affecting uniform implementation of its philosophy and principles. Some projects centre future advances and growth in PC provision with promising results in relation to identifying the founding ethos of PC by reproducing its initial way of showing the depth of society's concern for its more vulnerable members, based on its values when alleviating the suffering experienced while facing aging, disease, life threatening pathologies, dying and death.

Such ventures highlight the importance of setting the scene for possible advances to integrate ethical, legal and social implications in years to come to benefit the many likely to need it. It likens the development of the field to a journey; one that sets off on the knowledge the fullness of meaning and richness of PC can only be approached by taking its long view.

A sound understanding of PC foundational bases [2, 14] facilitates answers to many questions needing an answer, although some voices of those who seek a more bio-physical-psychological palliative care model strongly disagree. It is, for example, motivating to take into account the different creative initiatives born in clinical settings in the context of the COVID-19 pandemic; it confirms how man continues to look for ways to alleviate suffering in the most challenging situations making use of what they have to hand. In our time, the inventiveness brought to the bedside of the dying has been astonishing, giving hope to those of us who want to offer holistic care to those who see their lives threatened, including aging and the natural end of life, by some entity threatened life expectancy.

This chapter will aim to identify what constitutes the enduring ethos of PC as it continues to evolve and grow beyond the walls of St Christopher's Hospice, flagship of Cicely Saunders's endeavor to comfort the dying by letting them know that they matter because they are who they are; and they will matter to us until their last moment of their lives.

### **3.2 Modern hospice movement evolution**

Looking into what is understood by this vocable takes us along surprising trails as a Work of Mercy, with deep ancestral Judeo-Christian roots [2]. It is depicted well in both the Old and the New Testaments, for example, in the Parable of the Good Samaritan and many conceivable and incomprehensible healings. It can be followed in the labour of hospital religious orders over the centuries which persists to this day in initiatives such as the contemporary Pastoral of Health. It is doubtlessly, care that has historically been largely provided by Christian orders that hold to the divine 'Thou shall not kill', and are moved to love and compassion.

In our time, proud of its origins, it is a formalized and widely recognized as a growing medical field which has its foundational modern roots in (Dame) Cecily Saunders's concern and work to remedy the poor medical care being provided to dying hospital patients. Over time, its medicine had shifted [15] the focus away from the needs of those who could no longer benefit from evolving technology and life-saving treatments. But it did not stop there as the medical world continue in its way to ignore those dying in its institutions.

Cicely Saunders, established unambiguous foundations for the Modern Hospice Movement [2], one of which is to be found in the togetherness of Head (mind) and



Heart (compassion and our own vulnerability) when caring for these people. It was not, she explained, an idea that occurred to her, but rather the mandate received from David. David Tasma, a Polish Jew, mortally ill with pancreatic cancer, when, broken by the profound suffering he was experiencing, as he was facing his own mortality so far away from his own country and those he knew and loved well asked her:

“Can you say something to comfort me?” taking Cicely Saunders away from *doing* something to him, or giving him some medication to soothe his distress. A little later, he added “I only want what is in your mind and in your heart.”

The Modern Hospice Movement, generally known as *Palliative Care* outside Great Britain, was thus born to use scientific rigor to research and treat symptoms such as pain. Its focus on the holistic needs of patients: physical, emotional, social and spiritual, without forgetting the professional dimension. *Palliative Medicine* is the only medical specialty that recognizes care of the spiritual person as part of its mandate [16]. Its science and care are applicable to any person with an incurable, complex or life-limiting illness; its principles can be applied to that person’s care from the time of diagnosis. This means good symptom management plus supportive and holistic care occurring alongside: it may be provided by any health care clinician, using the same principles to provide a ‘Palliative Approach’ to medical and nursing care.

*Palliative* is derived from the Latin word ‘*pallium*’ meaning to cloak someone who is ill, sick, lonely or needing protection. Symptoms are eased even if the underlying condition be cured.

Maximizing wellbeing and nurturing the hope to maintain or improve perceived quality of life can be achieved in a variety of ways, however, it is imperative to guide all interventions by a common moral compass which indicate the manner by which teams allows someone to be themselves at what can be an extremely difficult time in their lives. PC strives to acknowledge the person as a whole - addressing snags affecting different aspects of their life. A multi-disciplinary approach supported by the skills of different professionals, pooled and utilized as necessary.

Hospices and Palliative Care Units alike house an ethos of care which should extend beyond their walls to places where symptoms need to be eased, the underlying condition not amenable to be cured [14].

### **3.3 Limits of action: caring, not killing**

PC acknowledges the reality of death and seeks to assist patients and those around them to accept its inevitability accepting dying as a normal part of life, teaching that helping people to die well, i.e. “in peace”. Nor should it be confused with actively helping people to die, i.e. to bring their deaths about.

Its distinction with euthanasia is at times obscured by claiming that the outcome (death) is the same for both and that the intention of both is to relieve suffering. These assertions are true, as far as they go, but there is a moral distinction between giving a “lethal injection” and the interventions that constitute palliative care. These interventions include the provision of symptoms relief by titrating medication against the symptoms. The aim being to achieve the best control of symptoms with the least side-effects, for which different medications are available: if one medication does not suit, there are usually others to try. *Giving the right medication for each symptom at the lowest dose necessary to alleviate the symptom.*

Sometimes, there might well be situations where relief of very difficult symptoms, such as pain that does not respond to analgesics and adjuvants or intractable shortness of breath and a number of catastrophic clinical events such as some hemorrhages or pulmonary embolism, can only be achieved by medication doses that result in deep sedation.

The clinical situation might be extremely complex leading to a binary status quo in which the options are either vigil and in unbearable anguish or unconscious and calm. In this scenario, the alternatives are either dying with intolerable suffering while being aware of it or dying comfortably while unconscious. There is no real choice here – the only morally good course is to address the patient’s symptoms accepting the side effect of sedation that inevitably accompanies this. The Lex Artis requires that all intervention is proportionate and relief of symptoms and suffering sought at all times by proportionate means, and regular reviews.

A frequently held fear or misapprehension when working to control symptoms is that the therapeutic maneuvers used in the process might be also shortening life and hastening death. Medication used need to be clearly explained regarding its purpose, effects and side effects; morphine is regarded with particular fear and suspicion. However, in most situations its careful titration following best practice guidelines under specialist’s advice will alleviate symptoms with no noticeable shortening of life. On the contrary, we should not underestimate the potentially life-shortening effect caused by the stress, and distress, of severe uncontrolled symptoms. This is an area in which good *Palliative Care* is able to help.

PC is certainly able to deliver sound, scientific based care with the vulnerable friendship of the heart. Not many could openly object to these foundations. Yet, many committed practitioners ignore them in their daily practice. Could there be a different reason behind? Or, could it be due to a lack of proper understanding of its place in science, health and social care?

Approaching Palliative Care from the point of view of its conceptual basis opens a fascinating quandary for the studious physician when the need to clarify to others, patients, family, cares, health and social professionals, society in general, what PC is and what is not, presents itself. It takes time and effort to work through it all when helping someone accept our help in a timely fashion. Communicating it in a conceptual nugget what PC is a complex task.

There are definitions put forward by organizations such as WHO and IAHPC. And there are also well defended theses, such as Randall’s, to deconstruct and determine how such definitions are rather aspirational “declarations of intention”.

WHO’s [17, 18] definition includes quality of life in their declaration of intentions. Unquestionably, a very important aspect of the palliative philosophy is its commitment to taking care of well-being by excellent symptom control to help maintain the quality of that life for as long as it such. For many, however, life -in its sanctity- cannot be classified and protected in direct relation to its perceived quality at a given time.

While life itself is an objective good, necessary to enjoy many others, its quality or lack of it, is a subjective good, dependent on many factors. For example, for many, happiness is essential to life and it is the pursuit of that happiness that gives meaning to life. It is particularly suggestive to understand the quality of life perceived by those who have learned to live life through the small, insensitive things that adorn it. While others think that the “core” of life can only make a concrete sense among those who believe in the Transcendent, be it God or not.

Dr. Pettus [19], a political sociologist claims that our modern and medicalized cultures make reason and mystery mutually exclusive, defining death from illness as a failure, and dying as shameful. Suppliers and legislators similarly marginalize older citizens and the dying, while formulating ineffective strategies largely to prevent deaths from violence or epidemics, terrorism or famine. The goal of PC is to support those with an incurable disease so that they can live the rest of their lives as well, and with as much sense as possible, giving them the necessary support when, eventually, they reach the natural end of their lives, and die from their illness.

Painful and distressing deaths without palliative care or relief from physical pain, in remote areas, attract neither political attention nor budgets, says Pettus. A growing effort is being made to establish and advance Palliative Care's contextualized advocacy around the world, based on its own "ethos" and spirituality that ensures its implementation and availability for many.

Those who work advocating PC believe that, to be faithful, the its safeguarding should reflect the "ethos" of the hospice movement. This is a central concern for many, particularly concerned to understand how such ethos could be established and how it could dissipate into loss, disappearing. It is worth knowing the work done by those who care about those intangible aspects of the hospice movement that precisely make it so. A particular apprehension is the one that asks how the "ethos" could be lost by spreading more widely t is marketed while losing its well-founded and carefully established training its approach to transmitting its philosophy and principles.

Cicely Saunders left a great number of written documents. This one is particularly representative of her work:

"The longer I work with the dying and their families, the more I learn about life and the small things that are so important to each one of us. Dying is never easy, it is done differently by each person. Fear of the unknown is what most of us can identify with. Having a terminal illness including diseases of cancer, MND and other neurological illnesses, Dementia will take us all, whether patient or a loved one, to places in our lives we would rather avoid and will often include fear of unknowns. How we often support our patients & families is to get alongside them as best we can and share some of our skills and experience to break down these fears. We don't always get things right because dying is not an exact science. What I think is also true is, yes, we put ourselves forward as a resource for the community, to show leadership in this field, but we can't do this on our own" [16]. She was not a theorist and understood others' suffering and distress and led the way to alleviate their suffering, advocating for a more comfortable dying process and a more acceptable memory of it to their loved ones who live on.

Nobody should be expected nor forced to consent to all life-prolonging treatment; *Palliative Care* does not preclude receiving life-prolonging treatment and, delivered alongside those treatments and interventions can be really productive. Each person should be able to choose for themselves how much treatment they are willing to tolerate for limited gains in life expectancy, and to refuse treatment they do not wish to receive. There is, however, a responsibility to use this life well in service to the end (and to reach one' full potential).

The challenge is perhaps discerning when is it time to let go of this life, and so it has been since humans inhabit the earth. St. Paul's illustrates this tension well in his letter to the Philippians (1:21-24).

Each individual will expect their remaining life to allow them to be and do what their very own idiosyncrasies such as age, illness or responsibilities to others requires to complete their lives. Often, we meet people who may feel that their life is approaching its natural end and are ready to relinquish this world when their time comes. Nowadays, PC has evolved to offer other services under the name *Supportive Care* [20, 21] based on patient's needs, increasingly used in the acute sector and well accepted by both patients and professionals in the context of potentially curative or life sustain treatments which, nevertheless, can be onerous to receive and follow. To many, the adjective *Supportive* is better accepted and understood than *Palliative*.

It is important to find a common base which help recognize PC under whatever wrapping it might come in. Much confusion has come from the different, often random translations of the vocable *hospitium* [22] which has come to be understood



different things in different languages. *Hospices*, as understood from its Anglo-Saxon use, are far more than mere buildings; they house a philosophy of human relationship and hosting which could be considered as direct descendants of the medieval form because behind their assertive philosophy sits a highly personal holistic approach which places the physical, emotional and spiritual welfare of patients and their families at its heart.

Still, many still identify them with places where patients go when there is nothing more to be done, where people go to die. The problem with this, is that much of the suffering that could be alleviated in the right space, is not, because it is left too late, thinking they are places one might go to die.

Much work is nowadays undertaken to facilitate the understanding of terminology in our field, many researchers look and write about palliative care. In Spain where it has been translated as *‘Cuidados Paliativos’*, thus stressing its most physically relevant aspects of care. Research groups such as ATLANTES. Instituto Cultura y Sociedad. Universidad de Navarra look for its secret, which they call “The Intangible”.

Our own research to define the ethos of PC moves in the same lines, recalling The Little Prince affirmation “And now here is my secret, a very simple secret: It is only with the heart that one can see rightly; what is essential is invisible to the eye.” [23], which links seamlessly with the thoughts of those pioneers whose legacy is now ours to work with and transmit forward “All those intangible values are expressed in concrete actions able to transmit unconditional acceptance and the affirmation of the patient’s worth as a person [24].

### 3.4 Scientific aspects

Having set its humanistic aspects, it is imperative to look for PC scientific bearings.

Much has been written and researched around “the scientific” and the Ethos of Science, which refers to the “toned affective complex of values and norms that is carried out to be binding on the man of science. Rules are expressed in form of instructions, prescriptions, preferences and licences” [25].

It is acknowledged that the end of all science is the extension of agreed knowledge and that it must be able to be explained through its technical methods: “empirically confirmed and logically coherent statements of regularities (these are often predictions)” [26].

PC has a strong humanistic element but it is also science [25, 27]. Predictions are even more important in this field, where informed assumptions are regularly made to underpin decision-making as it is also science and, as such, it must be governed by laws ordering any other science. This issue, together with poor conceptualization, could have contributed to the deficient PC extension [28] and expansion; the fact that some have arrogated themselves the right to choose what aspects of the palliative philosophy and principles to apply, choosing them at convenience, either out of ignorance or neglect might have arrested its expansion.

#### 3.4.1 *The science and its philosophy*

Cicely Saunders is known to have been a woman of multiple interests which she followed by training to be a nurse, almoner and a doctor. She had other interests such a full understanding of Christianity, Philosophy and is considered to be a humanist. She liked to read and study the different aspects of things in depth, often citing authors and philosophers such as Francis Bacon. Philosophy as science certainly underpins the philosophy of the Hospice Movement. Understanding this,



together with the great value she gave to the scientific foundations of palliation brings us to consider the Philosophy of science as necessary.

Science is a limited human activity that has its origin in man's observation of ordinary experiences and his desire to know the truth. In its output, science provides proven knowledge that goes beyond human experience. Its classic ideal seeks to achieve true knowledge based on reason, compatible with that which is provisional and reviewable.

Classical sciences such as philosophy, theology or mathematics share some features with many modern experimental sciences such as physics, biology or neuroscience. However, the notion of science is often applied almost exclusively to experimental sciences.

A broader perspective applies the concept of science in an analogue way. For example, experimental sciences and common philosophy both seek a knowledge that extends beyond ordinary experience; the difference is that the philosophical approach does not willingly exclude anything that can be rationally studied. Experimental sciences self-limit the search for empirical evidence using specific principles of reasoning.

The same reality, for example, the suffering of the human being is the subject of study of different disciplines (biology, sociology, sociology, psychology, medicine, which means that each science has its own objectives, methods and therefore, also, results. A situation which has leads to the fragmentation of knowledge which clouds the understanding of the discipline.

The philosophy of science is a philosophical reflection that seeks to understand the nature and value of science, given that philosophical reflection on scientific activity is carried out from reason. Logic, history, sociology ... but, especially from a meta-scientific perspective, experimental science is a clear test of human ability to transcend what is immediately given to observe by the senses.

Philosophy, as science has evolved in time. Among the current main current currents in the philosophy of science, Thomas S Kuhn's historical 'sociological' approach states that the paradigm shift is not due to logical reasoning but to a process of conversion of scientists.

Science needs to be communicated. Scientific communication demands clear conceptualization. Each concept has a meaning and a reference that does not have to be unique. Thus, terms can refer to many semantic fields (evolution of pain, evolution of human suffering) and encompass in their meaning various mechanisms related to their perception by society at that point in history.

But there is more as concepts, these most elementary scientific constructions can be either qualitative or quantitative.

Quantitative concepts are common in healthcare and have a mathematic expression, (temperature, blood pressure ... ) and are called magnitudes. They are associated with methods and measuring instruments, acting as bridges between theory and experimentation, because they make rigorous data processing as possible. These concepts, common to physical aspects of medicine are well used and known: they have extended to less measurable concepts such as physical pain by a number of conceptual models.

Concepts are not static. The understanding of the atom, today is much greater than a few years ago.

Science uses models to simplify reality, idealizing some of its aspects. Some models are schematic representations of what you want to study, while others are much more complex idealizations. PC is defined by many as a phenomenon and as such, for its realization the scientist needs to use informed guess (very common in PC advanced communication) to tease out what properties of phenomena form the appropriate basis for idealization and What features can be ignored.

To achieve which, the role of creativity and interpretation are essential, as is scientific induction, including inference.

For example, about could have been causing the back pain a patient suffers from. Or the reconstruction of a family distress from our knowledge of a patient's disease trajectory. Or extrapolation when a new cluster of symptoms appears in relation to biochemistry analysis results taken a few days before of an election from surveys.

A situation which tries to help complexity using models: The model is a scientific construct between theory and reality. On the one hand, it concretizes the theory and on the other it simplifies reality.

Scientific statements, are a very varied type of scientific construction. They range from expressing the data obtained to an experimental measure: "You have cancer causing you pain several times in 24 hours as the analgesic effect wears off". Up until a law is formulated: "Patients with cancer who have continuous pain shouldn't have to earn their analgesia; opiates should be given regularly" stated C Saunders. Like models or concepts, they are not an exact translation of what is going on in nature. The statements and laws that are constructed from them are, by definition, approximate, provisional and contextual, because in the future the concepts can be further specified and the measuring instruments can be improved.

Theoretical Systems arise from statements and laws that articulate and command each other. Well formulated, they become consistent and are susceptible to improvement, at the same time, they remain always open, i.e. they are not closed systems: at least they have initial conditions and contour conditions. They are formulated in a fragmentary way, just as a child acquires greater ease in the management of a language.

Science and scientific proceedings therefore, come supported by complex structures that need understanding and respect. Many work to help others understand these and give us principles to promote respect, setting out the Ethics of Science, worth of a chapter to itself.

Sociologist Robert Merton [29] identifies four institutional imperatives—universalism, collectivism, selflessness, and organized skepticism—such as the ethos of modern science—its "fundamental values." Mertonian laws cover aspects such as: volume of research funds, consistency of the professional network, community collectivism and involvement in non-academic content.

*Universalism.* Promotes the value of scientific claims for what they bring to society and not by who brings them to the scientific arena or even which personal or scientific background they bring their claims from. Merton recognizes and warns about the power of society at large and a scientific private cosmos which may clash with universalism. "Ethnocentrism is not compatible with universalism," he affirms and requires that "careers be open to talent," because science must be a meritocracy. Therefore, to hinder science ability to nurture knowledge, by excluding capable people from developing their scientific callings on the basis of competence, harms scientific progress at large.

This aspect could be detrimental to PC, where the *friendship of the heart* constitutes one of two foundational cornerstones, without which, extreme over-technification and medicalization might overrepresent its science. PC demands more impalpable aspects to achieve its mission and the vast volunteering that support it is testimony of the founder's vision to successfully combine both knowledge and compassionate doing.

Data and theories are valuable assets, continues Merton, which can be cond in models or scientific structures, even named after the scientist behind it when thought to constitute a significant contribution to the field and brings prestige to the so-named person or research group. Such prestige is in itself an honor best

respected by those who work in that field, hence the reason why communication of scientific results is prized by science which despises secrecy about them.

He [29] states that *Universalism* is also a democratic principle (*laissez-faire*), “impersonal criteria of realization and non-fixation of status characterize open democratic society”. established scientific knowledge should be accessible to all members of the scientific community to use, explore, etc.

*Collectivism*, also communism, does not refer to the Marxist-Leninist movement, but to the view that scientific knowledge is a resource to be shared with the entire scientific tribe, regardless of which individual scientists in particular have produced a particular discovery.

One of the things a scientist has to do to meet this standard is to communicate his findings to other scientists. Knowledge that is not made public does not help the scientific community.

Interestingly, Cicely Saunders took good care to encourage collectivism of the scientific ethos [30] of the new field of medicine was set to become. *Palliative Care* was born with no scientific secrets as she sought to tell others what she had found to help the dying from the very beginning when every Saturday morning the met to “work and pray for Hospice”.

*Disinterest*, maintains that scientific accounts ought not to be personal in their outlook and, rather than empower the individual scientist own plan, they should bring a greater good to a bigger group. Merton [29] argues that disinterest is an institutional obligation, not be disarranged by individual motives. Individuals should certainly have personal motivators such as scientific awareness, publications, recognition, curiosity, among others. Such desires are licit as far as that will encourage them to work with others to obtain the results that will made the group shine.

“Institutional control of a wide range of these motivations” better characterizes what is fundamental to science and helps avoid science scam. Merton [29] believes this is reinforced by the rigorous monitoring that scientist undergo at the hands of other scientists. Interestingly, he also highlights the connexion researchers establish with their *customers* different from those other professions. Alarmingly, when lay people and scientists establish closer working links, such connection frequently spurs fraud and pseudoscience.

Finally, Organized *skepticism*, encourage omitting one’s own judgment and using only empirical and logical criteria. This is frequently the strained connection between and those vital areas inclined to offer judgment.

While difficult, it is comforting to discover that the scientific aspect of Palliative Care, “its head” is up to any other scientific effort, although it is true that there would be much to analyze and work in order to give greater rigor. It is especially relevant to strengthen the learning in countries where *Palliative Care* and Palliative Medicine are not recognized as specialties. This leads to situations in which the expert becomes such by means of an expensive, often online, master degree and short clinical observational stays with experts who are such by the same method, very distant from the structured learning that a four-year specialist training affords the individual.

From its inception *Terminal Care*, as it was our field originally known, it was ambitious in its founder’s commitment to practice within scientific frameworks, to research and treat symptoms such as pain [2, 30–32]. The focus being the person as a whole and responding to patients’ physical, emotional, social and spiritual needs. Palliative Medicine, is today a consolidated [33] medical specialty which incorporates the care of the spiritual dimension of the individual as part of its decree although, sadly, not in every country.

On the other hand, most cultures and formalized religions [34, 35] have incorporated palliation to their teachings and fullness in some way, having also “come to join the movement” with their own array of richness which, although not known to



many until now, has always been present in any human grouping. It is such an interesting and fascinating aspect that deserves another full chapter to really learn how other communities look after their vulnerable members, the ill, the dying and how to support those who are bereaved.

### **3.5 Patient centred and directed palliation effort: quality of life**

It becomes necessary to position ourselves and acknowledge the conceptual *mare magnum* which too often blurs and disorders the delivery of timely PC, its scientific structures perhaps too vague to work on.

Probably, the best way to understand the undeniable value of PC is to allow others, those who have experienced PC, rather than deliver it, to inform our effort.

Patients' narrative recounting their experience is full of details; something we become aware of when we introduce someone, visitor or professional from other specialty, to the dynamic of our consultations. We are talking about its other foundation: "*The vulnerable friendship of the heart*".

As with any vital aspect, and Palliative Care is very much about living life to its natural end, we encounter have a static duality - dynamic, negative - positive, pain-pleasure, darkness-light, night day, death - life experience that makes this field one of very strong contrasts.

How many times have both patients and their families told us that they are "living on a real roller-coaster of emotions, experiences, illusions and losses.?"

Hundreds of sick people who tell us about what they experience when the afternoon falls and the day - perhaps their last day - becomes night. Likewise, the desolation of the last sunrise when a new day arrives that they do not know if they will have the strength to face in a dignified way. How much suffering holds the narrative of "I'm afraid of the night in case I die during it. I feel horror at dawn because I am still alive and have to face a new day and I don't know if I can."

As professionals, it is in these moments of very personal, intimate exchange and confidence, when we confirm that something very special imprints character to our work. Yes! something that reaches the other. Just as their desolation reached us. For me, the question is "how could we find what that something is?"

Occasionally, it's rare but extraordinarily motivating, people look us in the eye and ask "And how can you do this every day? Sometimes they tell how they have seen us tend to another patient and have seen the pain in our eyes. They insist "where do you get the strength to come back the next day with a smile? Where does the inspiration come from for your eyes to shine when you approach me, broken my useless body? Me who with my pain caused you pain?" We respond with professionalism, humanism and simplicity. In that therapeutic space, we left something of us. It is very likely that in such a personal exchange, the very spirit of PC is contained.

It would therefore appear that experiencing PC is possible by both: those who need it and those trained to deliver it. As an experience it falls into the phenomenological sphere which incorporate a combination or synthesis of the positive aspects described, experienced in situations of suffering and uncertainty which can be qualified as intensely relational. If these moments pregnant with human intensity are symbolized by a single quality, it would be one very close to life itself and characterized by light, beauty and love gathered in one. A phenomenon that can be experienced but difficult to describe and be identified by the someone else, not actively involved or not adequately trained.

Thus, life to its end can be a wonder in the development of images and s never seen before, thoughts never before thought, realities never dreamed of, constantly emerging, constantly reminding us that the person's individual universe might not yet have reached the limits of its possibilities.



Palliative Care might well be the force able to bring forward the life that remains as such, as an evolving universe, says R. Bruening, an organic chemistry scientist who says his work is that of anti-cancer drug maker and CEO. Practising good Palliative Care can help whoever receives it to reach their own, yet unrealized, potential as a human being.

These profound understandings come from experience; the problem is that trying to quantify subjective experience is like trying to create a metric for a favorite color. Or flavor of ice cream. Or to measure suffering by the volume of tears cried. It is also possible to use Scientific constructs and models to objectivize the experience.

Indeed, WHO's definition of Palliative Care, considered by some authors to be mere statement of intentions, incorporates the concept of quality of life since a very important aspect of palliative philosophy is its commitment to well-being, quality of life, as long as it exists. Many consider happiness to be essential to closing a full life, and their pursuit of what gives meaning to life. It is particularly suggestive to have learned to live life through the small, insensitive things that adorn it. Others say that the "essence" of life comes to its full meaning depending on how transcendent.

From a metaphysical (spiritual) point of view the essence, as in any matter of vital nature, and Palliative Care is very much about life and living it, incorporates static-dynamic, negative-positive, pain-welfare, darkness-light, night - day, death - life, soul-body duality, which make this field one of very strong contrasts.

It might be that experiencing the essence of Palliative Care is possible: combination- synthesis- of the positive aspects described, experienced in situations of suffering, uncertainty and very, very relational. If these moments pregnant with human intensity are symbolized by a single quality, it would be a very close to life, the very life characterized by - light, beauty and love - gathered in one and become like One, that could be identified.

The European Consortium in Healthcare Outcomes and Cost-Benefit Research's extensive study concluded that those theories based on a QALY approach do not give a true account of the manner real populations performance outlines (Quality Adjusted Life Year) is a non-specific measure of disease burden, which tries to encompass value and amount of life lived; used in economic appraisal to weigh the cost of healthcare interventions and their impact on society as a whole. An entirely foreseeable result: we can no more predict what patients will want or need when a given disease takes hold, than guess that their favorite color or the ice cream flavor they disfavor. Such understandings only come when know when we know them and we spend time with them and they tell us themselves. Or we observe their behavior and possessions as well as their loved ones.

Enabling patients to choose what they can has consequently become very relevant and organizations such as "Nothing about me without me" [35] leading the way help bring forward the more humanistic dimension of PC.

Consent laws focus on the ability to understand illness and treatment options, as well as the consequences of treatment selection or refusal. As patients often are not aware of their own goals and values because and they have not specifically paused to think about them or make them explicit, getting to know the patient through asking the right questions and listening carefully to answers which can be new to the person, can help us understand their choices. We learn what is most important to patients in their life right now, and what would their ideal end of life look like. *Active listening* [35] will afford us the knowledge of their wishes relating to spending time or even dying at home, not wanting to be in bed attached surrounded by machines. We often listen saying little while the patient comes to realize what they want and vocalize some outstanding goals of care. After this, the patient -as the

director of a well-rehearsed orchestra and the entire palliative team came up with a plan of care to meet those goals to the greatest extent possible.

*Patient choice*, as an entity, must become part of the medical Curriculum and take its rightful place as a basic starting point of all good medicine.

Bereavement is not to be forgotten. Frequently, the bereaved come with a card, cake or fruit to let the professionals know they are grateful for the great care provided to their loved one. They do not mention a single common research metric, but the team are motivated by their gratitude in remembering their patient. It is a very humbling experience as we are reminded of the uniqueness of each life and the impact of our common humanity.

#### 4. Chapter motivation and scientific interest

After almost 30 years of combining multilingual medical care in three countries with a special interest in *Palliative Care* practiced at all levels of care in the country in which it had its modern origin and at the political-organizational level of the country of origin itself, the pressure to address its expansion from different perspectives: conceptual, semantic and semiotic; anthropological, philosophical, political and welfare, of confronting the intrinsic philosophy seeking what imprints character on a multi-professional attention at the international level at a time when there is great confusion as to what constitutes the delicate spirit of a movement that has its roots in medieval *hospitium*. What remains today in a health system carelessly over-mechanizing its practice within a society that turns its back on the truth of that fluid *charity* of religious orders that knew how to welcome, attend, assist, care for and treat exhausted pilgrims [35] who had undertaken journeys with genuine hardship of those who did not know whether they would be able to return home?

The rigorous search for intangible fundamentals to make them available to all involved, within a strict research framework will result in new knowledge that, made available to all, results in undisputed palliative conceptions and important new paradigms.

The real impact on the defense of life in the context of an announced death is indisputably revealed by the immediate practical applicability of the theories used. These are issues that arouse great interest in acquiring greater knowledge, apprehensible by those who develop their clinical activity in this field.

The Anglo-Saxon *Palliative Care*, known among Spanish speakers as “*Cuidados Paliativos*”, changes the perspective from which we see the process of dying and death itself contributing to facilitate vital fullness and that the sick or close individual achieves his or her potential as a person even in the midst of complex multidimensional needs.

Cicely Saunders’ original biography [36] relays how she established that one of its the modern Hospice movement underpinning values would be thinking and incorporating “Those who one day will come to join us” referring to professionals from diverse specialties, countries and bringing their own contribution to the field strengthening.

Undoubtedly the urgent demographic need means that many of us allow ourselves to call what is nothing more than a part of the original *Palliative Care*, a successor of Canadian origin of the previous “*Terminal Care*” [30, 32]. Contemporary *Palliative Care* has not made a full conceptual incorporation making, in my opinion, imperative the need to adjust foundational concepts.

International contemporary PC has not always made full conceptual incorporation, making it necessary the effort to adjust current impressions to the

foundational ethos of the discipline, maybe contributing to the serious contemporary problem of PC's lack of expansion in some places, even regressing in some countries unable to take roots in different cultures and new times. A phenomenon that could be contributing to a great confusion of what can be legitimately undertaken to facilitate the end of life.

The IAHP. Global Consensus based palliative care definition [6], found it necessary to incorporate a glossary to define a long list of terms, an indication of the difficulty to agree on them when used in different languages and settings.

An example of this situation has come to worry many during the current pandemic: While in the Anglosaxon countries it is said to have come of age and helped reinforce services and support colleagues and professionals, in other countries, their activity has been reduced.

The growing interest in the political and institutional sphere PC has fostered in the COVID -19 demands increasing determination in its organizational assistance and political levels. Might It be possible that the careful conceptual clarification of terms common in the palliative field eases their extension and promotion? [36].

The depth of PC ethos, wherever it might lay, should be preserved to some level. Its transformation into *Cuidados Paliativos* is work in progress since 1989 [37] and continues to attract interest to clarify evolving conceptions [38]. It has slowly started moving over the years from *Cuidados* to a broader and less physical *atención*, (attention), to be true to its authentic foundational philosophy and inherent principles, their safeguarding of which should reflect the spirit of the modern hospice movement as it was when St Christopher's Hospice first opened its doors. How it adapts and evolves is a central concern for many, characteristically uneasy about understanding how such ethos could be more widely established and how to prevent it from dissipation until lost, disappearing under the increasing technology laden healthcare services. It is worth getting to know the work undertaken by those for whom intangible aspects matter, precisely because they constitute the hospice movement founding heritage. A particular apprehension is that the "ethos" could be lost by spreading more widely if it is "marketed", while losing its well-founded and carefully established approach to convey its philosophy and principles.

Interestingly, it precisely the collaborative effort between PC and other hospital specialties which is contributing significantly to its interdisciplinary progression and consolidation. The support of classic specialties, which once questioned the specific object of Palliative Medicine, a different entity from PC, is key to its advancement and development.

It is worthy of consideration the fact that Palliative Medicine is the only medical specialty that

- a. Does not wrap its expertise around an organ, as Cardiology or Gastroenterology do; or group by age, as Geriatrics or Pediatrics do; or even an entity such as Infectious diseases or Virology.
- b. Has adjectivized its specialism to qualify the medical expertise offered.
- c. Is truly transverse across all other areas of expertise, from Neonatology to Neurosurgery passing through Organ Transplantation and Primary Care.

It is, therefore hardly surprising its practitioners need to explain what they do and who they are many times a day!

A recent piece work reviews some important milestones in PC's history and development from which Palliative Medicine spirals in many countries; analyses its evolution in the world, studying current issues concerning consistency in its implementation and some possible projections for future progress and expansion, seen from the perspective of a central issue:

“What exactly constitutes the ethos of PC faithfully replicating its philosophy and founding principles wherever it is applied or used?” The author concludes that coming to that knowledge would help facilitate possible future advances that integrate ethical, legal and social implications in years to come that truly benefit those with palliative needs.

PC delivery and benefits fall under the Philosophy Phenomenological arena while the conceptualization of the main terms on which research is centered around its practice, as the phenomenon investigated. Conceptual construction. Life to its end is a prodigy in progress. Images and s never seen before, thoughts never before thought, realities never dreamed of, constantly emerging, constantly reminding that individual universe that it has not yet reached the limits of its possibilities. The essence of PC could well be life that remains as such, as an evolving universe. Or perhaps the sick person’s journey to his deepest self than the professional is more of a witness than an escort.

To identify themes to be found in the English and Spanish literature a systematic search was conducted (**Table 1**).

From those, the summary, the most important ideas to consider include

Palliative Care comes to change the perspective from which we see the process of dying and death itself contributing to facilitate the vital fullness and that the sick or close individual achieves his potential as a person even in the midst of complex multidimensional needs.

Cicely Saunders, as included in her biography [2], spoke of the PC bases would include “Openness to those who will come” referring to professionals from diverse countries and cultures who, one day, would join the Modern Hospice Movement. They would bring new ways to alleviate and contribute their own culture, ways of doing and even different specialties and specific needs in the final phase of different diseases. Another base was to be the *Freedom of the Spirit*.

Wanting to know what constitutes the essence of PC is a complex task; our search shows the need to do an in-depth analysis of the terminology used and its conceptual adequacy.

A relevant finding was the fact that other concepts such as *essence*, might be used to make reference to what philosophy and ethos bring. “Essence” is a term of alchemy from Latin *essere* (to be), then arguably embodies “meaning”, “purpose”. From a metaphysical point of view, it could be considered as the possibility of filling the living space of the individual with information gained through experience.

MESH Terms	
	“Palliative” (and) “Care” (and) “Ethos”
32	Other non-randomized, quasi-experimental, descriptive (comparative, correlation), case-control, cohort studies
1	Reports or opinions from expert committees or the clinical experiences of respected authorities
1	Systematic reviews and meta-analysis. Controlled Randomized studies
8	Books and Book Chapters
9	Clinical guides, documents
2	Thesis

**Table 1.**  
*Palliative care ethos literature review.*



## 5. Conceptualization

To the scholar mind, a multi-faceted approach is prerequisite to adequately conceive PC from the conceptual, semantic and meaning, anthropological, philosophical and political angles without forgetting that of *actively caring for others'* wellbeing and assisting them. There could be different ways to unveil its intrinsic philosophy by seeking what imprints character to a movement which began well before Medicine itself was considered an entity, from the medieval hospitium [39] (pl hospitia) ἡν'σπιτιᾶ Greek: ξενία, xenia, προξενία and positions the scholar in front of is the ancient Greco-Roman concept of hospitality as a divine right of the guest and a divine duty of the host. An archaic place of shelter for travelers, especially one kept by a monastic order, that we are trying nowadays to adapt to a very different society with unmet needs.

The encounter with the ancient vocables that give name to this *caring* movement whets the scholar's appetite to learn more about the semantic and semiotic correspondence of the most commonly used words in PC in order to fully understand the impact of language and its own development in its evolution.

A straightforward methodology pathway leads us to study the roots of the discipline key words, analyzing their semantic transformation over time to witnessing their morphological evolution and conceptual spirit of each vocable. Grounded on a careful conceptual description of those words used in the palliative field could facilitate its extension and promotion which should benefit more people.

### 5.1 Language and conceptualization

Linguistics is a science which object of study is language. Its analysis places language in context, as it takes into consideration social, cultural, historical, and political factors influencing language.

Conceptualization consists of processes observing language production. It takes language-specific perspectives and event understanding.

Such process is still little understood by the experts [40] in the field. At the same time, we find ourselves at a point in the history of the Modern Hospice movement when it seems to be imperious to start a rigorous process around strong, concise and unambiguous definitions. This is due to the expansion of the discipline throughout the different countries with their cultures and languages which need to adapt to a new way of formalized compassion. Within PC, too many words are translated almost literally from the English language, resulting in numerous concepts with multiple scopes or dimensions, often inaccurate. This is confusing and makes it hard to transmit the science to others outside the field as they are incapable of conceiving its objective without further clarification. Existing PC definitions are being currently contested, probably because concepts are neither tangible nor concrete. Characterizations of our field based on abstract concepts make for confusion needing an effort to interpret conceptually by act or process of forming a general notion or idea.

Interest in this matter comes from personal experience of palliation in both the Anglo-Saxon and Iberian cultures and language and observing the inadequate adoption of terminology without the right notions behind. We defend the proposition that it is important to know what notions different authors might use to refer to PC and establish which of those most faithfully represent its most intimate nature.

There are interesting efforts to establish useful, replicable models. Some are orientated to [41] building digital domain ontologies, incredibly interesting and potentially game changing in niche areas used across the world. However, the model chosen to conceptualize is one by Flores Talavera G. [42] for reasons relating to its clarity, teaching dimension and the fact that she writes in Spanish.

Professor Talavera's process guides the investigator to initiate conceptualization by undertaking documentary research on the meaning of the key terms; including a review of the meanings and clarification of semantic confusions, looking at the appropriate dictionaries to contextualize it and learn about the possible conceptual evolution of the term. She then suggests consultation of Thesauruses in which the terms are described in the way they are used by scientists followed by accounting for the definitions of the term from a specific perspective. - In specialized dictionaries (Philosophy, Psychology, Sociology, and Physicians and Education) and conceptual essays, definitions located in sources to broaden the search horizon to find the "sense" of the term.

It is then possible to compare related terms using three processes: defining each one of them, establishing similarities and then establishing differences. This would then facilitate term characterization by establishing its most important characteristics, not of the word but of the complex reality that the term tries to elucidate.

To consider types and uses of the object (term) of study from its conceptual definition and expand the understanding of the meaning and reality intended to be explained, it is useful to identify the key ones.

## 5.2 Palliative care conceptualization

Conceptual purity of words used in the palliative field could facilitate its extension and promotion by examining its intrinsic philosophy understanding *what* it is that imprints character to a movement that began from the medieval hospitium and has foundational Judeo- Christian roots.

Applying the chosen methodology to the conceptualization and semantics of the original Palliative Care entails an interesting linguistic and geographical *iter* that could decisively contribute to the dissolution of the original *karos* philosophy observed in some situations. There should have been a process of content-rich implementation, in its place this is truncated by a less nuanced implementation marked by external and constant pressure to achieve tangible and quantitatively relevant results.

### 5.2.1 Representative terms and words used in international palliative care

The number of terms that could be analyzed in order to be conceptualized could might be thought to be huge. This is not the case as there are a handful of terms, key to impulse palliative programs (**Table 2**).

However, there is a number of them that deserve immediate attention as they are used, maybe even abused, too frequently. An appropriate conceptualization of these is urgent due to their weight in planning, policy – making and the delivery of excellent *Palliative Care*.

Although it is a very specialized subject and deserves a full piece of work with more specialist direction, we present a first attempt here.

To begin with, and following the first two process points from guideline, we can start from the top of the organizational and planification pyramid from which all policy flows to inform health and social care, there are two vocables that could be used better to achieve the sought-after results.

	Dates from	Meaning	Original language (s)	Contemporary use	Of note
Hospice noun <i>Hospitium</i>	late 17 <sup>th</sup> century.1818.	Rest house for travellers	French <i>hospice</i> "hospital, almshouse" Old French <i>ospice</i> "hospice, shelter, ", "hospitality," 13c. Latin 1. <i>hospitium</i> "hospitable reception, entertainment; hospitality, bonds of hospitality, relationship of guest and host 2. <i>hospes</i> (genitive <i>hospitis</i> ) "guest; host," also "a stranger, foreigner"	1879.Sense of "home for the aged and terminally ill " 1978is first attested as <i>hospice movement</i>	The term "Hospice" is strongly repudiated in Spanish- Palliative Care Unit is used instead Used in the Netherlands as <i>Hospitium</i> , places for those who don't want euthanasia and go there for protection.
Implement verb <i>implemere</i> noun <i>Implementum</i>	<i>Verb.</i> early 18th century. 1707 <i>Noun</i> , in late Middle English. First used circa 1707c. in Scottish English. Legal term meaning "fulfilment,"	<i>Verb:</i> 1.-To put (a decision, plan, agreement, etc.) into effect. 2.- To start using a plan or system 3.- To complete, perform, carry into effect," <i>Noun</i> Used to refer to different artifacts: furniture, gear, or dress'.	Late Latin: <i>implementum</i> ; <i>implere</i> : filling up Made of two Latin vocables In (towards the center) Plere (to fill up) (Greek polis, many) Partly from Medieval Latin <i>implementa</i> (plural Partl from late Latin <i>Implementum</i> 'filling up, fulfilment', both from Latin <i>implere</i> 'fill up' (later 'employ'), from in- 'in' + Latin <i>plere</i> 'fill'.		From it comes implementation, its use first recorded 1913.
Implant <i>verb</i> <i>Noun</i>	16 <sup>th</sup> Century 1540c 15 <sup>th</sup> Century	<i>Verb</i> I.Transitive 1a: to fix or set securely or deeply 1b: to set permanently in the consciousness or habit patterns: inculcate 2. to insert in living tissue II.Intransitive To undergo implantation <i>Noun</i>	Old French <i>Emplanter</i> French "to insert, engraft" Medieval Latin. <i>Implantus</i> In (towards the centre) Plant (see in, to plant, and observe)	<i>Noun</i> Modern use From 1886 Meaning "surgically implant (something) in the body", originally of teeth. which is attested by 1981 short for breast implants (1976). 1890, "thing implanted;"	If you implant an idea or attitude in people, you make it become accepted or believed.

		graft "to plant in" abstractly, of ideas, emotions, etc. "to plant", literally "plant in," from assimilated form of in- "into, in, on, upon". -		1941 as "action of implanting," from implant	
IMPLEMENT /IMPLANT	The difference between the notions conceived through these two verbs is very important. Implementing a Palliative Care Program speaks of "working at it" and "being part of the development". While implanting a Palliative Care Program talks about "having something new to deal with or to put up with". Something that needs to be taken into account by politicians, managers, et as it might mean the difference between people being engaged or not.				
PALLIATIVE ADJ. PALLIATIF PALLIATUS VERB NOUN PALLIATIVUS VERB LATIN PALLIARE	Early 15c., Dates from 1724. As a verb, used since 1779.	"serving to mitigate or alleviate" (a wound, illness, etc.); other meanings "cloak, cover, concealing;" from "under cloak, covert," from Latin <i>pallium</i> "a cloak" 'to cloak', 'to protect' 'to conceal,"	<i>Adj.</i> French <i>Palliatif</i> , Late Latin <i>Palliatus</i> "cloaked," from past participle of Late Latin <i>palliare</i> "cover with a cloak, conceal," <i>Noun.</i> Medieval Latin <i>palliativus</i> <i>Verb.</i> Medieval Latin <i>palliare</i>	"serving to extenuate by Excuses or favorable representation". "that which mitigates or extenuates,". Used by politicians and journalists to express strong actions or will.	
CARE Noun Verb	circa. 1400 Circa 1580. Circa 1520s- 1550s	a. the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something. (safe keeping, supervision, custody, charge, protection,keeping) b. serious attention or consideration applied to doing something correctly or to avoid damage or risk. (caution, carefulness, wariness,awareness, heedfulness,heed) D. Meaning "object or matter of	Old English <i>caru</i> , <i>cearu</i> "sorrow, anxiety, grief," also "burdens of mind; serious mental attention" Late Old English "concern, anxiety caused by apprehension of evil or the weight of many burdens," Proto-Germanic * <i>karō</i> "lament; grief, care" Source also of Old Saxon <i>kara</i> "sorrow;". The primary sense is that of inward grief, and the word is not connected, either in sense or form, with L. <i>cura</i> , care, of which	C."charge, oversight, attention or heed with a view to safety or protection" is attested from; The sense in <i>care of</i> in addressing (used from 1840).	Of all the different meanings of Care, only <i>Cuidados &amp; Cura are</i> used in Spanish. There is a reluctance to Attend, Assist, have regard for etc..



concern" is from  
 To take care of "take in hand, do";  
 take care "be careful" also is from  
 Negative sense  
 1. Old English  
 "To be anxious or solicitous;  
 grieve; feel concern or interest,  
 2. "Proto-Germanic "grief, care"  
 3. Old Saxon *karon*  
 "to lament, to care, to sorrow,  
 complain,"  
 4. Old High German "complain,  
 lament,"  
 4. Gothic *karon* "to be anxious"),  
 said to be from PIE root \*gar- "cry  
 out, call, scream" (source also of  
 Irish *gairm* "shout, cry, call;").  
 6. Latin "curar".  
 think, consider.  
 Positive sense  
 senses, such as "have an  
 inclination";  
 "have fondness for" seem to have  
 developed later as mirrors to the  
 earlier negative ones.  
 a. feel concern or interest; attach  
 importance to something. (be  
 concerned, worry (oneself)  
 trouble oneself, bother, mind)  
 b. look after and provide for the  
 needs of. (look after, take care of,  
 tend, attend to, mind, minister to

the primary sense is pains or  
 trouble bestowed upon something.  
 [Century Dictionary]  
 Old High German *chara* "wail,  
 lament;" Gothic *kara* "sorrow,  
 trouble, care".  
 1. Old English *carian, cearian*  
 2. "Proto-Germanic \*karo-  
 "lament,"  
 3. Old Saxon *karon*  
 4. Old High German *charon*  
 5. Gothic *karon* "to be anxious"  
 said to be from PIE root \*gar- "cry  
 out, call, scream" (source also of  
 Irish *gairm* "shout, cry, call;").  
 6. Latin *Cogitatus, cura*.  
 Co (combined, global) Agitare (to  
 get moving, agitate, think things  
 through)  
 Cogitare – to think with  
 movement. (To be moved to ...)

ATTEND	Late 14c.	a. "giving heed," "attention, attentiveness,"	Both <i>verb</i> and <i>noun</i> share origin from two Latin vocables	Very little in Spanish Palliative Care	Attention "Mental heeding" This finding is highly relevant as id
<i>Aspect of Care</i>	12c				
<i>Verb</i>	14c	b. "to direct one's mind or	a. Latin <i>attentionem</i> (nominative		

Attention <i>Aspect of Care</i> Noun		energies," "Mental heeding" "give heed to," literally "to stretch toward", "be subject to" (now obsolete), "direct one's mind or energies" (archaic), from (...)	<i>attentio</i> ) <i>ad</i> "to, toward" + <i>tendere</i> "stretch," b. Old French " <i>atendre</i> "	directed related to Cicely Saunders's " <i>Active listening</i> "
ASSIST <i>Aspect of Care</i> Verb	early 15c 14c	<i>assisten</i> 'take one's stand'. stand by, take a stand near, attend," to set, place, cause to stand," <i>assister</i> "to stand by, help, put, place, assist" to help someone, aid, collaborate, cooperate, benefit	Origen from two Latin vocables Ad- to; + iuvare – "to help" from <i>ad-</i> 'to, at' + <i>sistere</i> Late Middle English, from Old French Latin <i>assister</i> "	Related: Assisted; assisting gives way to Medical assisted suicide attested from 1884
INSIST <i>Aspect of Care</i>	1580s 14c.	"take a stand, stand on, stand still; follow, pursue; insist, press vigorously, urge, dwell upon," from in- "upon" "take a stand," from PIE *si-st- reduplicated form of root *sta- "to stand, make or be firm."	French <i>insister</i> Or directly from Latin <i>insistere</i> from root *en "in") + <i>sistere</i>	Interesting use of <i>insist</i> tends to happen when patient's symptoms or family anguish are present.
ASSISTANCE & ASSIST <i>Aspects of</i> <i>Care</i> Noun(s).	early 15c., 1570s	take one's stand by', 'take one's stand'. "act of helping or aiding; help given, aid," from the respective verbs "to help, aid, give assistance or support to in some undertaking or effort," "stand by, take a stand near, attend," To take a stand; to set, place, cause to stand"an act of assistance," from assist" stand still.	Late Middle English: from Old French <i>assister</i> , from Latin <i>assistere</i> 'from ad- 'to, at' + <i>sistere</i> from Old French <i>assistance</i> and Medieval Latin <i>assistentia</i> , Late Latin <i>adjuva</i> Latin <i>assistere</i> from assimilated form of <i>ad</i> "to" + <i>sistere</i>	

**Table 2.**  
*Palliative care terminology: vocables evolution through time and languages*

## I. Hospice

*Noun.*

Dates from late 17th century, 1818.

Meaning: 1. Greek: ξενία, xenia, προξενία.  
2. “rest house for travellers”

From: Greco-Roman concept of hospitality as a divine right of the guest and a divine duty of the host.

French *hospice* “hospital, almshouse”.

Old French *ospice* “hospice, shelter,” also “hospitality,” 13c.),

From Latin *hospitium* “hospitable reception, entertainment; hospitality, bonds of hospitality, relationship of guest and host.

From *hospes* (genitive *hospitis*) “guest; host,” also “a stranger, foreigner” and positions the scholar in front of is the ancient.

## II. Implement [43–46]

*Verb.* /'implɪmənt/

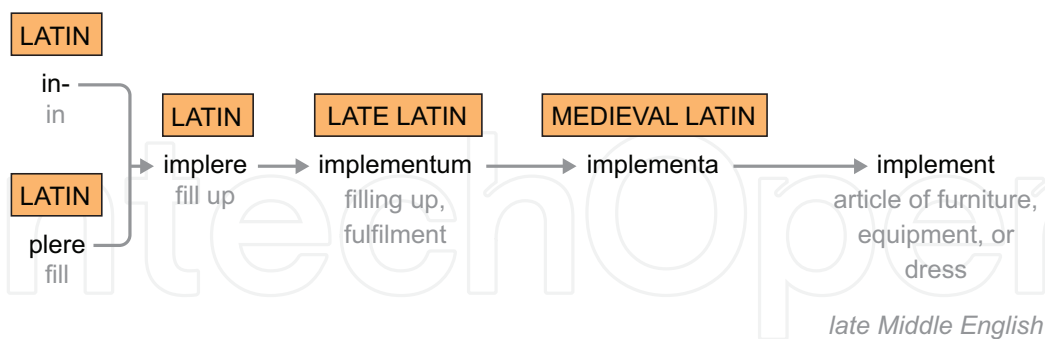
Dates from the early 18th century.

Meaning: 1. To put (a decision, plan, agreement, etc.) into effect.  
2. To start using a plan or system  
3. To complete, perform, carry into effect,” 1707

From Late Latin: *implementum*; *implere*: filling up.

Made of two Latin vocables

1. In (towards the center)
2. Plere (to fill up) (Greek polis, many)



*Noun.* /'implɪmənt/

Used in late Middle English to refer to different artifacts: furniture, gear, or dress'. Originates in part from the medieval Latin *implementa* (plural), in part from late Latin *implementum* ‘filling up, fulfilment’, both from Latin *implere* ‘fill up’ (later ‘employ’), from in- ‘in’ + Latin *plere* ‘fill’.

First used circa 1707 initially in Scottish English. As a noun it was a legal term meaning “fulfillment,” From it comes implementation, its use first recorded 1913.

## III. Implant [43–46]

*Verb.*

Dates from 1540, Old French.

## Meaning:

### I. Transitive verb

1a: to fix or set securely or deeply

1b: to set permanently in the consciousness or habit patterns: inculcate

2: to insert in living tissue

### II. Intransitive verb

To undergo implantation.

If you implant an idea or attitude in people, you make it become accepted or believed.

Medieval Latin.

In (towards the center).

Plant- see in, to plant, and observe.

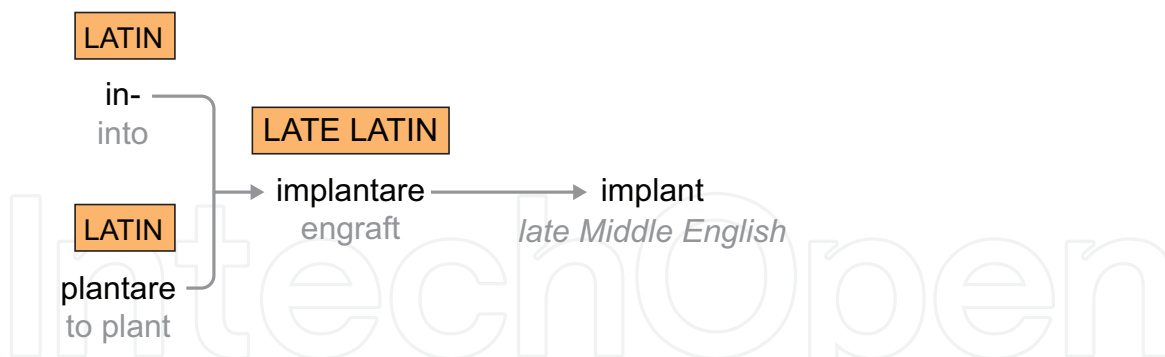
implant (v.)

1540s, “to plant in” (abstractly, of ideas, emotions, etc.), from French *implanter* “to insert, engraft” (alongside Old French *emplanter* “to plant”), literally “plant in,” from assimilated form of in- “into, in, on, upon” (from PIE root \*en “in”) + *planter* “to plant” (see *plant* (n.)). Meaning “surgically implant (something) in the body” is from 1886, originally of teeth. Implanted is attested earlier, from early 15c., probably based on Medieval Latin *implantus*. Related: *Implanting*.

*Noun.*

implant (n.)

1890, “thing implanted;” 1941 as “action of implanting,” from *implant* (v.). Related: *Implants*, which is attested by 1981 as short for breast implants (1976).



late Middle English: from late Latin *implantare* ‘engraft’, from Latin in- ‘into’ + *plantare* ‘to plant’. (Oxford Languages Definitions)

*implant* (v.) 1540s, “to plant in” (abstractly, of ideas, emotions, etc.), from French *implanter* “to insert, engraft” (alongside Old French *emplanter* “to plant”), literally “plant in,” from assimilated form of in- “into, in, on, upon”. (Online Etymology dictionary).

*Relevance:* The difference between the notions conceived through these two verbs is very important. Implementing a Palliative Care Program speaks of “working at it” and “being part of the development”. While implanting a Palliative Care Program talks about “having something new to deal with or to put up with” Something that needs to be taken into account by politicians, managers, et as it might mean the difference between people being engaged or not.



## IV. Palliative Care

The term “Cuidados Paliativos” (Spanish/Portuguese) seem not to have incorporated the richness of meaning *Palliative Care* has afforded those who request, practice and receive it in the Anglo-Saxon context.

### IV.a. Palliative

As a concept, in my experience, requires much explanation to those who encounter it for the first time, both as a patient or carer and as professionals. Explaining its meaning and aims to the general public can be very challenging indeed, although it must be said it has brought about really creative ways of explaining it in a practical way.

It is said that its use in English has seen a significant increase in the last 200 years due to the development of *Palliative Care*. Its Spanish translation is often used in politics such as in “we are going to remedy such a situation without palliatives”, as a plural, indicating with harshness.

#### IV. Palliative [43–46]

*Adj.*

Early 15c., french Palliatif, “serving to mitigate or alleviate” (a wound, illness, etc.); other meanings “cloak, cover, concealing;” from.

From Late Latin *Palliatus* “cloaked,” from past participle of Late Latin *palliare* “cover with a cloak, conceal,”

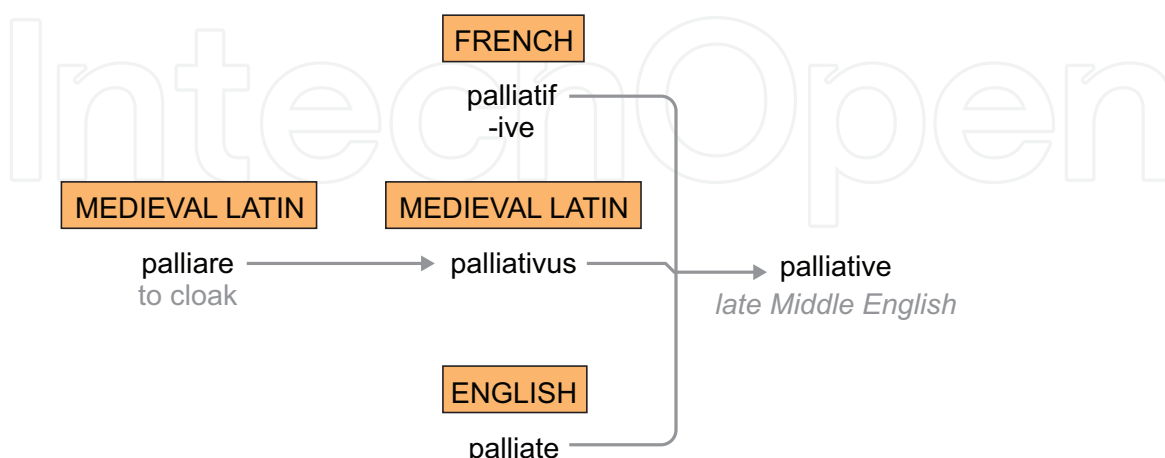
*Noun.* Medieval Latin *palliatus* “under cloak, covert,” from Latin *pallium* “a cloak” (see pall (n.)).

Dates from 1724.

Meaning “serving to extenuate by excuses or favorable representation”. “that which mitigates or extenuates,”

*Verb.*

1779c. from the verb *palliare* ‘to cloak’, ‘to protect’. (Online Etymology Dictionary)



late Middle English (as an adjective) from French *palliatif*, –ive or medieval Latin *palliatus*, from the verb *palliare* ‘to cloak’.

#### IV.b. Care [43–46]

The Spanish and Portuguese vocables “Cuidar” and “Cuidados” fall short of representing its multiple meanings within this context. The question to try

to answer is: could this happen because it ignores certain conceptual aspects such as those of “that I care about the other”, “care”, “pay attention”, “assist”, “give assistance to”, “medically treat.” beyond “hacer curas” (wound and dressing management) and “curar” (cure in English) that has been reduced to in the Spanish language (while trying to offer its whole range of attentions)?

#### 1. Noun

##### Origen

Old English *caru*, *cearu* “sorrow, anxiety, grief,” also “burdens of mind; serious mental attention”.

Late Old English “concern, anxiety caused by apprehension of evil or the weight of many burdens,”

Proto-Germanic *\*karō* “lament; grief, care” (source also of Old Saxon *kara* “sorrow;”. The primary sense is that of inward grief, and the word is not connected, either in sense or form, with L. *cura*, care, of which the primary sense is pains or trouble bestowed upon something. [Century Dictionary].

Old High German *chara* “wail, lament;” Gothic *kara* “sorrow, trouble, care”.

Dates from c. 1400

##### Meanings.

- a. the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something. (safe keeping, supervision, custody, charge, protection, keeping)
- b. serious attention or consideration applied to doing something correctly or to avoid damage or risk. (caution, carefulness, wariness, awareness, heedfulness, heed)
- c. “charge, oversight, attention or heed with a view to safety or protection” is attested from;

The sense in *care of* in addressing (1840).

- d. Meaning “object or matter of concern” is from 1580.

To take care of “take in hand, do” is from 1580s; take care “be careful” also is from 1580s.

#### 2. Verb

##### Dates from

- a. Old English *carian*, *cearian*.

##### Meanings

- a. “be anxious or solicitous; grieve; feel concern or interest,
- b. “from Proto-Germanic *\*karo-* “lament,“ hence “grief, care”.

Source also of Old Saxon *karon*.

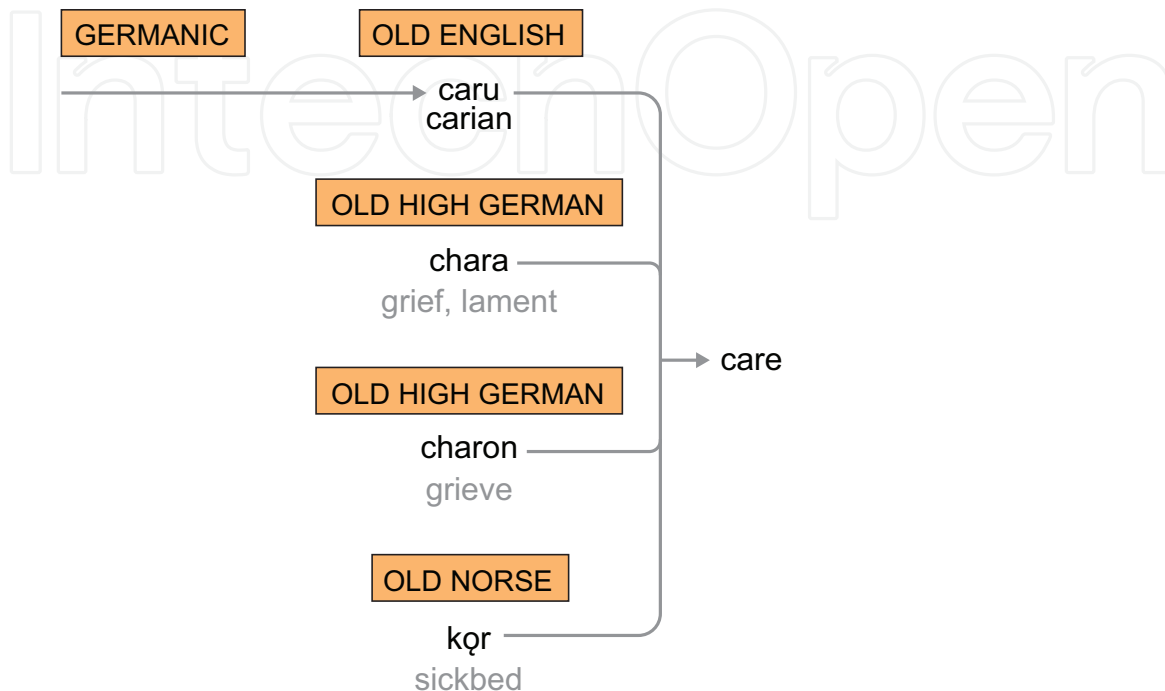
“to lament, to care, to sorrow, complain,” Old High German *charon* “complain, lament,”

Gothic *karon* “to be anxious”), said to be from PIE root *\*gar-* “cry out, call, scream” (source also of Irish *gairm* “shout, cry, call;”).

If so, the prehistoric sense development is from “cry” to “lamentation” to “grief.” A different sense evolution is represented in related Dutch *karig*

“scanty, frugal,” German *karg* “stingy, scanty.” It is not considered to be related to Latin *cura*. Positive senses, such as “have an inclination” (1550s); “have fondness for” (1520s) seem to have developed later as mirrors to the earlier negative ones.

- a. feel concern or interest; attach importance to something. (be concerned, worry (oneself), trouble oneself, bother, mind).
- b. look after and provide for the needs of. (look after, take care of, tend, attend to, mind, minister to).



Old English *caru* (noun), *carian* (verb), of Germanic origin; related to Old High German *chara* ‘grief, lament’, *charon* ‘grieve’, and Old Norse *kǫr* ‘sickbed’.

Proto-germanic. *Karo*. “Lament, grief, Care”.

Old Saxon. *Chara*; wail, lament.

Old high German. *Charon* To wail.

Old English. *Carucearu*. “Sorrow, anxiety, grief”.

Old English. *Carian, cearian*. “Be anxious, to grief, to feel concern”.

“CARE”.

To find the Spanish *Cuidados* translation, we need to look further and find how *care* has other interesting close relations that help work with a more active manner of manifesting one’s need of being attended to.

Cogitatus (Latin)

Origin & history

Perfect passive participle of *cōgitō* (“think, consider”).

Participle

*cōgitātus* (*masc.*) (*fem.* *Cōgitāta*, *neut.* *cōgitātum*)

1. thought, having been thought.
2. considered, having been pondered.

Descendants

- Asturian: *cuidáu*
- Galician: *coidado*

- Portuguese: *cuidado*
- Spanish: *cuidado*

Latin: cogitatus

Co (combined, global) Agitare (to get moving, agitate, think things through)

Cogitare – to think with movement.

The same studies could be undertaken for all of *Care* meanings and “close friends”.

#### IV.b1 To Attend to [43–46]

##### 1. *Verb*

Dates from.

- a. Late 14c.

Originates from

- a. Latin *attentionem* (nominative *attentio*).
- b. Old French “*atendre*” (12c.)

Meaning

- a. “giving heed,” “attention, attentiveness,” 1300,
- b. “to direct one’s mind or energies,”

#### IV.b2 Attention

ad “to, towards” (see ad-) + *tendere* “stretch,”

*Noun*

*Ad* (to).

*Tendere* (stretch) one’s mind to.

Dates from early 14c, 1300.

Originates from

Old French *atendre* “to expect, wait for, pay attention” (12c., Modern French *attendre*) and directly from Latin.

Meaning

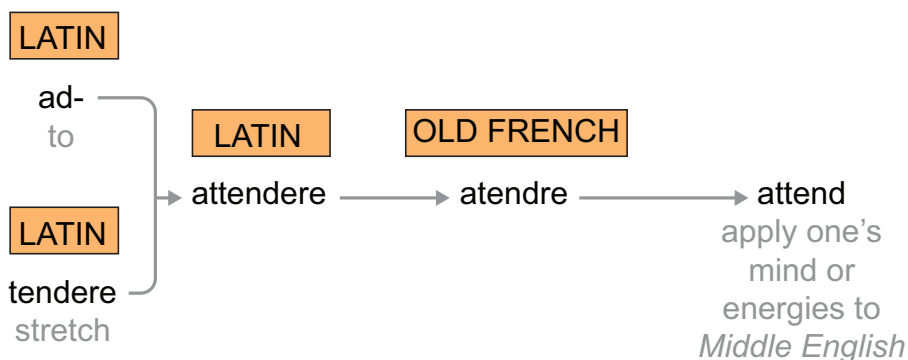
–Attention “Mental heeding”.

Note.

This finding is highly relevant as it is directly related to Cicely Saunders’s “*Active listening*”.

“give heed to,” literally “to stretch toward”, “be subject to” (now obsolete), “direct one’s mind or energies” (archaic), from (...).

(Online Etymology Dictionary)





Middle English (in the sense ‘apply one’s mind or energies to’): from Old French *atendre*, from Latin *attendere*, from *ad-* ‘to’ + *tendere* ‘stretch’.

#### **IV.b3 To Assist** [43–46]

*Verb.* *Ad-* to; + *iuvere* – “to help” from *ad-* ‘to, at’ + *sistere* ‘take one’s stand’.  
Late Middle English, from.

Old French Latin *assister* “stand by, take a stand near, attend,”  
from assimilated form of *ad* “to” (see *ad-*) + *sistere* “stand still, take a stand; to set, place, cause to stand,”

from PIE *\*si-st-*, reduplicated form of root *\*sta-* “to stand, make or be firm.”  
Latin *assister* Take one’s stand by”.

Originates

1. early 15c., *assisten*, “to help, aid, give assistance or support to in some undertaking or effort,”
2. 14c old French *assister* “to stand by, help, put, place, assist”

Dates

to help someone, aid, collaborate, cooperate, benefit.

#### **IV.b4 To Insist**

Dates 1580s,

Originates

French *insister* (14c.)

Or

directly from Latin *insistere*.

“take a stand, stand on, stand still; follow, pursue; insist, press vigorously, urge, dwell upon,” from *in-* “upon”.

(from PIE root *\*en* “in”) + *sistere* “take a stand,” from PIE *\*si-st-*, reduplicated form of root *\*sta-* “to stand, make or be firm.”

*assist* (v.) Related: *Assisted*; *assisting*. Medical assisted suicide attested from 1884.

#### **IV.b5 Assistance**

late Middle English: from Old French *assister*, from Latin *assistere* ‘take one’s stand by’, from *ad-* ‘to, at’ + *sistere* ‘take one’s stand’.

*Noun.*

“act of helping or aiding; help given, aid,” from the respective verbs.

Dates

early 15c.,

Originates from

from Old French *assistance* and Medieval Latin *assistentia*, Late latin *adjuva*

Meaning

“to help, aid, give assistance or support to in some undertaking or effort,”

Originates

Latin *assistere*

“stand by, take a stand near, attend,”

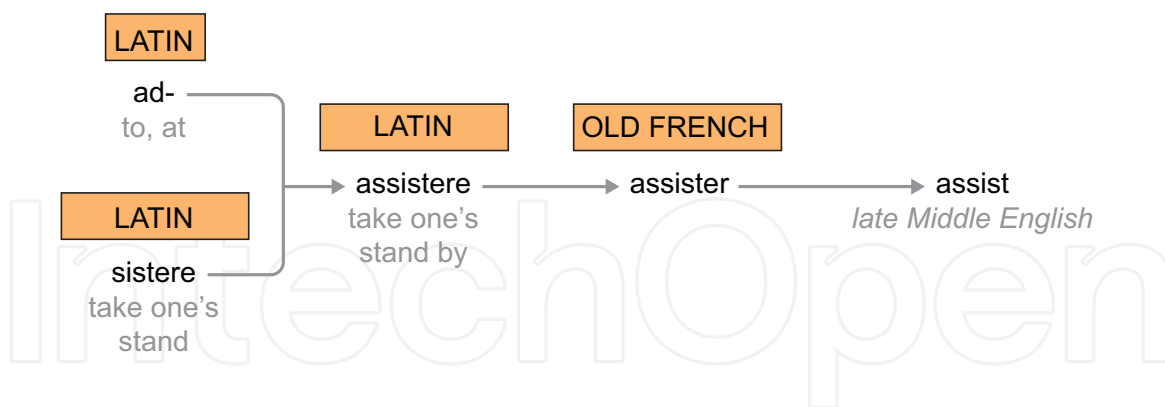
from assimilated form of *ad* “to” (see *ad-*) + *sistere* “stand still,

Meaning

To take a stand; to set, place, cause to stand,

“from PIE *\*si-st-*, reduplicated form of root *\*sta-* “to stand, make or be firm.”

Related: Assisted; assisting. Medical assisted suicide attested from 1884. assist (n.) 1570s, “an act of assistance,” from assist.



late Middle English: from Old French *assister*, from Latin *assistere* ‘take one’s stand by’, from *ad-* ‘to, at’ + *sistere* ‘take one’s stand’.

## 6. Conclusion

*Can you say something to comfort me?* The Polish man Cicely Saunders considered to have been the *Palliative Care* patient to set the bases for the Modern Hospice Movement, asked her. A beautiful research question which proves incredibly difficult to give an answer to in a timely, honest and personalized way [46, 47]. A question that demands words constructed and delivered in a soothing, comforting manner. A question that leaves out action, doing to, as we often want to do: administering medication, offering therapeutic and surgical options less sought than human verbal interaction.

Language in its different forms is very important to transmit knowledge, affection, security ... and so much more too. PC uses not only spoken and written language but also body language. Language requires the support of concepts known, accepted and used by most. We conclude that too often those notions are not crystal clear and can provoke rejection, fear, isolation, doubt and increase the very suffering they should help alleviate.

Standing for and advocating for the promoting and contributing to the expansion and of Palliative Care [48], clear messages are important to avoid creating confusion. These messages should state truths such as “Palliative Care facilitates the process of dying without interfering with its natural course beyond the legitimate and ethical limits”. It’s a complex phenomenon that recognizes the intrinsic reality of professional work while touching on the most humane and compassionate principles of the art of palliating.

Today there is no doubt that the expansion and scope of Palliative Care is neither the desired nor the necessary [49]. In this the agreement is widespread. Where there is no agreement is in why this situation and therefore how to overcome it.

To appreciate and love something, it is necessary to know it. The better we know it, the easier it becomes to enjoy its bounties. The less we know it, the longer it will take us to accept it while finding what is needed to accept its place in our lives.

How much more difficult it is to accept something new when our life is threatened by a medical condition and we feel forced to face our own mortality. This is the reality found by professionals who try to introduce *Palliative* or *Supportive Care* to reinforce the person’s own strengths, both natural and acquired.

It is at that point that the professional needs to give the sick and their family a master class on what they do, what they offer, where and when. Were they going to

be seen by the cardiologist, the question might be “is that for the heart?” The number of questions that come up before accepting *Palliative* or *Supportive Care* are many more and are related to many different facets and it takes time to address each one of them appropriately. It has been the linguistic, semantic and its meaning and their impact on the patient’s outcome that has fascinated me after many years working in the field and observing the change in the often the angry, frightened and frustrate people I meet when responding to a colleague’s call for help and the relaxed, understanding, grateful and collaborative demeanor in the, by then patient under our care, we leave behind. Often part of our goodbye includes the question “will we see you again?” We have managed to establish a connection with the patient by spending time with them and their family and by talking to them about our role in their situation.

At a time when reassurance, otherness and presence can communicate so much, the power of language is immense in relationships that are short at the same time as they are intense.

Our work confirms the power of words and the importance of exerting the *Active Listening* key in the holistic care promoted by Cicely Sanders to alleviate Total Pain [7]. It pioneers in the recognition of scientific linguistics as fundamental to improve delivery of Palliative Care improving quality of translation to new languages. This will need promoting due care is taken by working towards methodologically scientific ways of conceptualization in language production with language-specific perspectives and event construal for different cultures who communicate in different languages.

An exciting topic to research, *Palliative Care Linguistics* will need further work in the future because, just as Cicely Saunders said about *pain* “There is so much to learn about explaining palliative concepts and the models of care!”

This chapter invites the reader to recognize the relationship between the expansion of PC and the appropriate conceptualization of the ideas, terminology and words used by those working in what constitutes its “deepest core”, where its true significance is.

## **Additional information**

Figures in this chapter are adapted from Oxford Languages Definitions & Online Etymology Dictionary.

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