



The Role of the Physician in the Community in Running the Palliative Care Interdisciplinary Team: “Thinking out Loud”

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Introduction and Definitions

There are no miracles, no exceptions to the laws of nature. – (Stephen Hawking: *The Grand Design*, 2010)

“Your illness is no longer susceptible to specific and effective treatments. I’m sorry, but there is nothing more we can do”: this was, and perhaps still is, the phrase commonly communicated to patients and their families to state that their illness was incurable. At this point, the patient had no hope for assistance nor the possibility of receiving any hospital or home treatment. It was precisely this phrase, repeated dryly and with glacial detachment, that stimulated the birth of “palliative care,” because when there is nothing more to do, there is still much to do. Palliative care (hereafter indicated as PC) was created to fill the care gap between the active therapeutic phase

of poor-prognosis diseases and the patient’s death, guaranteeing the active care and global assistance in the terminal phase of incurable diseases. The definition formulated by Law 38 of March 15, 2010 [1], says that PC is “the set of therapeutic, diagnostic and care interventions, aimed at both the sick person and his family, with the goal of active and total care of patients whose underlying unresponding disease is characterized by an unstoppable evolution and a poor prognosis” (Article 2, Paragraph 1a). The World Health Organization frames PC as “an approach that improves the quality of life of patients and their families who face the problems associated with incurable diseases, with the prevention and relief of suffering through early identification and by optimal pain treatment of physical, psychophysical and spiritual problems.” Among the most recent definitions is the one presented in 2018 by the International Association for Hospice and Palliative Care (IAHPC): “Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those nearing the end of life. It aims to improve the quality of life of patients, their families and their caregivers.” In the common Italian language, the term “palliative” is usually associated with the low value and uselessness of any intervention or even with the

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concept of deception and illusion, but in the Anglo-Saxon countries and in the international medical field, the term “palliative care” finds its meaning in the Latin verbum “pallium” which indicates a cloak or blanket, i.e., an object of total protection, which wraps and consoles those who suffer. According to this meaning, therefore, PC is a health and care approach that treats the patients for all of their conditions, to alleviate suffering and to meet their needs with the aim of improving their quality of life, even when it continually decreases both in quantitative terms and in terms of function. The palliative approach is global and considers the sick person as a whole, with all the physical, psychological, and spiritual components as well as with the family and social dimensions; therefore, it addresses the patient’s family members as well as the caregivers as recipients of help, support, and assistance.

Legislative Procedures

Legum servi sumus ut liberi esse possimus. – (We are slaves to the laws to be free – M. T. Cicero, Rome)

Just in the last 20 years, since 1999, many regulatory directives in this area have been issued in Italy. But, as it often happens, PC was established in some Italian regions before the laws that regulated it, thanks to the free initiative of doctors, other voluntary professionals, and citizens who, sensitive to the discomfort of patients and families affected by oncological diseases, pioneered various forms of voluntary home care aimed at treating the associated symptoms of end-stage patients. The first legislative act that recognized a citizen’s right to PC was the Law 39 of February 26, 1999 [2], but it was necessary to wait for the publication of the Ministerial Decree implemented on September 28, 1999 [3], to see the birth of the “National Program for the Construction of Structures for Palliative Care.” In this decree there was already the far-sighted and still current concept of a NETWORK of assistance for terminal patients, consisting of “a functional and integrated aggregation of districts and

hospitals, health and social services, which work in synergy with the network of social solidarity present in the territorial context, respecting the clinical-assistance autonomy of the respective components” (see Annex 1 of the Ministerial Decree of September 28, 1999). The original vision of a local network offered a variety of components, with the aim of ensuring diversified care interventions for the different health and living conditions of the patients. The forms of PC proposed in this document were (1) outpatient care, (2) integrated home care, (3) specialist home care, (4) hospitalization in the ordinary regime or day hospital, (5) residential care in residential palliative care centers, and (6) consultations and palliative assistance in hospital wards for acute care. The local network model aimed to create a convergence of forces and skills not only for health but also for social and welfare purposes and therefore tended to involve local authorities as being primarily responsible for integrating between different subjects and the so-called third sector, i.e., voluntary and private non-profit organizations. Shortly before, in 1998, it was the National Health Plan (PSN) for the 3-year period of 1998–2000 [4] courageously subtitled “A Solidarity Pact for Health” that urged the bodies of the National Health Service to provide the necessary attention to all patients suffering from end-stage pathologies, identified as weak subjects and therefore deserving of a specific and appropriate form of assistance. This population was considered to be bearers of complex and peculiar needs and the PSN established a “Solidarity Pact” in which the strengthening of assistance at various levels, including home care and psychosocial support to the patient and the family, was guaranteed. Starting from the aforementioned plan, all subsequent documents of equal value have reserved a space for palliative care in accordance with the citizen’s right to access them and have implemented the organizational care model throughout the nation. Each National Health Plan, which is the main health planning tool, gives a direction to the regions and healthcare companies indicating the general rules, the objectives to be achieved, and the

actions and strategies for their realization. It is not necessary to remember them all, but one may just refer to the PSN 2011/2013 [5], which dedicates an entire section to palliative care and pain therapy (page 117, B 10) and finances a series of objective projects which gives impetus and concreteness to the enhancement of home palliative care and the creation of hospices. It would become pedantic and tedious to examine all the rules that have been enacted in this period of time by the Italian government and other state or regional bodies with legislative functions, but it certainly deserves to be mentioned once again, as a milestone, the Law 38 of March 15, 2010, "Provisions to ensure access to palliative care and pain therapy" [1], which established the citizen's right to receive appropriate care and assistance during the end-of-life path and incorporated PC among the competencies of the doctors, health structures, and the National Health Service.

Among the most recent decisive legislative steps taken is the Decree of the President of the Council of Ministers (Prime Ministerial Decree) of January 12, 2017, "Definition and updating of the essential assistance levels (LEA)" [6], which includes both palliative home care and residential care in hospices among the services that the NHS guarantees and ensures for people in the terminal phase of life affected by progressive and advanced diseases, with rapid evolution and poor prognosis. An important institutional body that has guided the birth and development of palliative care in Italy is the State-Regions Conference, which translated the directives of the government and Parliament into agreements and understandings concretely achievable at the local level by all the regions and the autonomous provinces [7–9]. In order to carry out a constant, careful monitoring system for the start and development of palliative care throughout the national territory, a Technical Health Committee was created, composed of experts in palliative care (including nine doctors and one psychologist), found among the most successful professionals in the sector, and four representatives from the Ministry of Health, who work in close synergy with the General

Directorate of Health Planning of the ministry itself. Among other obligations, the Ministry of Health had the task of periodically proceeding with the drafting of the Report to Parliament on the State of Implementation of Law 38 of March 15, 2010, "Provisions to guarantee access to palliative care and pain therapy." The last of these reports, relating to the 3-year period of 2015–2017 [10], shows the level reached by the organizational and welfare path of PC services in Italy, along with the numerical data relating to the structures built and the services provided, the critical issues that still slow down the flow, and the goals and the results that followed. From this report to Parliament, it can be seen how each Italian region, from Sicily [11] to Lombardy [12], already had its own decrees and specific programs implemented before 2017, which, on the one hand, favors the creation of local networks and the provision of services and, on the other hand, explains the presence of significant differences and uneven levels of assistance between the various national territories, precisely in relation to administrative decentralization and local autonomy.

Professional Roles

Lieve è l'oprar se in molti è condiviso. – (Light is the task where many share the toil – Omero)

Over the years, greater attention has been paid to the needs of the sick person and to analyzing the demands, explicit or implicit, of families and society to find the most suitable skills and conditions available in order to meet expectations. Professionals responded to this need with the goal of better defining the requirements and experimental paths required to bridge the gap of specialization in palliative care. In Italy, still no learning institution for acquiring a specialization in palliative care for doctors and other health professions has been established; therefore, in order to make up for this educational gap, there are now several post-graduate master's degrees that graduates in the various healthcare disciplines

can access offering varied and specific courses for each profession.

1. As part of PC, the medical physician certainly represents the primary and indispensable figure for identifying patients' needs with relation to the state of their health and the stage of the disease; the physician defines a therapeutic plan for the multiple and complex symptoms and guides the team in disease trajectory. With the current regulations, the palliative care operative units (i.e., teams operating at home or in hospice) must be directed by a physician with documented experience and training in PC, recognized by the region of origin or with specialization in related branches such as oncology, anesthesia and resuscitation, internal medicine, hematology, geriatrics, infectious diseases, neurology, pediatrics, or radiotherapy. The PC physician and the general practitioner, who already know the patient and his/her needs, can take on the role of case managers and can monitor the health of the patient.
2. Equally important is the professional nurse, who keeps in close contact with the patient, administers the treatments, observes the patient's physical and mental state, detects the compliance and effectiveness of the treatments, evaluates any changes or the emergence of new needs, and reports findings to the other members of the team. Specific expertise in PC is required for the nurse as well as for the physician and for the other healthcare professionals on the team.
3. Psychological aspects are considered fundamental in PC to support the patient and the family during the path of illness and the difficulties that arise when caring for the sick person. A psychologist can connect between patients and healthcare providers and can facilitate communication between the family and the PC team. In addition to a specialization in psychotherapy, the psychologist must have the skills necessary to evaluate and manage the team supervisor and the teamwork of the healthcare providers to prevent the occurrence of "burn-out."
4. The social worker must work with the team to analyze the patient's personal and family history, the socio-cultural framework, and the possible presence of minors or fragile family members. The social worker must be able to offer suitable solutions to social and welfare needs, to provide information to the social welfare institute, and to carry out networking and community work.
5. The primary task of the social healthcare worker (O.S.S.) is to respond to the physical needs of the patient. The O.S.S. must possess critical thinking skills, clinical analysis, and judgment and attend and listen to emotional, psychosocial, and spiritual needs to empathize with those who suffer and to be able to communicate in a team.
6. A physiotherapist evaluates the patient's ability to recover autonomy, or at least partial autonomy, in order to carry out daily life activities and must know how to plan a physiotherapy program. The physiotherapist plans activities that help to achieve maximum possible autonomy and mobility and to modify and adapt the objectives of physiotherapy to the patient's conditions with regard to the evolution of the disease.
7. The dietician is an important part of the team; however, he/she is not always present or sufficiently valued; the dietician must collaborate with the team when evaluating the nutritional needs of the patient, providing specific indications regarding the nutritional status and food support appropriate for the state of illness and the patient's condition and educating family members in providing the appropriate nutrition for the patient.
8. The spiritual advisor's function and importance in PC are better described in the following paragraph dedicated precisely to spirituality in the context of culture and well-being.
9. The requirements of the various professionals and their respective competences have been identified and defined in the State-Regions Agreement of July 10, 2014 [9].

Home Settings

The most beautiful thing about a trip is the return home. – (Fausto Brizzi: Cento Giorni di Felicità – 100'one hundred Days of Happiness, 2013)

PC is best provided at home, which allows the patient and his/her family to maintain familiarity and the emotional relationships with people, animals, or objects surrounding them while avoiding long hospitalizations with all the inconveniences that may derive from them.

The DPCM Decree on Minimum Health Assistance (Prime Ministerial Decree of January 12, 2017: Definition and updating of essential levels of assistance – Art. 23 [6]) places palliative home care among the health services guaranteed by the Italian state and specifies that they must be comprised of various professional services including medical, nursing, rehabilitation, and psychological care from diagnostic testing to the supply of drugs and medical devices to preparations for artificial nutrition, when necessary.

The National Health Service wanted to establish a single system of PC home care for the entire national territory, but it has, in fact, differentiated from region to region and sometimes even among different areas within the same region. The various agreements reached by the permanent State-Regions Conference have accelerated the development of greater uniformity, but a satisfactory result which would guarantee every citizen the same level of assistance and the same type of services has not yet been reached.

Home PC is normally provided by a multi-professional team, consisting of a palliative doctor, professional nurse, psychologist, social-health worker, physiotherapist, social worker, and general practitioner. The team is not always used in the same way in each region of Italy or in each individual case. This is due both to the different models adopted by the regions themselves and to the specific conditions and welfare needs that each individual case presents. Some healthcare institutions have an internal palliative care unit able to offer assistance at the patient's home, but,

in the majority of cases, the service is entrusted to external accredited bodies which work with their own staff sometimes arising from volunteers driven by a deep sense of solidarity with the patients and their families.

Theoretically, according to the scientific and legislative directives, home care presupposes the global management of the patient and family in which the individual services of each operator are not considered, nor is the sum of the visits to the patient's home; however, there is a unified and interactive vision promoted between all of the healthcare providers on the one hand and the patient and family on the other, to provide a complete approach to the needs of the sick person as well as appropriate responses to the needs of the entire family. The patient as a person is seen as a whole entity with many components – physical, psychological, social, spiritual, etc.

The DPCM Decree on Minimum Health Assistance provides only two levels of care with regard to the patient's status: a level of basic assistance and a level of specialized assistance; the first is coordinated by the general practitioner or "free choice pediatrician" and presupposes a partial commitment on the part of the competent team, while the second is totally entrusted to the multi-professional palliative care team and requires highly skilled and complex interdisciplinary working methods.

In 2017 throughout Italy, the number of patients treated at home reached 40,849, an increase of 32.19% compared with the total number of patients treated in 2014; at the same time there was an increase in the total number of days palliative care assistance was provided at the home, which reached 326,000. Although this increase appears to be significant, the number of days of palliative care provided at home was far lower than the standard identified by Ministerial Decree 43 of 2007, Indicator 4, which was calculated taking into account that 45% of the deaths were from cancer (representing the average number of patients in home PC) multiplied by 55 days (representing the average duration of home palliative care) [13].

Hospice

*...and this hedge, which, from so many parts
of the last horizon, the sight excludes.
But sitting and gazing, endless
spaces beyond it, and superhuman
silences, and the deepest quiet,
I fake myself in my thoughts; – (G. Leopardi:
“L’Infinito,” 1819)*

A hospice is a social-health reception structure in which patients are welcomed, cared for, and recognized as a person entitled to all needs and rights; it is not the place where the patient goes to die, but the place where he or she can carry out end of life with dignity. In Italian legislation, further recognition of the hospice and its characteristics came from the aforementioned Prime Ministerial Decree of January 12, 2017, “Definition and updating of essential levels of assistance” (DPCM) [6], which states:

“Art. 31. Residential social and health care for people in the terminal phase of life”

1. The National Health Service within a palliative care local network guarantees people in the terminal phase of life – affected by progressive and advanced diseases with rapid evolution and poor prognosis – the integrated variety of services through the use of methods and tools based on the most advanced scientific specialized medicine, nursing, rehabilitation assistance, diagnostic testing, and psychological and pharmaceutical assistance along with the supply of preparations for artificial nutrition, social, tutelary services, and spiritual support. The services are provided by multidisciplinary and multi-professional teams in the specialized centers of palliative care hospices which, even when operating within a hospital, remain within the context of territorial social-health care. Hospices ensure medical and nursing assistance and the presence of technical assistance operators 7 days a week, 24 hours a day, and have formalized protocols for the control of pain and symptoms, sedation, nutrition, and hydration as well as formalized programs for information, communication, and support for the patient

and the family, death and bereavement assistance, clinical auditing, and psycho-emotional support for the team.

2. The treatments referred to in Section 1, above, are the total responsibility of the National Health Service.

A hospice is not only a healthcare residence that provides the necessary medical care but also a place where the patient can spend his/her end of life with a familiar domestic and family model and, if possible, while maintaining residual autonomy, surrounded by people who support the patient in the best possible conditions allowed by the patient’s state of health.

Generally, it is preferable for the hospice to be located in an extra-hospital structure, but even if it is intra-hospital, the hospice maintains a welcoming and familiar atmosphere with common spaces available to patients and carers and single rooms with an attached bathroom, where patients are hospitalized and where a family member or caregiver can stay. Each room is equipped to provide healthcare, but it is also equipped with private home-style furnishings, where dignified conditions are offered for the continual care of the patient and the companion.

Often hospices have a small number of beds (8–20) and are open to family members and volunteers who collaborate with the multidisciplinary team to improve the quality of life of patients. Some hospices have kitchen facilities or herbal tea available to everyone, while others have a kitchenette inside each room; in each case the aim is to create opportunities for all hospitalized patients to feel free to prepare a meal or refreshments as if they were at home. It is helpful to have an outdoor space or a garden available, where guests can relax and take pleasant walks.

The number of beds required in hospices in Italy was calculated based on the standard set by Ministerial Decree 43/2007 (1 bed for every 56 cancer patients) [13] and, at the end of 2017, there were 2777 posts with a shortage of just 244, or 8% of the total expected. It was recorded that the Italian regions of Lombardy and Lazio had the highest number of hospices and available

beds, while Piedmont, Calabria, Campania, and Sicily had the most significant shortage.

While patients in hospices are mainly cancer patients, in 2017 the ratio between the number of patients who died in hospice following a diagnosis of malignancy (ICD-9 CM 140-208 codes) and the total deaths from malignancy stood at approximately 13%. There were significant inequalities between the northern and southern regions due to both the difference in the number of beds available and the socio-economic and cultural differences between the two areas. On the other hand, if we consider the total number of deaths from all causes, we find that the number of deaths in hospice was about 7% in 2017.

Reassuring data was found regarding waiting times for admission to hospices in all regions: most admissions took place within 2 days from the request, while a low number of admissions took place between 4 and 7 days from the time of the request.

Considering that the number of non-oncological patients admitted to hospice is constantly growing, the prospect of a gradual but significant increase in non-oncological pathologies requires multi-professional teams to have an equally significant update of the assessment tools, therapeutic techniques, and communication styles necessary for global management and appropriate living conditions for the changing needs and numerous variables of new patients.

Pediatric PC

Three passions, simple but overwhelmingly strong, have governed my life: the longing for love, the search for knowledge, and unbearable pity for the suffering of mankind. – (Bertrand Russell: The Autobiography of Bertrand Russell, 1969)

Younger patients affected by particular pathologies for which specific interventions are necessary to support specialized care, called pediatric palliative care (PPC), require careful attention to both the specialists' competence and the requirements and organization of the facilities responsible for assistance. The remarkable delicacy and complexity of the pediatric palliative environ-

ment, the greater difficulties and the emotional intensity that denotes an empathic and caring relationship between very young patients and their families, and the need for appropriate structures and conditions for children (as opposed to teenagers) have caused the development of a dedicated and satisfactory system to be slow and fragmented.

The directives issued by the Italian institutions responsible for the entire national territory indicate organizational references within a general model, in which “the care network must guarantee each child in need of pediatric palliative care the answer to its main current and evolutionary health needs and those of the family. In particular, essential actions must be guaranteed as part of the diagnostic assessment process and taking charge, with active participation in the decision-making processes of the family, and, as far as possible for age and condition, for the child” [3–7]. Point 4 of the same agreement states that “home care remains the main objective for children. Despite this, there are moments during the path of care and particular transitional conditions of families that may require a residential solution. In these cases, the place of care must be adequate to accommodate the minor as well as the staff specifically trained for pediatric palliative care.”

According to the Technical Document of the Ministry of Health, implemented by the State-Regions Conference and annexed to the aforementioned agreement [7], in Italy there are, on average, about 11,000 children (between 7500 and 15,000) who are eligible for PPC and to whom the regions and healthcare facilities must guarantee an adequate and appropriate level of assistance.

The Report to the Parliament [10] found that, at the end of 2017, only 14 regions out of 20 issued a legislative or regulatory document for the creation of a regional network of services capable of responding to the needs of the local population; these findings were provided by the State-Regions Conference (CSR) of July 25, 2012 [8], and some of these focused only on pain therapy in children. In nine regions, the reference centers for pain therapy (PT) and PPC were

clearly identified and the services were already activated in accordance with the organizational model envisaged, although they are still being implemented [14].

Three pediatric hospices are currently active throughout the nation; the first was built in Padua in the Veneto region in 2007; the other two are located in Basilicata and Piedmont, and five are under construction or in the activation phase in Emilia-Romagna, Liguria, Lombardy, and Tuscany.

A structured pediatric home care network in pain therapy (PT) and PPC is present in five regions: Basilicata, Friuli-Venezia Giulia, Liguria, and the autonomous provinces of Trento and Bolzano and Veneto. The structure of the PT and PPC and pediatric services in the regions of Emilia-Romagna, Lombardy, Piedmont-Valle d'Aosta, and Tuscany is unclear. Specialist and dedicated home care in PT/PC are absent in the rest of the regions.

The number of minors being followed-up in adult PC units and PPC centers is very small in all Italian regions, especially when compared with the estimated requirements. In fact, out of approximately 11,000 eligible children, only 109 were very young patients being followed-up in the aforementioned structures and, in particular, the number of minors followed-up by the PC centers for adults was practically zero. If this last datum can be seen as a positive element in understanding the specificity of dedicated pediatric responses confirmed as necessary and optimal by more research and scientific literature, the lack of specifically activated centers and networks dedicated to pediatric PC highlights a serious lack of care responses for minors with incurable and highly complex diseases. Therefore, young patients remain in acute care units or are followed-up by their own family members at home, but do not receive any appropriate and specific type of palliative care.

The notable gaps in care are accompanied by the serious shortage of specialized training offered in the pediatric field for all of the professional figures required to constitute a multidisciplinary team; this has become the cause and, at the same time, the effect of the lack of professionals and competent bodies. It is evident that,

while the PC for adults is establishing itself throughout Italy with dedicated and increasingly specialized facilities, pediatric palliative care is just in the initial stages and is currently unable to meet at least part of the actual need.

Family

*My dear father, cling to my neck; I will hold you up
on your shoulders;
this effort will not be heavy for me.
One danger, one salvation for both. – (Virgilio:
“Eneide,” v. 1152–1155)*

“The show must go on” seems to be the imperative that governs habits, rhythms, logic, and intentions within society today, and this reflects on the family. In Italy, the family model tends to establish itself through the hectic society, always running to pursue affirmation of the self in all its manifestations and the subjective right to have what one wants most, searching for both psychophysical and socio-economic well-being. In this context, the disease is not only the reason for suffering, concern, and the commitment to find adequate therapeutic responses but also becomes an unexpected event that confuses and hijacks each person's routine. Families are never prepared to suffer the stress of a sudden and disruptive change such as an incurable disease or one that could become such. As understandable as this serious sense of confusion may be in the face of fearing a serious and demanding disease, families become upset because they have not considered the possibility of experiencing such a drama during the course of their lifetime and, even more, deny the inevitability of death.

The traditional family structure in Italian culture was always regarded as a nest of indissoluble affection, protection, and mutual help in good and bad times; however, the contemporary family model often assumes a new hierarchy of needs and a different scale of values. Consider, for example, households reduced to only a few members, either with separated or divorced parents or single parents with an only child who lives far away. With the complex and demanding problems that advanced and terminal disease presents,

there is, therefore, a breakdown of families rather than cohesion and support between the various family members and the sick patient.

As part of PC, it is said that when a member of the family gets sick, it is the whole family that gets sick. On an emotional level, distress can be caused by the threat of separation from one's relatives due to cancer. If a family member takes on the role of caregiver, he or she must take on the full weight of the care of the patient, which sometimes causes considerable suffering and may become a real burden. This emotional load is difficult to bear. Often the consequences of caregiving on one's mental state and physical health may persist even beyond the duration of the assistance.

Like the patient, the family member is also dragged from the diagnosis into that tortuous path, officially recognized as "Kubler-Ross phases" [15], perhaps not perfectly parallel or with the same intensity, but there is sometimes excessive rationalization due to the common fears and the carer's sense of protection toward the patient.

Under these conditions, the family cannot always be a resource for the patient, nor for the team of carers, but may become the recipient of help and assistance, in need of emotional and social support, clear information, and reassurances. Patients' relatives are therefore seen in the dual role of "potential carer" and "potential patient," and the task of the different healthcare professionals is to help the family members, each according to their respective needs, to best play his or her role in the relationship with the sick relative and to protect themselves from overbearing emotions in order to be able to take care of oneself, the patient, and the rest of the family.

The Spiritual Dimension of Palliative Care

Eli, Eli, lemà sabactàni?

My God, my God, why did you abandon me? –
(Vangelo secondo Matteo, 27, 46)

As a serious illness progresses, with the prospect of an end-of-life path and the possibility of

death no longer deferrable, patients sometimes start to ask themselves, in a frantic and insistent way, many questions related to the meaning of their current condition or to the sense of one's whole existence, the reason for the disease or the reason for the separation from all that they love, the importance of the things they have done or the value of the sacrifices they sustained, and the futility of the projects pursued with commitment or the lightness of living the next day in an irresponsible "carpe diem."

Why me? What harm have I done to have this disease?

What will become of me and us? What will become of our past and our future?

Where do we come from? Where do we go?

The need to seek answers to these and many other questions is considered an integral part of the human dimension, and it is the spiritual yearning that pervades the existence of each person. Spirituality concerns all life, identity, values, emotional and social relationships, the ethics of the human being, and the relationship with the real and the supernatural, with the present and with the eternal.

The global care of patients, according to any palliative model and according to all scientific and regulatory indications, presupposes specific attention to the spiritual needs of the sick person; Italian legislation constantly emphasizes that the patient and family must receive assistance without ever neglecting the spiritual dimension of the human being. Public and private organizations that provide PC must ensure spiritual support and, therefore, must include a spiritual advisor among the members of the team.

Although the definition of spirituality is not always clear, it is widely accepted that it should not be simplistically confused with religiosity or belonging to a specific faith. In the same way, the distinctions among spiritual assistance, psychological support, or empathic listening can be blurred.

In light of the above reflections, it seems urgent, in Italy as in other countries, to deepen the sense of spirituality in PC and to help deal

with the issues that arise and affect the patients, their families, and the carers themselves, who face daily questions regarding their own spirituality as well as being severely tested with the patient's own spiritual issues.

According to the Italian Society of Palliative Care (SICP ONLUS [16]), each team must be able to identify not only the symptoms of physical suffering but also those of inner suffering and must understand that the two require the same attention as they often coexist and enhance each other; they must be responded to adequately and with the same commitment to all needs. In particular, before proceeding to the terminal or palliative sedation of the patient, it is considered necessary for the teams to have tended to and satisfied all spiritual aspects. SICP itself recommends that particular attention be paid to the patients' need for reconciliation with themselves, with family members, and, for believers, with God.

Alongside the spiritual advisor, who primarily and specifically takes on this task, all health professionals should be prepared to talk about the profound aspects of existence and the prospect of death, not only with patients who express this need but also with family members who often ask about the reason for illness and death, while not projecting their own cultural conceptions, values, and beliefs onto them. Precisely because they are properly trained, healthcare professionals are instructed to learn how to communicate their ideas, fears, expectations, death experiences, and feelings regarding their own death, as the acknowledgment and understanding of common experiences in illness can sometimes help one to understand the meaning of life.

Volunteering

Do you want to live happily? Travel with two bags, one to give, the other to receive. – (J. W. Goethe: *Maximen und Reflexionen*, 1833)

Volunteering is encouraged and supported by Italian PC legislation, both in the home and at hospices; in fact, it completes the concept of global assistance, humanizing treatment and

being available wherever carers and healthcare professionals cannot be present. Volunteers participate in the internal life of the hospice through coordinated and individualized interventions of the patients' needs, assist the staff, and promote recreational, social, cultural, and artistic activities.

The participation of volunteers in PC is not taken for granted; however, both patients and family members must be protected from any inappropriate interventions, and the volunteers themselves must be protected from painful or harmful experiences for their own emotional well-being. Therefore, it is appropriate for those who intend to carry out voluntary activities in PC to first attend a training and motivational course, at the end of which the trainers can evaluate the suitability of the volunteers to take on this role. To this end, the Italian Society of Palliative Care has developed a core curriculum [17] for volunteers who intend to serve in these areas, to acquire the skills, knowledge, and empathic abilities required.

Conclusions

In light of the subjects presented here and despite the shortcomings in some critical aspects of PC in Italy, over the past 20 years, there has been a significant increase in palliative care services, providing assistance and disseminating the acceptance of PC in social, cultural, and family contexts, as well as bringing recognition and respect to the various healthcare professionals concerned, especially by the medical community and specialized scientific organizations. This is also associated with growth on a technical-professional level and an increased variety of organizational models which can respond to the many needs of the sick and of the entire population. In all regions of Italy, there are now more or less stable and accessible forms of structures capable of ensuring adequate and appropriate PC.

PC is a new and dynamic approach to the care needs of a community, which is ever evolving and seeking appropriate resolutions for the most severe and pathological conditions. In a society

where the progressive aging of the population and chronic, disabling diseases are an emerging problem, professionals and professional organizations are called upon to redefine their identity and role, to advocate for political attention and health choices, to find and implement care paths capable of supporting the health problems of the sick, to improve patients' quality of life wherever possible, and to listen to the expectations of the entire community and take responsibility for them.

The world of PC in Italy is, in reality, in strong turmoil; however, it is growing thanks to numerous innovative endeavors and the search for more adequate solutions to health and social issues affecting the community, the patients, and the health carers themselves. Today we speak of PC not only for cancer and non-cancer patients but also for the simultaneous treatment and early and timely administering of PC. The various organizational models presented in the different regions and the changing approaches to welfare have echoed the guidelines suggested by the scientific and political institutions' choices, witnessed by the vast and courageous establishment of laws and documents. From the guidelines for palliative sedation to the suspension of treatments, from the Law on Early Treatment Provisions [18] to the heated cultural debate on euthanasia and assisted suicide, and from the training of health-care providers to the supervision and staff support, there are many topics in which PC is reflected in Italy. Continued efforts to make further significant progress will ensure provision of the best service possible for those who need it.

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