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# Italian Committee for Bioethics

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## Palliative care

14th December 2023



*Presidenza del Consiglio dei Ministri*





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## **PALLIATIVE CARE**

**14 December 2023**



## Presentation

The National Committee for Bioethics, with the drafting of this Opinion on Palliative Care, intends to urge politics to implement it in an accomplished manner and as an integral part of the Essential Levels of Care, as these have already been recognised with the Prime Ministerial Decree of January 12<sup>th</sup>, 2017. The Opinion is also intended to be an encouragement for healthcare Organisations, training Organisations and professionals in the sector, to ensure that Palliative Care is provided with professionalism and ethical integrity, respecting the principles of universality, equity and justice, and granting each person the opportunity to deal with illness and the last stretch of the journey of life in a dignified manner and free from unnecessary suffering.

In the opening section of the Opinion, the CNB outlined the nature of Palliative Care through the fundamental definitions that have traced its evolution, configuring such care as a comprehensive approach, aimed not only at patients, but also at families dealing with chronic-evolving pathologies. Such an approach requires a deep understanding and extreme sensitivity to the different dimensions of the human experience that are intertwined with illness, recognising and responding to the complex needs that emerge in this delicate phase of life.

The second section addresses the issues that could compromise or slow down the progress and implementation of Palliative Care. Barriers to universal and equitable access to these essential services, the need for their timely activation, and the inalienable right of patients to receive comprehensive information about their care pathway are examined. The adequacy of Palliative Care in various healthcare settings, both home and hospital-based, and the influence of this care on healthcare costs were also addressed. In the Recommendations, the NCB indicated the need to pursue strategies for strengthening and enhancing Palliative Care networks and services, even in a context of scarce resources. The importance of adopting integrated and advanced management models to raise their quality and promote them as a strategic priority in the medical landscape, ensuring both clinical efficacy and the safeguarding of patients' dignity and rights, in all situations, was emphasised. The Opinion also highlighted the need for high-level training for healthcare professionals and the importance of research for the development of innovative treatments and practices, which are still sorely lacking in this area.

The NCB has intentionally focused its attention on these urgent matters to ensure that the development of Palliative Care throughout the country is considered a top priority. When we speak of the end of life, this issue intersects with others of great importance, sometimes crossed by divergences and contrasts, starting with assisted suicide and euthanasia, which are nevertheless characterised by distinct regulatory frameworks and ethical profiles. The two orientations that emerged on the relationship between Palliative Care and assisted suicide in the 2019 NCB Opinion 'Bioethical reflections on medically assisted suicide' can actually be read together to illuminate this context: in many cases the request to be helped 'to' die can be reformulated as a request to be helped not to suffer, but it is equally true that this does not apply in all situations and for all patients. It was decided to avoid, also in the structure of the text, overlapping with questions and issues that might have distracted the attention from the objective of illustrating the reasons for the necessary strengthening of Palliative Care. The possible question of anticipating death, which, moreover, is not only posed in this context, has nevertheless been addressed as a moment in the doctor-patient relationship and the associated communication responsibilities.

Prof. Angelo Luigi Vescovi  
President of the ICB

## Introduction

The National Committee for Bioethics (NCB) is tackling for the first time in a systematic way the issue of Palliative Care (PC)<sup>1</sup>, the development of which is crucial for guaranteeing the dignity of people suffering from serious and evolving diseases that cannot be cured. There are now many documents that the most important international organisations have devoted to this subject and which help to reconstruct the evolution of the concept, highlighting the growing awareness of the potential of PC in different pathologies, in the various stages of illness and in multiple care contexts.

The most common idea - and which nevertheless contains, as we shall see, an element of bias - remains that which refers to the definition proposed in 1990 by the World Health Organization (WHO)<sup>2</sup>. In PC, with the intention of improving the quality of life of both the patient and his or her family<sup>3</sup>, considered as a single entity of care, the comprehensive approach that should belong to all areas of medicine is emphasized: the 'mantle' (*pallium*) offered in this way is intended to cover not only the symptoms associated with the disease, but all the physical, psychological, social and spiritual aspects of a care that remains active until the last moment of life<sup>4</sup>, recognizing in the person an intrinsic dignity and inalienable value that persist, without any reduction, until death<sup>5</sup>. This approach, however, was initially limited - also in the public perception - to cancer patients no longer responding to treatments aimed at recovery and in the terminal phase of their illness.

This is also the source of a difficulty that continues to hold back the spread of PC and its timely activation. Hesitancy in suspending treatments aimed at the specific pathology, when they are no longer proportionate from a diagnostic and therapeutic point of view, is understandable from a human point of view, but it must be measured against the duty to

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<sup>1</sup> The subject has already been referred to by the NCB in other Opinions: *Bioethical Issues Relating to the End of Human Life* (July 14<sup>th</sup>, 1995), *Advance Declarations of Treatment* (December 18<sup>th</sup>, 2003), *Continuous Deep Palliative Sedation in the Imminence of Death* (January 29<sup>th</sup>, 2016) and *Medically Assisted Suicide* (July 18<sup>th</sup>, 2019).

<sup>2</sup> "PC is the active total care of patients whose illness is not responsive to curative treatments. Control of pain, of other symptoms, and psychological, social and spiritual problems is paramount. The goal of PC is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatments" (Cancer pain relief and palliative care. Report of a WHO Expert Committee; *WHO Technical Report Series* 804: Geneva, 1990:2).

<sup>3</sup> The term 'family', commonly used in PC definitions, refers in this Opinion to all those whom, at a specific moment in life, the sufferer himself freely identifies as important persons. "Family", in this sense, are the deepest and most significant affective relationships in the life of the patient, within and outside the formal parental structure. The network of support and understanding that the patient needs crucially depends on them. In them - and it is necessary to remember this - tensions and pressures may naturally also arise, from which the patient must be protected.

<sup>4</sup> In the literature on this subject, it is commonly referred to as the holistic approach. The assumption of course remains the rigorous application of the scientific method for the diagnosis and treatment of specific illnesses, while at the same time aiming at this broader understanding of human well-being.

<sup>5</sup> This vision is well illustrated by one of the most famous phrases of Dame Cicely Saunders, the founder of the hospice movement: 'You are important because you are you, and you matter until the last moment of your life'.

avoid any 'clinical obstinacy'<sup>6</sup> and any 'unreasonable obstinacy'<sup>7</sup> and may delay the activation of PC, when such a suspension is considered the necessary premise. This difficulty may concern the health professionals themselves, who persist in treatments with no evidence of efficacy, but even more so the patients and their relatives, who, trusting in the progress of science, urge recourse to any treatment that might still allow them to cherish the hope of an improvement. It must be remembered, in these cases, that there comes a time when the goal is no longer to fight the disease head-on, but to treat the symptoms, to make them tolerable. And it is precisely with this objective in mind that timely access to PC is crucial. It may be that the improvement of symptoms may also have, as a side effect, an improvement in prognosis, but this outcome, however desirable, is not the primary goal.

A decisively important step has been the abandonment of the strict link to the proximity of death and the broadening of the scope of PC to all incurable diseases: cancer, but also neurodegenerative diseases, the complex frailties of the great elderly and dementia, and in general all diseases in the final stages<sup>8</sup>. The commitment to overcome the obstacles to the development of PC and research in this area<sup>9</sup> is, in this way, oriented towards a more general perspective of wellbeing, which includes the connection to all the fundamental aspects of life and allows greater effectiveness in combating pain in its 'total' dimension<sup>10</sup>. It is necessary, in this new perspective, to design prospective clinical studies, and much remains to be done both regarding psychological aspects and the pharmacological approach to critical symptoms. The very communication of 'incurable disease' can generate significant suffering. Often, the concept of 'non-curable' does not allow patients to understand the permanence of the possibility of 'care'. In any case, the responsibility remains to respect the patient's inalienable right to be adequately informed about his or her actual health condition, available treatment options and life expectancy. Hence the need to continue 'researching' and developing effective tools and strategies also to facilitate communication with patients and their active involvement in the therapeutic decision-making process.

The view of death as a 'normal' process, which is an ineliminable part of life, and the importance of inter-professionality are two key aspects highlighted in the definition of PC

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<sup>6</sup> The NCB, in its Motion of January 30<sup>th</sup>, 2020 on *Clinical obstinacy or unreasonable obstinacy in the treatment of young children with limited life expectancy*, highlighted a semantic contradiction in the term 'obstinacy in therapy', pointing out that the word 'therapy' has a positive connotation and 'obstinacy' implies instead a negativity that does not reconcile with the positivity of the first term. If a treatment is defined as 'obstinacy', it is very unlikely that it can also be considered 'therapeutic'; also to be rejected are 'technological obstinacy' (referring to the use/abuse of technologies, often of a high standard) and 'experimental obstinacy', which occurs when experimental treatments turn out to be a futile exercise and not productive of benefits for the patient and his quality of life.

<sup>7</sup> Law No 219, December 22<sup>nd</sup>, 2017: *Rules on informed consent and advance treatment arrangements*, Art. 2.

<sup>8</sup> In the definition proposed in 2002, the WHO speaks of *life-threatening illness*, of prevention and of 'relief of suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual'. Under the heading *Palliative care* currently available (October 2023) on the organisation's website, cancer is one among many conditions cited as a possible cause of *serious health-related suffering*, and the 2002 definition is taken up in the opening of the *key facts* section (cfr. <https://www.who.int/health-topics/palliative-care>). Resolution 1649/2009 of the Parliamentary Assembly of the Council of Europe, significantly titled *Palliative care: a model for innovative health and social policies*, recommends member States to consider symptom control of seriously ill patients as a fundamental aspect of both the doctor-patient relationship and the self-determination of the latter, urging them to promote this approach and to bring the innovative potential of the PC method into the field of curative medicine (point 22.1).

<sup>9</sup> E.K. CHEN, C. RIFFIN, M.C. REID, *et al.*, *Why is High-quality Research on Palliative Care so Hard to do? Barriers to Improved Research from a Survey of Palliative Care Researchers*, "J Palliat Med" 2014 Jul; 17(7):782-7.

<sup>10</sup> One of the most revolutionary concepts introduced by Dame Cicely Saunders in the care of the terminally ill was precisely the concept of 'total pain', i.e. suffering that affects all spheres of the patient's life, not just the physical.

formulated by the European Association for Palliative Care (EAPC)<sup>11</sup>. Regarding the first aspect, PC helps to draw the line between what medicine can solve and what continues to require attention and care, despite the impossibility of recovery. And this happens precisely by restoring value to life, albeit within the restrictions imposed by illness. This acceptance does not imply passive waiting by the health professionals, who remain committed, on the contrary, to the effort of mitigating all forms of suffering in the constant respect of the patient's will (the current will or, in the case of unconsciousness or inability to express one's views, the will expressed in advance treatment statement or as progressively agreed upon in the relationship with health professionals, in particular through the instrument of advanced and shared care planning). Two fundamental considerations arise in this context. The first concerns the need to effectively communicate to those working in the health care world and to the public the nature and benefits of PC, to break down prejudices and misunderstandings. The second relates to the possibility of the patient expressing a wish to anticipate death, even when he or she is looked after by a PC team<sup>12</sup>. The well-established experience of PC teams shows a tangible preventive effect in many cases<sup>13</sup>. Regarding the second aspect highlighted in the definition of the EAPC, i.e. inter-professionality, the awareness of the need for an integrated approach, involving the convergence of specialised skills from multiple disciplines and professions (doctors, psychologists, nurses, physiotherapists, social workers, spiritual assistants, volunteers), as well as family members, friends and the community at large<sup>14</sup>, poses a further problem. The specific university training offer for these figures, pre- and post-graduate, is insufficient and deficient. Communication and the psycho-social and spiritual aspects<sup>15</sup> of care appear to be the most neglected areas and where more needs to be invested in terms of educational objectives<sup>16</sup>. In order to ensure an optimal quality of care, it is essential that each PC team has the training, skills, ethical sensitivity and capacity

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<sup>11</sup> " Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope [...]. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death. S. PAYNE, P. HUDSON, G. GRANDE, *et al*, *White Paper on Improving Support for Family Carers in Palliative Care: Part 1*, "European Journal of Palliative Care" 17(5):238-245.

<sup>12</sup> The scientific literature, on the other hand, as early as 2016 identifies the 'wish to hasten death' (WTHD) as '[...] a reaction to suffering, in the context of a life-threatening condition, from which the patient sees no other way out than to hasten his own death' (quotation from A. BALAGUER, C. MONFORTE-ROYO, J. PORTA-SALES, *et al.*, *An International Consensus Definition of the Wish to Hasten Death and Its Related Factors*, "PLoS One" 2016 Jan 4;11(1): e0146184). The most interesting specification, also for bioethical purposes, however, concerns the subsequent differentiation between the simple wish (almost an aspiration) to die (WTD or wish to die) and the concrete intention to anticipate death (HDI or hasten death intention): this, moreover, presents a wide spectrum, from the simple mention to the concrete planning. A. BELAR, M. MARTINEZ, C. CENTENO, *et al.*, *Wish to die and Hasten Death in Palliative Care: a Cross-sectional Study Factor Analysis*, "BMJ Support Palliat Care" 2021 Oct 14.

<sup>13</sup> A. COLOMBO, G. DALLA ZUANNA, *The demography of the end of life*, "Italian Review of Sociology", II Mulino Riviste WEB, 2023. Cfr. <https://dx.doi.org/10.1423/107578>.

<sup>14</sup> S. LIBRADA FLORES, E. HERRERA MOLINA, J BOCETA OSUNA, *et al.*, *All with You: a new Method for Developing Compassionate Communities-experiences in Spain and Latin-America*, "Ann Palliat Med" 2018 Apr; 7(suppl 2):15-31. The idea of health protection as a 'multidimensional human dimension', recalled by the NCB in its Opinion of 10<sup>th</sup> December, 2021 on *Vulnerability and care in community welfare. The role of the ethical space for a public debate*, can also be integrated and promoted through the valorisation of this 'space', understood as a place for reflection, exchange of experiences, comparison of opinions in which the interlocutors, with respect for roles, knowledge and skills, build a common pathway and can experiment with interventions adapted to the new health needs, with the taking into account of the most fragile subjects. The first ethical space was opened in October 2023 at ASL 4 in Chiavari.

<sup>15</sup> The term 'spiritual' does not refer to a particular religious faith, but to an inner dimension based on a value system that gives meaning to existence.

<sup>16</sup> J. PIETERS, D.H.J.M. DOLMANS, D.M.L. VERSTEGEN, *et al.*, *Palliative Care Education in the Undergraduate Medical Curricula: Students' Views on the Importance of, their Confidence in, and Knowledge of Palliative Care*, "BMC Palliat Care" 2019; 18(1): 72.

for integrated management of highly complex issues.

In Italy, the fundamental right to health protection guaranteed by Article 32 of the Constitution acquired further specification with Law 38 of 2010, also becoming the right to access PC and pain therapy, subsequently included by the Prime Ministerial Decree of January 12<sup>th</sup>, 2017, in the essential levels of care. In this way, Italy, thanks also to the impulse of the NGOs and the initiatives that had been promoted autonomously by various associations, introduced one of the most advanced legislations in Europe, in line with the WHO's call for PC to be considered a fundamental human right<sup>17</sup> and the numerous requests from the Parliamentary Assembly of the Council of Europe to urge the member States to make palliative care effective in their respective healthcare systems<sup>18</sup>. Also, in Law 38 - and this passage is of decisive importance in a context characterised by an epidemiological transition with an increase in chronic illnesses and ageing - the opinion that sees PC limited to the end of life is overcome. The application of palliative medicine is extended to the early stages of incurable diseases with an unfavourable prognosis, and the current trend is to make them available as early as possible, depending on the clinical situation, the complexity of care and the expected prognosis of each patient. Today, there is more and more talk of early and simultaneous PC, placing the figure of the palliative care physician alongside that of specialists in the various disciplines. And this is consistent with the development of scientific research and the increasing availability of drugs and devices that allow life expectancy to be prolonged, even in the presence of evolving diseases.

The fact that the lawmaker has decided to bring together in a single law the provisions aimed at guaranteeing access to PC and pain therapy points to a convergence that can be traced back to the very roots of the development of the former. Pain control is the first objective indicated in the 1990 WHO definition. The need for a shared commitment, while being aware that these two fields of action do not simply coincide, is reaffirmed, for example, in point 11 of the 2002 *European Charter of Patients' Rights*: 'Each individual has the right to avoid as much suffering as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative treatments and simplifying patients' access to them'. As far as Italy is concerned, it is in 1997 that the 'Charter of the Rights of the Dying' recognises the fundamental rights of people in the terminal phase of an illness and, among others, that to the relief of pain and suffering (art. 5)<sup>19</sup>. And the right not to suffer uselessly was reaffirmed, in 2005, in the Charter of Rights on useless pain by Cittadinanzattiva, promoter also of the Tribunal of Patients' Rights. In this direction there was also the Project "Hospital without pain" fruit of the State-Regions agreement of May 24<sup>th</sup>, 2001, then evolved, in the same law 38/2010, in the Project "Hospital-Territory without pain" where it was intended to give more space to the figure of the general practitioner, who can be considered the centre of the pain care network through functional territorial aggregations, connected with hospital centres and hospital facilities dedicated to pain care. In this panorama, coherently with the recognition, precisely in Law 38, of a real subjective right to the provision of PC, Law 219 of 2017 on informed consent and advance care planning is inserted: the physician, in order to alleviate patients' suffering, must always guarantee appropriate pain treatment and the provision of PC, even in the case

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<sup>17</sup> See WHO Definition of Palliative Care ([www.who.int/cancer/palliative/definition/en](http://www.who.int/cancer/palliative/definition/en)). Also, WHO, 20 December 2013, *Strengthening of Palliative Care as a Component of Integrated treatment Throughout the Life Course*, Report by the Secretariat. See also the *Global Atlas of Palliative Care at the End of Life* of the *Worldwide Palliative Care Alliance (WPCA)*, 2014, 7. On palliative care as a human right, already F. BRENNAN, *Palliative Care as an International Human Right*, "J Pain Symptom Manage", 33(5), May 2007: 494-499.

<sup>18</sup> See in particular Resolutions No. 1649/2009, *Palliative care: a model for innovative health and social policies* and No. 2249/2018, *The Provision of Palliative Care in Europe*.

<sup>19</sup> By the Floriani Foundation Ethics Committee, later evolved into the End of Life Ethics Committee.

of refusal or withdrawal of consent to the indicated health treatment<sup>20</sup>.

The importance of paediatric PC is also fully recognised in Law 38. This is a unique and complex speciality, which deserves specific and in-depth consideration, to which the NCB intends to devote itself in the near future, also considering the cognitive investigation of the Social Affairs Commission of the Chamber of Deputies in April 2019<sup>21</sup>, unanimously approved, from which it emerged that only 10% of the approximately 35,000 Italian children in need of PC manage to find an adequate response to their needs<sup>22</sup>.

The increase of the number of pathologies treated and the extension of the period of time for which they are required have also made it essential to diversify the places where PC can be provided: hospitals, hospices, nursing homes, specialist outpatient clinics, the patient's home. This spread raises two important questions. The first: how can the right to PC and equal access throughout the course of the disease be reconciled with the economic, social and geographical inequalities that afflict health care (and palliative care in particular, especially with reference to non-oncological patients) in Italy? Secondly, how can we guarantee PC and respect for the dignity of patients hospitalised in internal medicine wards, ICUs, nursing homes, considering the severe shortage of qualified staff? In this perspective, the silent service performed by millions of *informal caregivers*<sup>23</sup>, whose importance has been recognised by the Parliamentary Assembly of the Council of Europe<sup>24</sup> must also be considered. These figures are destined to further increase in number soon and deserve support from the institutions.

One last point should be mentioned: the fundamental role of the patient in the complex web of relationships and interactions that are generated in this sphere, together with other well-established aspects, is emphasised in the definition of the International Association for Hospice and Palliative Care, highlighting the importance of supporting his and his family's ability to outline the objectives of care<sup>25</sup>. Early and shared care planning, to which reference has already been made, thus becomes an essential tool for concretising the patient's involvement in his or her treatment pathway in a logic of genuine 'alliance' between the patient, the family and the healthcare team, also helping to avoid unreasonable obstinacy in inappropriate treatments no longer aligned with the needs and goals of care. This can improve not only the well-being of patients, but also the efficiency in the use of healthcare resources, by reducing expenses related to ineffective therapies, unnecessary diagnostic investigations, as well as frequent hospitalisations and intensive care<sup>26</sup>. Of course, it remains essential to ensure that the decision to offer PC is not driven by the desire to reduce costs and is

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<sup>20</sup> Law No 219 of December 22<sup>nd</sup>, 2017, Article 2: *Pain therapy, prohibition of unreasonable obstinacy in treatment and dignity in the end of life*.

<sup>21</sup> XII Committee on Social Affairs, Wednesday 10<sup>th</sup> April 2019, Annex 2 to the Knowledge Survey:113.

<sup>22</sup> An even smaller subgroup is the perinatal area. Some Italian teams are organising themselves for this type of service: cfr. M. BOLOGNANI, P.D. MORELLI, I. SCOLARI, *et al.*, *Development of a Perinatal Palliative Care Model at a Level II Perinatal Center Supported by a Pediatric Palliative Care Network*, "Front Pediatr." 2021 Jan 15; 8:574397.

<sup>23</sup> The difference between formal and informal *caregivers* lies in the nature of the relationship with the sick person: the former are paid professionals, the latter belong to affective relationships. The latter, then, often bear a considerable economic outlay, either direct or indirect. The service of informal caregivers was recognised and outlined normatively for the first time by the 2018 Budget Law (Article 1, paragraphs 254-256 of Law 205/2017).

<sup>24</sup> Resolution No. 2249/2018: *The provision of palliative care in Europe* (item 6), <https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=25214&lang=en>.

<sup>25</sup> PC are a "support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care". They are also provided "recognizing and respecting the cultural values and beliefs of the patient and the family"; see <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/>.

<sup>26</sup> X. LUTA, B. OTTINO, P. HALL, *et al.*, *Evidence on the Economic Value of End-of-Life and Palliative Care Interventions: a Narrative Review of Reviews*, "BMC Palliat Care 2021" Jun 23; 20(1):89.

always based on the need to improve the quality of life of the patients and their family.

The idea and practice of PC have developed through a series of progressive expansions: the target pathologies (no longer just cancer); the duration of care (not just the terminal phase of the illness, after the suspension of treatment aimed at a possible cure); the places of care; the professional figures involved. This generates a complex set of issues and responsibilities, which are accentuated by the recognition of PC as part of the fundamental right to health and deeply question our conceptions of dignity, suffering, and death. The NCB believes that some of them must be indicated as priorities and intends, with this document and the proposed recommendations, to offer a contribution to a thoughtful reflection oriented towards urging the necessary actions in the political and clinical spheres.

## 1. The goal of universal and equitable access

*The ageing of the population, combined with changes in disease types, has led to an increasing need for PC. It is estimated that between 1 and 1.4 % of the adult population requires such care<sup>27</sup>. This dynamic, especially in relation to non-oncological diseases, could exacerbate the imbalance between actual needs and the availability of services. A survey on non-communicable diseases conducted by the WHO in 2019, in 194 States, showed that funding for PC was available in only 68% of countries, and only 40% of them reported that the service reached at least half of the patients who needed it<sup>28</sup>. In Italy, although Law 38 of 2010 established a solid basis for enhancing care in this area, regional inequalities remain in terms of access and standards of care<sup>29</sup>. Moreover, the right to universal and equitable access goes beyond patient care and extends to family members, who in PC are an integral part of the treatment pathway: they face challenges that affect their health, but also significant burdens related to the extensive time spent, extra expenses and potential changes or suspensions in their job<sup>30</sup>.*

To ensure excellent services for each person, regardless of their place of residence or other specificities that define their need for care, the NCB recommends:

1. ensuring a balanced distribution of resources to secure quality PC in all regions of the country, with particular attention to areas where access is currently insufficient. It is necessary to accelerate the development and accreditation of networks at the regional and local level, so that they are fully integrated into the care pathways for people with chronic and developmental pathologies of all ages, making effective the application of Law 38/2010, the DPCM on LEAs of 2017, the most recent Laws 106/2021 and 197/2022, which devote specific chapters precisely to the strengthening of networks and indicate a precise timeline to arrive at ensuring the coverage of 90% of PC needs in 2028. It is equally important to unify the fees reimbursed by the NHS for activities in the hospice and home care settings, thus bringing the goal of ensuring equity between the regions closer.

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<sup>27</sup> X. GOMEZ-BATISTE, S. CONNORS, *Building integrated Palliative Care Programs and Services*. University of Vic Eumo Editorial, 2017.

<sup>28</sup> *Assessing national capacity for the prevention and control of noncommunicable diseases: report of the 2019 global survey*. World Health Organization: Geneva, 2020; <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.

<sup>29</sup> See Ministry of Health (ed.). Report to Parliament on the state of implementation of Law No. 38 of 15 March 2010: Provisions to guarantee access to PC and pain therapy. Year 2019 (reporting period: 2015-2017); see [https://www.salute.gov.it/portale/documentazione/p6\\_2\\_2\\_1.jsp?id=2814](https://www.salute.gov.it/portale/documentazione/p6_2_2_1.jsp?id=2814). It is important to mention, however, that the most recent AGENAS report, dated December 31<sup>st</sup>, 2021, and carried out by a working group that collaborated with the Ministry of Health, shows that the situation of Palliative Care in Italy has been partly improving.

<sup>30</sup> B. GIVEN, G. WYATT, C. GIVEN, *et al.*, *Burden and Depression among Caregivers of Patients with Cancer at the End of Life*, "Oncol Nurs Forum 2004" Nov 16; 31(6):1105-17.

2. guaranteeing the uniformity of the various regional regulations and their application, both in the definition of eligibility criteria and in the organisation of the relationship between the various subjects and places in the PC network, according to the standards indicated at national level (Ministerial Decree 77/2022, art. 1). In particular, it is necessary to implement assessment criteria for patient access based on inclusiveness, excluding all forms of discrimination. Chronological age or diagnostic categories should never be used as a priori grounds for exclusion and everyone, including minority groups, prisoners and other marginalised populations should always have their right to PC recognised, in line with their preferences and values.

3. ensuring access to drugs that the scientific community considers essential to reduce physical and mental suffering and facilitating access to all analgesics, especially opioids<sup>31</sup>, by making them free of charge. At the same time, thorough training of doctors and nurses is essential to ensure that treatments are provided according to solid scientific evidence.

4. guaranteeing synergy between the Pain Therapy Networks and the Palliative Care Networks, identified by Law 38 of 2010 as autonomous but integrated, to ensure all treatments, pharmacological, procedural, complementary, aimed at controlling pain, which, among the symptoms, is the most feared and disabling, since it affects quality of life.

5. setting up appropriate support services and provide tax breaks for those who engage in caring for patients, starting with family members and *caregivers*, to alleviate their emotional burden as well<sup>32</sup>. This is in line with the aim of PC, which is to promote the overall well-being not only of the patient, but also of those who accompany him or her during treatment.

## 2. The importance of early activation

*Although PC is not only aimed at the terminal stages of disease, but can be integrated with treatments targeting the primary disease, as indicated by authoritative guidelines on early and simultaneous treatment<sup>33</sup>, such integration is still largely an untreaded path, especially for non-oncological diseases. Delays in the application of PC, understood in this perspective, may arise from the difficulty of coordinating therapeutic approaches traditionally considered sequential, rather than simultaneous. These obstacles are intertwined with the complexity of administrative processes for the recognition of simultaneous palliative interventions and are aggravated by the absence of clear protocols and not always effective communication between services and departments. In addition, the implementation of early and simultaneous palliative care requires adequate resources, such as adequate time for comprehensive counselling and experienced staff, which are crucial both for dealing with delicate choices such as the possible discontinuation of specific treatments, and for meeting the goals of care established together with patients and their families<sup>34</sup>. The difficulty, as mentioned above, may be exacerbated by factors such as resistance to exhausting all treatment options and a narrow view of PC as an option confined to the last days of life. It should also be borne in mind that patients and their families may experience understandable*

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<sup>31</sup> *Why Palliative Care is an essential function of primary health care?* World Health Organization: 2018.

<sup>32</sup> R. SPATUZZI, M.V. GIULIETTI, M. RICCIUTI, *et al.*, *Does Family Caregiver Burden Differ Between Elderly and Younger Caregivers in Supporting Dying Patients with Cancer?, An Italian Study*, "American Journal of Hospice and Palliative Medicine". 2020; 37(8):576-581.

<sup>33</sup> *Early and concurrent Palliative Care. AIOM-SIPC working table paper 2015*; see also B.R. FERRELL, J.S. TEMEL, S. TEMIN, *et al.*, *Integration of Palliative Care into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update*, "J Clin Oncol" 2017 Jan; 35(1):96-112.

<sup>34</sup> J.J. LO, N. GRAVES, J.H. CHEE, *et al.*, *A Systematic Review Defining Non-Beneficial and Inappropriate End-of-Life Treatment in Patients with Non-Cancer Diagnoses: Theoretical Development for Multi-Stakeholder Intervention dDsign in Acute Care Settings*, "BMC Palliat Care" 2022 Nov 9; 21(1):195.



*moments of disorientation and distress whilst waiting for the PC team to begin their assistance.*

In order to promptly recognise the need for PC and proceed with appropriate interventions in tune with the needs and wishes of the parties involved, the NCB recommends:

1. disseminating a deep understanding of the nature and purpose of PC among healthcare professionals, with the involvement of general practitioners<sup>35</sup>, so that PC is truly integrated into primary healthcare<sup>36</sup>. There is also a need to foster effective collaboration between primary care specialists and palliative care practitioners<sup>37</sup>, so that the goals, the expected benefits and the potential risks of treatment options, together with respect for patient dignity, are always collegially assessed and addressed<sup>38</sup>. A deep sensitivity to the wishes of patients and families must be integrated with the best scientific evidence and clinical *expertise*.

2. maintaining a clear distinction between the competencies related to the different stages of the disease. In early and simultaneous PC, when the goal may still be oriented towards a significant prolongation of life, the already defined role of the disease specialist is complemented by the emerging role of the palliative care specialist, in a shared care plan with the patient and family members. As the disease progresses to more advanced stages, the palliative care specialist's role becomes prevalent, focusing on symptom control and maintenance of quality of life. The 'taking charge' by the PC Network is thus part of a continuous pathway, and should not be considered by patients and families as a refuse to care: treatments remain proportionate to the clinical needs.

3. disseminating information on the value and scope of PC to the entire population, implementing Article 4 of Law 38/2010, so that it is adequately considered when dealing with an evolving and complex disease. Raising awareness on a large scale would have the benefit of de-stigmatising PC, which is often wrongly associated only with the terminal phase of life, and facilitating its recognition as a fundamental component of healthcare.

4. ensure that the patient and, in accordance with his or her wishes, the family receive accurate, transparent and comprehensible information on the reasons why curative treatments may not achieve the desired goals and on the alternatives available. This information process, if conducted with empathy, respect and sensitivity, can safeguard the emotional state of those receiving such information, but also create optimal conditions for the exercise of informed consent and shared care planning, preventing late or hasty decisions.

5. adopt organisational models and administrative procedures that promote and facilitate integrated care, guaranteeing gradual and coordinated transitions, including through a 'one-stop shop' as an exclusive point of contact for patients and their families with the Local PC Network and health and social services, to be able to benefit from the complexity of services without feeling disoriented with the inevitable intertwining of competences and responsibilities. Integration of facilities and health personnel is essential to ensure that health-related events are perceived as continuous and consistent by patients and families, reducing the feeling of abandonment that can arise when faced with fragmented care responses.

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<sup>35</sup> Articles 2(f), 4 and 8 of Law No 38/2010

<sup>36</sup> World Health Organization, *Integrating palliative care and symptom relief into primary health care*, Geneva 2018.

<sup>37</sup> T.H. NEVILLE, J.F. WILEY, M.C. YAMAMOTO, *et al.*, *Concordance of Nurses and Physicians on Whether Critical Care Patients are Receiving Futile Treatment*, "Am J Crit Care" 2015; 24(5):403-10.

<sup>38</sup> "At all events, in uncertain and complex situations like those generated by the end of life, decisions should be the culmination of a proactive, collective process ensuring that patients are placed at the centre of decisions [...]" (Council of Europe, DH-BIO. *Guide on the decision-making process regarding medical treatment in end-of-life situations*. Council of Europe, May 2014: 8).

### 3. The patient's right to receive full information on the pathway

*When a patient finds himself in the situation of having to consider the option of PC, the importance and consequent responsibilities of recognising that 'communication time between doctor and patient constitutes treatment time'<sup>39</sup> is emphasised. The duty to provide complete, accurate and comprehensible information on the prognosis and the available therapeutic options, which applies to PC as to any other health treatment, is measured by the clinical and psychological peculiarities of these patients: frailty, which may make it more difficult to ask for or receive complex information; possible deficiencies in previous diagnostic or prognostic information and awareness; the evolution of the latter in relation to the evolution of the experience of the disease; a capacity (competence) that may also be greatly reduced<sup>40</sup>. The patient, moreover, 'may refuse in whole or in part to receive the information or indicate family members or a person he trusts to receive it and to give consent on his behalf [...]'<sup>41</sup>. Added to this are the difficulties of communication and understanding that can arise in relations with patients and families who come from different linguistic and cultural backgrounds and place death in a framework of values, traditions and practices that are also symbolically peculiar. A very special communicative context is thus created, for which the very forms and environments of the doctor-patient relationship, as well as the availability of all the necessary time, may be as important as the information on clinical data.*

*The issue of communication can also be seen in the context of a more general cultural problem. Traditionally, in fact, medicine has focused mainly on recovery, making it difficult to deal appropriately with issues such as the end of life and how to accompany the sick person in this delicate phase. Healthcare personnel must be fully aware of the impact that the omission of correct information can have on patients<sup>42</sup>, who must be given the opportunity to make informed decisions on where they wish to spend their last moments (preferably at home, but taking into account the actual socio-familial sustainability, which today appears increasingly complex), organise their personal affairs, conclude emotional relationships in a meaningful way, and leave room for spiritual needs. It is also important to avoid discrepancies between what healthcare professionals think they have shared with a patient and what the latter has actually understood<sup>43</sup>, with emotional and behavioural consequences that could delay the necessary adaptation processes.*

In PC, to ensure respect for the patients' right to be informed about their health condition, treatment options and end-of-life prospects, without compromising their emotional and psychological well-being and that of their family, the NCB recommends:

1. ensuring that both patient and family members do not embark on a PC pathway without first being fully aware of what this entails. To this end, it must also be remembered that many of these patients are in a particularly fragile condition, often with reduced or no capacity for self-determination. The communication context created in these circumstances is particularly delicate and requires appropriate attention and tools, also to avoid possible conflicts. In many cases, doctors will have to interact with trustees, support administrators, guardians. In order to ensure respect for the patient's decision-making autonomy and that of others who may be involved, it is important for health professionals to be aware of the

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<sup>39</sup> Law No. 219 of 22<sup>nd</sup> December, 2017, Art. 1, c. 8; Code of Medical Ethics, Art. 20.

<sup>40</sup> Italian Society of PC. *Information and progressive consent in PC: a shared evolutionary process*. SICP Recommendations. Milan, 2015:21-23.

<sup>41</sup> Law No. 219 of 22<sup>nd</sup> December 2017, Art. 1, c. 3.

<sup>42</sup> L.J. FALLOWFIELD, V.A. JENKINS, H.A. BEVERIDGE, *Truth May Hurt but Deceit Hurts more: Communication in Palliative Care*, "Palliative Medicine" 2002; 16(4):297-303.

<sup>43</sup> C.F. QUIRT, W.J. MACKILLOP, A.D. GINSBURG, *et al.*, *Do Doctors know when their Patients don't? A Survey of Doctor-Patient Communication in Lung Cancer*, "Lung Cancer" 1997 Aug; 18(1):1-20.

appropriate moments (when), the specific contents (what), and the modalities (how) most suitable for communicating the information that is essential for obtaining well-considered informed consent.

2. (when) providing accurate and complete communication about treatment options, including PC, at an early stage of diagnosis of a developmental disorder. This communication process must be replicated at a later stage, during the review of the treatment plan, to ensure that the patient and family members agree with the changes to be made to the treatment. Finally, at an advanced stage of the disease, when the choice of PC becomes incapable, it is imperative to maintain an open and circumstantial dialogue so that all parties involved are fully aware of the implications and expectations associated with the adoption of a palliative pathway.

3. (what) developing information content appropriate to the various stages of the disease. In the initial phase of diagnosis, it may be useful to introduce the purpose of PC, emphasising its complementary function with respect to causal therapies. During the revision phase of the causal treatment plan, especially when there is a reconsideration dictated by the progression of the disease and the results of the treatments employed so far, it is crucial to focus communication on PC as an approach to ensure the best possible quality of life. In the advanced phase of the disease, then, it is essential to prepare the patient and family members for PC to become the main therapeutic approach, informing them of all the intervention strategies available for the control and management of symptoms, and of those that are 'difficult' due to their complexity and variability. In the presence of refractory symptoms, which persist despite the most advanced therapies, it is necessary to inform the patient and/or, as the case may be, the eventual trustee, support administrator or guardian, acquiring their consent, of the possibility of palliative sedation, which can be carried out in various forms up to deep and continuous sedation<sup>44</sup> in a patient with an unfavourable prognosis within a few hours or a few days, with the aim of alleviating suffering and avoiding unnecessary or potentially harmful interventions.

4. (how) to communicate with the patient and family in a bearable and progressive way<sup>45</sup>. This does not mean concealing relevant information. On the contrary, the intention is to enable the patient to receive it in accordance with his or her ability to understand and process it. Each one deals with the emotional, psychological and physical challenges of a diagnosis and prognosis in a unique way, finding his own rhythm and ways of coping with the situation with the resources at his disposal and living with the disease, accepting it as a part of his life that, while changing many aspects of existence, does not define it entirely.

5. communicating and disseminating the importance of PC as a recognition of the limits of medicine, and thus as a guarantee against the risk of clinical obstinacy or unreasonable obstinacy, while at the same time keeping the role of PC distinct from assistance in suicide - should the patient manifest this intention - and bearing in mind, of course, that the patient may refuse them or ask for them to be discontinued, as is the case with any other medical treatment. The defence of this distinction is also in line with ruling no. 242 of 2019 of the Constitutional Court, which, indicating the conditions that exclude the punishability of the crime of aiding suicide, recalls the NCB's opinion of July 18<sup>th</sup>, 2019 on *Bioethical Reflections*

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<sup>44</sup> On which we refer to the opinion of this NCB, *Continuous Deep Sedation in the Imminence of Death*, January 29<sup>th</sup>, 2016. Let us recall that palliative sedation is a medical act, which consists of the intentional reduction of the state of consciousness, in the presence of intolerable suffering, caused by refractory symptoms, in a manner proportional to the symptoms; it can therefore be superficial or deep, continuous or intermittent, progressive or immediate. It can never be an excuse for refusing to assist a patient with difficult symptoms. See R. TWYCCROSS. *Reflections on Palliative Sedation*, "Palliat Care" 2019 Jan 27.

<sup>45</sup> G. GONZÁLEZ-BARÓN, F. DÍAZ-MARTÍNEZ, A. ORDÓÑEZ-GALLEGO *et al.*, *La relación médico-paciente en Oncología*, Ed. Ars Medica, 1983. See also E. ESPINOSA, G. GONZÁLEZ-BARÓN, P. ZAMORE, *et al.*, *Doctors also Suffer when Giving bad News to Cancer Patients*, "Support Care Cancer" 1996 Jan; 4(1):61-63.

on *Medically Assisted Suicide*, to reiterate that the effective provision of PC and pain therapy should be considered "an absolute priority for health policies", "a pre-requisite for the patient's choice, later on, of any alternative pathway", and concluding that it would be a paradox "not to punish aiding suicide without first having ensured the effectiveness of the right to Palliative Care"<sup>46</sup>.

6. devote extra attention to foreign patients and families who might experience this situation with greater difficulty and discomfort, due to a less than perfect command of the Italian language or in any case to a reduced awareness of how the health system works, of the principles on which it is based, and of the rights guaranteed in it. Death is one of the experiences most strongly characterised by the specificity of cultures and traditions, which must find acceptance and respect in the CP pathway.

#### 4. PC in different health care contexts

*The activation of PC in the various healthcare settings encounters a number of barriers that limit its effectiveness and dissemination, especially in those areas where most deaths occur and where intensive goal orientation prevails<sup>47</sup>. In geriatric hospital wards, for example, the perceived lower need for palliative support - due to the advanced age of patients - and the common association between PC and cancer, with the consequent emphasis on interventional care, may delay the adoption of the palliative approach. Similar problems are also encountered in nursing homes<sup>48</sup>, which house very elderly people with chronic medical conditions and limited physical function. In these contexts, there is a greater risk that a significant proportion of the residents are not appropriately referred to PC services, resulting in an increase in inappropriate hospital admissions, treatments that prove burdensome with limited benefits<sup>49</sup>, dissatisfaction of family members, also due to shortcomings in communication strategies<sup>50</sup>. These elderly people frequently present pain and physical symptoms that are not adequately treated<sup>51</sup> and many of them express high levels of loneliness, depression, lack of care for needs, such as spiritual ones. These situations are exacerbated by the perceived lack of adequate training of healthcare workers<sup>52</sup>, enabling them to provide comprehensive and holistic care. Even in intensive care units there are numerous barriers to the implementation of an appropriate approach<sup>53</sup>: the orientation precisely towards*

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<sup>46</sup> In the 2019 NCB opinion "Bioethical reflections on medically assisted suicide" in addition to underlining what is mentioned in the text, reference is made to two different orientations regarding the relationship between PC and assisted suicide: according to one orientation, PC "constitute an alternative to the request for medically assisted suicide" because this request can "be reformulated together with the patient as a request for help not to suffer"; according to another orientation "it is illusory to believe that they are able to respond effectively to all the situations that the patient faces at the end of life". In any case, the same opinion confirms that "the philosophy that inspires and permeates the PC is to accompany <in> dying, abstaining from providing help <to> die" (p. 20)

<sup>47</sup> F. SGANGA, C. BARILLARO, A. TAMBURRANO, et al., *The Benefits of a Hospital Palliative Care Team*, "Int J Palliat Nurs" 2019 Jul 2; 25(7):345-352.

<sup>48</sup> S. GONELLA, I. BASSO, M.G. DE MARINIS, et al., *Good End-of-Life Care in nursing Home According to the family Carers' Perspective: A systematic Review of Qualitative Findings*, "Palliat Med." 2019 Jun; 33(6):589-606.

<sup>49</sup> J.G. CARPENTER, P.H. BERRY, M. ERSEK, *Nursing Home Care Trajectories for older Adults following in-Hospital Palliative Care Consultation*, "Geriatric Nurs" 2017; 38:531-536.

<sup>50</sup> S. HALL, A. KOLLIAKOU, H. PETKOVA, K. FROGGATT, et al., *Interventions for Improving Palliative Care for older People living in Nursing Care Homes*, "Cochrane Database Syst Rev" 2011:CD007132.

<sup>51</sup> J.N. HUNNICUTT, C.M. ULBRICHT, J. TJIA, et al., *Pain and Pharmacologic Pain Management in Long-Stay Nursing Home Residents*, "Pain" 2017; 158:1091-1099.

<sup>52</sup> E. BATSTONE, C. BAILEY, N. HALLETT, *Spiritual Care Provision to End-of-Life Patients: A Systematic Literature Review*, "J Clin Nurs" 2020 Oct; 29(19-20):3609-3624.

<sup>53</sup> S. MERCADANTE, C. GREGORETTI, A. CORTEGIANI, *Palliative Care in Intensive Care Units: Why, Where, What, Who, When, How*, "BMC Anesthesiology" 2018 Aug 16;18(1):106.

*intensity can make it difficult to give due attention to the identification of PC needs<sup>54</sup> and their integration into daily clinical practice. Clear protocols for the identification of patients suitable for PC are often lacking, as are operational models for their application and objective criteria for consulting external experts. In emergency rooms, barriers are represented by the limited access of physicians to patients' past medical histories, the reduced availability of PC teams, the chaotic and often hectic environment, time constraints, and the tendency to favour immediate stabilisation of health conditions<sup>55</sup>.*

To ensure respect for the dignity and wishes of patients requiring PC in the various healthcare settings, the NCB recommends:

1. promoting the implementation of PC-focused training and refresher programmes for all social and health service professionals (such as geriatricians, anaesthesiologists, intensive care physicians, nurses, etc.), with the aim of developing appropriate skills and encouraging interprofessional collaboration and the decision sharing of the treatment plan.
2. developing and disseminating protocols<sup>56</sup> and guidelines for the identification of patients suitable for PC<sup>57</sup>, for expert consultation and for the management of the palliative care pathway, ensuring the availability of PC teams in every social and healthcare facility.
3. implementing systems for monitoring and evaluating the quality of PC provided, identifying areas for possible improvement, with the aim of raising standards of care and reducing the distress of patients and families.
4. to explore and test new organisational and therapeutic models, promoting the sharing of good practices in all health care settings, especially in home care settings.

## **5. The positive impact of PC on health expenditure**

*There is evidence on the contribution of PC to reducing healthcare expenditure, starting, as mentioned above, with reducing the use of unnecessary investigations and treatments, but also prolonged and inappropriate hospitalisation<sup>58</sup>, which contributes to the fact that more than 70% of healthcare expenditure is concentrated in the last six months of life<sup>59</sup>. Early activation of PC is systematically associated with a significant cost-saving effect, particularly in the presence of comorbidities with respect to the dominant disease<sup>60</sup>. Of course, this awareness should not become the main reason for their enhancement. PC is not a 'cost-effective' option and therefore to be favoured even when there are other treatments that are still effective but more expensive, thus sacrificing the duty to offer the best available treatment to the need to contain NHS costs. Patients' decision-making autonomy could also be*

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<sup>54</sup> "Major end-stage organ failure: intensive care or Palliative Care?" Shared paper SIAARTI and other scientific societies 2011.

<sup>55</sup> S. LAMBA, R. NAGURKA, A. ZIELINSKI, et al., *Palliative Care Provision in the Emergency Department: Barriers Reported by Emergency Physicians*, "J Palliat Med" 2013 Feb; 16(2):143-7.

<sup>56</sup> G. CASALE, C. MAGNANI, R. FANELLI, et al., *Supportive and Palliative Care Indicators Tool (SPICT™): Content Validity, Feasibility and Pre-test of the Italian Version*, "BMC Palliat Care" 2020; 19 79.

<sup>57</sup> It is obviously intended to include cancer and non-cancer patients. See, for example, V. VALENTI, R. ROSSI, E. SCARPI, et al., *Identification of Palliative Care needs and prognostic Factors of Survival in Tailoring Appropriate Interventions in Advanced Oncological, Renal and Pulmonary Diseases: a Prospective Observational Protocol*, "BMJ Open". 2023 May 30; 13(5):e065971.

<sup>58</sup> X. LUTA, B. OTTINO, P. HALL, et al., *Evidence on the Economic Value of End-of-Life and Palliative Care Interventions: a narrative Review of Reviews*, "BMC Palliat Care" 2021 Jun 23; 20(1):89.

<sup>59</sup> G. SCACCABAROZZI, F. LIMONTA, E. AMODIO Hospital, *Local Palliative Care Network and public Health: how do they Involve Terminally Ill Patients?*, "Eur J Public Health" 2017 Feb 1; 27(1):25-30. K. SPILSBURY, L. ROSENWAX, *Community-based Specialist Palliative Care is Associated with Reduced hospital Costs for People with Non-Cancer Conditions during the Last Year of Life*, "BMC Palliat Care" 2017 Dec 8; 16(1):68.

<sup>60</sup> P. MAY, C. NORMAND, J.B. CASSEL, et al., *Economics of Palliative Care for Hospitalized Adults with Serious Illness: A Meta-analysis*, "JAMA Intern Med" 2018 Jun 1;178(6):820-829.

*negatively affected if they perceive pressure to adopt PC for economic reasons. Lack of transparency on such sensitive issues could erode the relationship of trust between patients, families and care providers, and communication about treatment decisions itself could become difficult. PCs should be valued for their support of patients' quality of life and dignity, not for the savings they may provide.*

In order to ensure that the decision to opt for PC is not unduly influenced by economic reasons, but is based exclusively on the care needs of patients and families, the NCB recommends:

1. providing continuous and in-depth training for health personnel on ethical issues of responsible resource management, support research aimed at this goal and encourage investment in the development of PC networks in this perspective.

2. promoting open and honest communication between carers, patients and families about treatment options, clearly setting out costs and benefits and ensuring full transparency about possible economic considerations and issues.

3. implementing continuous review, evaluation and feedback processes on clinical decisions, with a particular focus on balancing economic considerations with the well-being and dignity of the individual.

4. Set up policies to prioritise adequate financing of PC by central and regional bodies, both in terms of the re-use of savings derivable from PC themselves, and in terms of a more appropriate direct allocation of financial resources.

## **6. Training and information**

*Training in PC is a fundamental element to ensure quality care and to foster understanding, positive attitudes, and trust on the part of both healthcare personnel and families and the community at large<sup>61</sup>. In Italy, the issue was incisively outlined in Article 8(1) of Law 38 of 2010, initiating a fruitful discussion on the need for specific training courses, facilitating the launch of Level I and II Masters in PC and enabling the establishment of the School of Specialisation in Medicine and PC. In parallel, Article 4 of the same law promotes the activation of large-scale information campaigns aimed at the population.*

*In spite of the regulatory and educational efforts undertaken, a persistent weakness emerges and the educational offer is insufficient and deficient. In pre-graduate training - in terms of credits allocated and dedicated university courses - the teaching of PC is, in fact, marginalised. The dominant approach to care, in medical education, remains mainly focused on disease management and offers limited space for understanding the complexity of the human condition, especially in relation to end-of-life scenarios<sup>62</sup>. The Master degrees that have been activated do not confer a professional qualification. This means that, despite the acquisition of specific knowledge and skills in the field, participants in such training courses do not receive formal recognition attesting to their specialisation in PC practice. At the same time, the establishment of the School of Specialisation in Medicine and PC, while representing a significant step towards the expected qualification of medical personnel, underlines the existence of a significant gap in post-graduate training for other professions. It emerges, moreover, the absence of inter-professional training paths that can guarantee homogeneity in training levels among the various figures involved in palliative care. This situation can lead*

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<sup>61</sup> W.W. LI, J. CHABRA, S. Singh, *Palliative Care Education and its Effectiveness: a Systematic Review*, "Public Health" 2021 May: 194:96-108.

<sup>62</sup> J. PIETERS, D.H.J.M. DOLMANS, D.M.L VERSTEGEN, *et al.*, *Palliative Care Education in the Undergraduate Medical Curricula: Students' Views on the importance of, their Confidence in, and Knowledge of Palliative Care*, "BMC Palliat Care" 2019; 18(1): 72.

to a disparity of skills and knowledge between physicians and other health professionals, such as nurses, psychologists, social workers and rehabilitation therapists, resulting in a less effective collaboration with respect to the multidimensional approach needed to address the complex challenges associated with PC.

Finally, there is a shortage of university lecturers specialised in PC, capable not only of teaching it, but also of facilitating its recognition and integration in the academic landscape. Moreover, even though Law 38 provides for awareness-raising campaigns, the actual implementation and impact of these campaigns do not seem to have bridged the information gap, leaving large sections of the population without any essential knowledge about not only CP, but also and even more about pain management. Thus, it remains the old taboo identifying these treatments with those addressed only to the so-called 'terminal' patients.

To ensure that the PC team has the necessary training, skills and ethical sensitivity to guarantee optimal quality of care, and that the population is adequately informed to use PC appropriately, the NCB recommends:

1. expanding and enriching pre-graduate education<sup>63</sup>, ensuring that all healthcare professionals have the necessary skills to identify the need for PC at an early stage in any healthcare setting and to provide quality care to people with uncomplicated needs during a serious and non-recoverable illness. It is recommended to promote an educational approach that overcomes the reductionist approach focused exclusively on the disease, preparing professionals to manage, with empathy and competence, the challenges associated with all the stages of transition to death, valuing the dignity and complexity of the human experience.
2. establishing compulsory post-basic training courses for all health professionals working in the field of PC, to ensure the acquisition of advanced skills necessary to secure high quality care. This recommendation also aims to promote a homogeneous level of training and competence among professionals within the same group and to reduce disparities in the quality of care provided in different healthcare settings.
3. actively promoting continuous training for health workers and volunteers, to enhance the skills already acquired and enhance personal and professional commitment, including through recognition and certification mechanisms that incentivise health workers and volunteers to pursue excellence in their area of intervention.
4. to foster a comprehensive view of medicine, both as a discipline aimed at the treatment of illness (cure) and as attention to the subjectivity of the patient (care).
5. enriching all training programmes with specific modules on applied bioethics<sup>64</sup>, providing the tools needed to address the ethical dilemmas associated with the therapeutic and diagnostic treatments that are implemented in the course of illness at the end of life, and promoting an educational approach that enhances both the scientific-experimental and humanistic dimensions. The latter must accompany the clinical management of symptoms and be understood as an openness to all dimensions of human experience, including individual values, beliefs and needs.
6. establish effective evaluation and monitoring mechanisms for PC training, with the aim of detecting strengths and areas for improvement and ensuring that training provision keeps pace with emerging needs in the field. In parallel, it is recommended to establish a continuous and constructive dialogue with all the stakeholders, including healthcare professionals, patients, families and associations, in order to gain a deeper understanding of training and information-education needs.

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<sup>63</sup> G. BIASCO, T. BELLINI, A. LENZI, *La formazione pre-laurea in cure palliative e in terapia del dolore: una raccomandazione*, "Medicina e Chirurgia" 2018; 77:3446-3450.

<sup>64</sup> G. SCHOFIELD, M. DITTBORN, R. HUXTABLE, *et al.*, *Real-World Ethics in Palliative Care: A systematic Review of the Ethical Challenges Reported by Specialist Palliative Care Practitioners in their Clinical Practice*, "Palliat Med" 2021 Feb; 35(2):315-334.

7. Encourage the training and recruitment of university lecturers specialised in PC, in order to ensure qualified teaching and facilitate the recognition and integration of the discipline in the academic landscape. Valuing and integrating experts with solid practical experience into training courses. The latter, both in hospices and at patients' homes, should always be included in training.

8. design and implement information campaigns aimed at the general population, ensuring that they are clear, up-to-date, effective and easily accessible. It is essential that the competent bodies at national and local level, healthcare institutions and professional associations work in a coordinated manner on these initiatives, with the aim of creating greater awareness among the population around end-of-life issues and in this way facilitating access to quality PC.

## 7. Research

*There is convincing evidence that PC is associated with improvements in the quality of life of critically or terminally ill patients, especially regarding pain and symptom management and psychosocial support<sup>65</sup>. However, there are considerable shortcomings in the quantity and quality of scientific literature on PC<sup>66</sup> and the Cochrane reviews themselves still fail to provide conclusive evidence for clinical practice, as primary studies are few, small, clinically heterogeneous and of poor quality. As is well known, in medical research, randomised controlled trials are considered the gold-standard for establishing the effects of treatments, but in PC, such studies often encounter numerous methodological problems<sup>67</sup>, to which are added further factors that hinder research, such as: the lack of specific funding; the lack of adequately trained personnel; the difficulty of recruiting and monitoring patients over time; ethical issues that arise when research is conducted on seriously ill and/or dying subjects and on families already severely tried by suffering<sup>68</sup>.*

*There is, therefore, a vast field of research yet to be explored, both in relation to effective interventions to address psychological, social and spiritual issues, and in terms of pharmacological strategies.*

*Challenges also emerge in translating research findings into clinical practice: the uniqueness and complexity of patients' needs can make it even more difficult to directly apply information drawn from research, just as the not always optimal communication between researchers and clinicians can frequently slow down the adoption of new findings in daily practice<sup>69</sup>.*

To overcome the challenges that hinder the advancement of research and its application in PC, and with the aim of ensuring that each patient receives the best care available, the NCB recommends:

1. increase funding for research in the field of CP, in particular CP pain management, and the conduct of clinical trials, with the aim of comprehensively exploring their various

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<sup>65</sup> I.J. HIGGINSON, C. EVANS, *What is the Evidence That Palliative Care Teams Improve Outcomes for Cancer Patients and Their Families?*, "Cancer J" 2010 Sep-Oct; 16(5):423-35.

<sup>66</sup> D. HUI, J. ARTHUR, S. DALAL et al., *Quality of the Supportive and Palliative Oncology Literature: a Focused Analysis on Randomised Controlled Trials*, "Support Care Cancer" 2012; 20, 1779-1785.

<sup>67</sup> B. WEE, G. HADLEY, S. DERRY, *How Useful are Systematic Reviews for Informing Palliative Care Practice? Survey of 25 Cochrane systematic Reviews*, "BMC Palliat Care" 2008 Aug 20; 7:13.

<sup>68</sup> E.K. CHEN, C. RIFFIN, M.C. REID, et al., *Why is High-Quality Research on Palliative Care so Hard to do? Barriers to Improved Research from a Survey of Palliative Care Researchers*, "J Palliat Med" 2014 Jul; 17(7):782-7.

<sup>69</sup> W.G. KERNOHAN, M.J. BROWN, C. PAYNE, et al., *Barriers and Facilitators to Knowledge Transfer and Exchange in Palliative Care Research*, "BMJ Evid Based Med" 2018 Aug; 23(4):131-136.



aspects and bridging the gap between the need for effective interventions and the current state of research.

2. fostering collaborative networking between clinicians and researchers to promote knowledge sharing, interdisciplinary collaboration and the effective transfer of research results to clinical practice, taking into account the need to integrate the best available evidence with the needs, preferences and values of the patients and their families.

3. stimulating research and development of new treatments specifically geared to the multiple needs of PC patients and especially to 'orphan symptoms', which do not receive sufficient attention in everyday research and clinical practice (e.g., but not limited to, hiccups, itching, dysgeusia, hyperhidrosis).

4. aligning national research efforts with international trends and priorities to ensure an effective and synergetic contribution to global knowledge in the field of PC.

5. promoting sound guidelines for conducting studies on seriously ill and/or dying subjects, ensuring the right balance between protecting the rights and welfare of patients and the importance of conducting research to contribute to scientific progress and the development of new therapeutic approaches.

## Conclusions

The NCB recognises PC as comprehensive and integrated care, aimed at preserving and improving the quality of life of patients with serious and progressive illnesses and their families, and tailored to their specific needs to alleviate their pain and suffering. PC, firmly anchored in medical practice, adhere to a care model that accepts the dying process as an event to be accompanied, without intending to accelerate it, or delay it in an unreasonably obstinate manner<sup>70</sup>. This model is realised in care settings (home, hospices, hospitals, nursing homes) characterised by an interdisciplinary approach, in which different professionals collaborate closely with patients and families, actively including them in the decision-making process concerning their care pathways. The NCB considers of great value the ability of PC to blend scientific rigour and humanistic sensitivity, creating places of care centred on relationships, where the empathic dimension is harmonised with scientific evidence, enhancing both the patient's individuality and the skills of the health professionals involved.

Therefore, the NCB, recognising the principles and values intrinsic to PC, recommends:

### to the Institutions in charge of health policies

- The determination to pursue strategies to strengthen and enhance PC networks and services, adhering to the principles of *Equity* and *Social Justice* and ensuring a distribution of resources, currently scarce, that facilitates uniform access to quality PC throughout the country.

- Respect for the *Dignity* of the Person and his or her *Autonomy* as a marker of health care decisions that are oriented towards the continuous and unconditional support of patients and their families, especially in the phases approaching the end of life.

- Concrete recognition of the value of the *Solidarity* commitment witnessed daily by so many families and *caregivers* in caring for patients.

- The importance of *Innovation*, which is to be pursued in the PC sector through continuous improvement of the quality of care, also through research, which is currently totally insufficient in our country.

- Countering prejudice and misconceptions by educating and informing the

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<sup>70</sup> See National Committee for Bioethics, Opinion of 18/7/2019, cited above.

population, promoting a culture that values *Public Awareness* and *Participation* in health policy decisions on PC.

- An adequate level of organisation, rationalisation and financing of CP in order to urgently address the delay in its provision to all potential needs in the population with adequate quality and quantity standards.

#### **to Health Organisations (Companies and Services)**

- The enhancement of PCs, adopting organisational Network models based on the principles of *Integration* and *Competence*, to effectively coordinate care and transitions and aiming to achieve levels of care excellence, starting with primary care.

- The importance of ensuring *Compassionate care* supported by Scientific Rigour.

- The development of organisational policies inspired by the values of *Accountability*, to promote continuous improvement in the quality of care, and the values of *Transparency*, for the sharing and dissemination of clear and open communication strategies within healthcare organisations.

- The removal of unnecessary bureaucratic routes that make *Access to PC* arduous and the guarantee of the *Availability of* drugs and medical devices and aids deemed useful for the treatment of symptoms, favouring the availability of time, humanity, empathy and understanding.

- *Sustainability*, with the aim of proactively addressing emerging PC challenges through responsible and ethical resource management.

#### **to Educational Institutions**

- The promotion of a culture of excellence in PC, ensuring adequate training courses and thus contributing to the recognition and enhancement of the *Professionalism* of the operators.

- The relevance of a pedagogy that combines *Science* and *Humanity*, suggesting the adoption of inter-professional training models, enriched by high *Ethical standards*.

#### **to Health Care Professionals**

- Commitment and expertise in a caring practice geared towards ensuring the best possible *Quality of life* for patients and families, through effective clinical management of pain and suffering, based on relationships characterised by *Empathy* and *Respect*.

- The importance of *Communication* with patients and families, especially when dealing with sensitive, sensitive and critical news, in order to reduce the emotional impact and facilitate processing, in order to support informed decisions and shared planning of the treatment pathway.

- The importance of inter-professional collaboration, which must be pursued with active involvement of all professionals working at all stages of the disease.

- The promotion of PC as a *strategic priority* in the landscape of medicine, which always has the task of ensuring quality practice that ensures both clinical effectiveness and the safeguarding of patients' dignity and rights.

- The commitment to work in an *Interprofessional Work* actively involving patient and family.

## ***A personal remark by Prof. Luca Savarino and Prof. Grazia Zuffa***

We have expressed our favourable vote on the document because it is very clear and comprehensive and can become a guide for institutions towards the ethically significant goal of enhancing the provision of palliative care, which is currently largely insufficient, within the entire Italian socio-health system. In particular, we appreciate the notion that the realm of palliative care should not be confined to end-of-life care alone, and the suggestion of an approach to medicine (valid – it is important to emphasize - not only for palliative care) that focuses not only on the objective aspects of the disease (and the search for scientifically effective treatments) but also on the patient's subjectivity, that is, on the experience of emotions, beliefs, and experiences gained in their life story. The valorisation of subjectivity is all the more important when the person, facing the prospect of imminent death, is confronted with the difficult and absolutely personal task of confronting life's limits; and it is all the more precious for giving meaning to the concept of human dignity, within the concrete framework of 'sense and sensibility' of the patient.

However, some aspects of the document have raised our perplexity. As stated in the Introduction, the opinion chooses to focus on enhancing and developing palliative care, deliberately setting aside other, more controversial themes, such as the relationship between palliative care and medically assisted suicide. We consider this choice undoubtedly appropriate, if only because the link between palliative care and assisted suicide requires in-depth discussion and is bound to register differences of position (as already evidenced in the 2019 NCB opinion 'Bioethical reflections on medically assisted suicide'). This claim of neutrality notwithstanding, there are some assertions in the text regarding the relationship between the two themes. We refer in particular to a passage in the introduction which states that 'the well-established experience of palliative care teams shows a tangible preventive effect' with respect to the possibility of the patient expressing the desire to hasten death and to the statement contained in paragraph 3, which says it is necessary to keep 'the role of palliative care well distinct from assistance in suicide - should the patient express this intention'. It is not clear whether this second statement should be understood simply as a (trivial) clarification of a regulatory nature, or whether such emphasis is again alluding to the 'preventive' value of palliative care in relation to voluntary death.

On this point, we believe a clarification is appropriate, which we intend as a contribution to the document and not as anticipation of future themes that the NCB will decide to address.

The perspective of the patient must be distinctly separated from that of the healthcare institution and therein of the individual operators called upon to provide palliative care. We do not at all mean to deny the observation that in the experience of operators, a good offering of palliative care can limit the patient's request for assisted suicide, but suggest that this same observation requires a fundamental addition: palliative care, which statistically may have a preventive effect with respect to the request for medically assisted suicide, is at the same time a *fundamental prerequisite* for ensuring the patient's full exercise of their autonomy, which could lead him to request assisted suicide. This is something the document itself recalls when it emphasizes that an essential requirement for admitting the non-punishability of assisted suicide is precisely the effectiveness of the right to palliative care.

This makes all the more pressing the duty of institutions to equip the socio-health system with an adequate offer of palliative care. And it is obvious that any deficiencies in the provision of palliative care cannot in any way be considered an obstacle to fulfilling the request of an individual patient. It would indeed be ethically illegitimate to constrain the patient's freedom by reversing the possible shortcomings of the healthcare institutions onto him/her.

In conclusion: experience shows that palliative care statistically reduces the demand for assisted suicide, but also demonstrates that it cannot always respond to all the needs of the patient facing the terminal phase of his life. The personal struggle of confronting one's own

death is evidently well beyond the provision of better conditions for spending the remaining time of existence with less pain and suffering. Even palliative care, like the medicine of healing, here encounters its own intrinsic limit, because it cannot always succeed in responding to the existential suffering of the dying.

Luca Savarino

Grazia Zuffa

## ***A personal remark by Prof. Maurizio Mori***

### **Against the (implicit) ethics of the Palliative Care model presented in the Opinion**

I intend to explain here the points where I disagree with this Opinion on Palliative Care (PC), which is also the first of the Vescovi Presidency. The National Committee for Bioethics (NCB) 'for the first time' undertook to present 'in a systematic way' what PC are, and did so in order to 'urge politics' to implement and promote PC as a 'top priority' for Italian healthcare and for our entire society: an undoubtedly lofty and highly important goal. Moreover, as the President points out in his presentation, PC have as their own theme the end of life, and thus raise issues that 'deeply question our conceptions of dignity, suffering, and death' and that necessarily intersect with the issue of 'voluntary death', i.e. assisted suicide and euthanasia: another issue of great importance given that in our time the first steps are being taken to establish a new social practice in this regard.

Since the subject of voluntary death is controversial and there are different ethical and legal profiles on it, the CNB decided not to address them in this Opinion. As the President writes in his Presentation, they are only 'distinct' and therefore that they can 'actually be read together', so the Opinion merely noted that 'in many cases the request to be helped "to" die can be reformulated as a request to be helped not to suffer, but it is equally true that this does not apply in all situations and for all patients'. On the basis of this non-oppositional reading, the Opinion avoided the controversial issues of the end of life that "might have distracted the attention from the objective of illustrating the reasons for the necessary strengthening of Palliative Care" and limited itself to examining the question of "the possible question of anticipating death [...] as a moment in the doctor-patient relationship and the associated communication responsibilities".

The commitment to find ethical convergences is certainly appreciable, but since there is a clear contrast on voluntary death, some convergence can perhaps only be achieved after bringing it forth and making explicit the different positions in the field. The choice to avoid the subject, however, has led to the position against voluntary death remaining implicit and entrusted to a few allusive references and passages with nuanced tones. Based on this implicit position, the Opinion identifies a single model of PC, which is the one that prevails today. My disagreement is not with PC per se, which if understood as a mere palliative pathway, i.e. as a set of clinical-social interventions aimed at alleviating human suffering at the end of life, are certainly good and should be supported with strength and determination. What is more, they constitute real progress in civilisation, in line with the more general perspective that promotes respect for people's choices, autonomy and the blossoming of self-realisation.

My dissent is limited to the specific model of PC presented in the Opinion, a model which proposes PC as an *alternative* to voluntary death in the sense that its provision would be such as to *prevent* voluntary death, making the choice to 'anticipate one's own death' an entirely marginal and secondary practice both statistically and morally. PC, on the other hand, is a *complementary* pathway to voluntary death, in the sense that the provision of PC in no way precludes the choice for voluntary death: PC in itself is a set of techniques and practices, a pathway which, as such, is *neutral* with respect to ethical choices on how to die, and must remain *open* to different options. PC in this sense, I repeat, is an advancement of civilisation and must be promoted and implemented immediately and without delay. However, the reference to the 'holistic approach' should be avoided, the gateway through which the ancient Hippocratic idea of nature as the norm is reintroduced into the palliative pathway, thus making the PC model proposed by the Opinion a specific 'medical philosophy' or a kind of 'philosophy of life' that does not conform to scientific medicine and the ethical needs of

people who today put autonomy and self-realisation first - not the following of nature as the norm.

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In order to clarify in what sense the Opinion takes a precise position on the issue of voluntary death and espouses (albeit tacitly) a specific 'medical philosophy', I will begin here with an examination of two general background points. The first concerns the nature of medicine as a scientific enterprise.

Unlike what happened in other areas of science (astronomy, physics, etc.) in which the paradigmatic revolution was explicit and clear to all, as far as the biomedical field is concerned, a real 'revolution' took place without any clear perception: in the last century, within the space of a few years, medicine grew so much as to lead to the acquisition of control over the life process, and this led to a paradigm shift from the established Hippocratic model. In the Hippocratic paradigm, medicine was only 'therapeutic' in the sense that it limited itself to helping nature where nature was in difficulty, with the physician acting as a mere assistant to the natural biological process, which because of its own intrinsic finalism established the (ethical) norm to be followed. Today, on the other hand, medicine can modify the biological process and no longer follows nature as the norm, but rather transforms nature and moulds it to meet human needs. Biomedical engineering, assisted reproduction, cosmetic surgery are just a few examples of what is sometimes (in a derogatory tone) called the 'medicine of desires'<sup>71</sup>, the mature fruit of scientific medicine that has now abandoned nature as its norm.

A paradigmatic revolution is always something grandiose that produces undoubted successes but also significant disruptions. In our case, the acquisition of control over the life process has been combined, for example, with the fact that scientific medicine has become impersonal and detached from the humanistic dimension, and this has led to discomfort. I am not going to list its other faults here, but I do want to point out that, apart from blatant inconsistencies and other entanglements, scientific medicine has abandoned nature as an ethical reference standard, and that on this level it acts as a technique at the service of people's needs: it is the 'medicine of desires' that provides contraception, assisted fertilisation, etc., and now even assistance in voluntary death, where this is required.

On the contrary, the Opinion states that PC is proposed as a 'comprehensive approach that should belong to all areas of medicine', thus suggesting that it is foreign to scientific medicine (which would instead be reductionist), so much so that footnote 4 states that the literature speaks of a 'holistic approach' for this: an approach that envisages 'the rigorous application of the scientific method for the diagnosis and treatment of specific illnesses, while aiming at this broader understanding of human wellbeing', i.e. a wellbeing capable of including in the *pallium of PC* 'not only the symptoms related to the disease, but all the physical, psychological, social and spiritual aspects of a care that *remains active until the last moment of life*' (emphasis added).

This last clarification about care 'active until the last moment of life' is extremely significant because on the one hand it reveals how the holistic approach is a way of reintroducing nature as an ethical norm, and on the other hand because it refers to the second basic point that needs to be made explicit here, voluntary death. As we have seen, attempts were made

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<sup>71</sup> The expression 'medicine of desires' is an unfortunate one because in Italian, when one speaks of 'desire', one's thoughts run to the ice cream or cool drink desired when it is hot, that is, to something superfluous and perhaps even a little frivolous. In contrast, in the medical field, above mentioned desires refer to a person's deep-seated needs that are essential for the realisation of one's life plan. Although aware of all this, I use the expression both because it is now widespread and because it was used many times by the late Carlo Flamigni, and its revival here is intended as a deferential tribute to his memory.

in the Opinion to avoid it by saying that it is an issue like others and that dealing with it would distract from other more pressing issues. Instead, the issue of voluntary death is by no means an issue like any other, but is inevitable and 'crucial' in the literal sense of the term, which derives from '*experimentum crucis*': the test that decides between two opposing perspectives. Death, the lapse of time that brings life to a close, is a window of time that is "crucial" because it is not a phase like any other, but has a very special significance because it decides between two opposing visions: for those who are religious and see existence as a pilgrimage to the beyond, how to die decides a person's eternal destiny; while for those who are secularised, how to die is a fundamental part of their life project and therefore has a decisive significance for the crowning of their existence.

In both worldviews, how to die is 'crucial', which is why the ethical conflict over whether voluntary death is licit or not is inescapable and must be made explicit. The point is even more important because today it concerns not only the level of ideas, but also the practical-institutional level. Indeed, the possibility of access to medically assisted suicide means that the foundations are being laid for a new mass social practice: that of voluntary death. In the past, the practice of voluntary death was limited to a small elite (Cato, Seneca, and a select few others), while today it is an option open to all. For now in Italy it is limited to exceptional cases and some say it will never exceed the 4-5% threshold as it seems to be today. But we do not know what the future holds for us, and there are various factors to consider, such as the increase in longevity, the type of pathologies, and changes in values: should life expectancy, for example, become 250 years and values change significantly, it could be that requests for voluntary death will also increase, and that the percentage will rise, and by a lot. Can it be ruled out that it will become the norm? Who knows ...!

We do not know if and how the new mass social practice that is taking its first steps in Italy today will develop. In order not to close the doors to a prospect that today is in its infancy, but which may well develop, I disagree with the PC model proposed by this Opinion, which instead moves in the opposite direction. Having clarified the general reasons for my disagreement, I now move on to identify four more specific points of disagreement with the Opinion. By necessity I have had to be brief, and I apologise if I have not managed to reconcile conciseness with due clarity.

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**First: 'anticipation of death'?** The Opinion states that the development of PC is 'crucial for the guarantee of dignity of persons with major chronic-evolving diseases that are not amenable is crucial for guaranteeing the dignity of people suffering from serious and evolving diseases that cannot be cured' and that the WHO urges that PC be considered 'a fundamental human right'. The fact that the development of PC is 'crucial for guaranteeing the dignity of people ' and its provision is a 'fundamental human right' by implication leads one to believe that, in the absence of PC, neither dignity nor respect for the basic human rights of the persons in question are guaranteed. This claim seems excessive and perhaps even a bit self-referential.

This is even truer if one considers that the PCs involved refer not to PC per se, but to the specific model proposed by the Opinion, so it becomes important to understand well what it says. The Opinion emphasises that PCs are careful to avoid both obstinacy and therapeutic abandonment because death is to be seen 'as a "normal" process which is an ineliminable part of life'. Prospecting death as part of life makes death something analogous to other events in life, and therefore something to be accepted like the others. Hence the idea that PCs accept " an event to be accompanied, without intending to accelerate it, or delay it ". PC does not anticipate or postpone death, but allows it to happen according to its own given (natural) destiny, and in grasping the value of this point lies that "broader

understanding of human well-being" that constitutes the differential character of PC with respect to scientific (reductionist) medicine: a perspective well condensed in Cicely Saunders' famous phrase: "you are important [...] until the last moment of your life". This is why those who accept this model of PC see 'wish to anticipate death, even when he or she is looked after by a PC team' as something abnormal and strange, to be explained not as an autonomous choice but as 'a reaction to suffering, in the context of a life-threatening condition, from which the patient sees no other way out than to hasten his own death. In short, something immediate, if not unconscious, so much so that "the well-established experience of PC teams shows a tangible preventive effect in many cases" of PC themselves against the anticipation of death.

This, in short, is the 'medical philosophy' that informs the PC model proposed by the Opinion. The error of the perspective lies in the very beginning of the discourse, namely in believing and making people believe that the death of the person is a 'normal' process that is part of life. This may be true for other animals, but not for human persons, because for the individual-person, death is the end of his or her life and therefore cannot be an 'ineradicable part' of that life that ends. If anything, one could say that his individual life is part of the more general life of the family, group or species, but this is different from the former. As soon as the logical leap (from the individual to the group) inherent in the initial proposition becomes apparent, it also becomes clear that that thesis is the flywheel of the general idea of life as a (natural) cycle from which derives the central operative conclusion in the PC model presented that life and death are events to be welcomed and accepted as others, and that specifically death is neither to be anticipated nor postponed.

However, the very idea of 'hastening death' is wrong, because it conceals the assumption that death has its own specific 'given' (natural) deadline to be respected ethically. Death becomes something analogous to retirement, which occurs at the completion of the work cycle: one can then also ask for early retirement, but only exceptionally and in any case subjecting oneself to some penalty precisely because of the failure to complete the cycle. Similarly, the 'wish to hasten death' is anomalous, because at the very moment it is categorised as 'hastening' it is assumed that the natural cycle is the ethical norm against which non-completion should be assessed. This is why, for the PC-model proposed by the Opinion, 'hastening death' raises a problem that does not fit in with the 'broader understanding of human well-being' arising from the holistic approach.

On the other hand, instead of talking about 'anticipating/postponing' death, it suffices to say that among humans death 'happens' and that it is permissible for this process to occur from natural causes or by the will of the person concerned, either through withdrawal of treatment (letting die) or voluntary death (euthanasia). PC as a pathway to improve the quality of life of patients is neutral about the latter choice, which is up to the person concerned, and this dissolves all other problems.

**Secondly, the role of the family?** PC poses itself as an alternative model of medicine to the scientific one because the holistic approach leads to "comprehensive and integrated care" and to a "broader" understanding of human well-being than that based on the individual's wishes, which is characteristic of wish medicine. In this line the PCs aim to 'improve the quality of life "of both the patient and his or her family, considered as a single entity of care", and in footnote 3 the Opinion immediately states that 'family' are those persons whom the patient 'freely identifies as important' to him or her, regardless of legal constraints.

From an 'ideal' point of view, the specification in favour of the 'family of affections' is welcome, but it appears rather irenic because in the concrete reality of things one cannot ignore the legal family members and the possible conflicts between them and the affective family members. Apart from this, it is not a little surprising that for the PC model presented,



patient and family are 'a single entity of care': unitary, undifferentiated and without precise priorities or hierarchies.

Besides being inapplicable, this thesis about the patient-family entity is contrary to recent bioethical ethos and does not comply with Italian law. To understand that it is inapplicable, one only has to ask oneself what to do if at the same time the patient and two or three family members need some kind of care: if patient and family are 'one entity of care', to whom should precedence be given? Can it be argued that it is right for the patient to come after the family members? Regardless of these thought experiments, it is clear that both widespread ethical sensibilities and Italian legislation place the patient at the centre, and that family members are subordinate and have no right to be involved in care decisions unless the person concerned so wishes. When it comes to shared care planning, it is clear that in principle the decision is the patient's and the patient's alone, even if in the majority of cases we know that doctors share the decision with family members because the person concerned is confused and has in any case involved and delegated family members in the decisions, but this does not change the fact that the person concerned remains at the top.

Instead of emphasising this obvious point, the opinion on several occasions stresses that the interdisciplinary and integrated approach (holistic approach) proper to PCs means that they encompass 'the patient, the family and the community' as a whole, including friends. Already the failure to clarify the priority of the patient over the family is in itself a source of insuperable difficulties, but the further extension to the wider community makes the argument incomprehensible. One wonders why there is so much insistence on the patient-family dyad as the 'one entity of care' instead of clarifying the hierarchy of precedence.

Not being able to find precise and direct answers to the question, one wonders whether the repeated involvement of the family, itself considered as a caring entity, is not a way of reinforcing the idea of death as a natural process and part of (wider) life; or why the production of meaning is a collective process and the family is an entity capable of being the source of those meanings without which - according to the common opinion - the patient would be tempted to 'anticipate death'. Both responses converge in noting that the active inclusion of family members 'in the decision-making process' is supported for its preventive effect of 'anticipating death'. Having rejected the latter thesis, even more reason not to accept the idea of patient and family as a single entity of care, another return to old and obsolete models. The patient must be put back at the centre, and family members in a subordinate position.

**Thirdly, telling the truth?** In Hippocratism, the doctor had the 'therapeutic privilege', i.e. the discretionary power to tell or not to tell the patient the truth about the clinical condition. In the 1970s, the emergence of bioethics led to the criticism of the therapeutic privilege and the affirmation of the right to know: receiving bad news is not pleasant and often creates great bewilderment and serious upset, but the person has the right to know what is concerning his or her condition, and this must be done. It is all too obvious that when it comes to giving bad news, it is appropriate for the giver to have empathy and tact, but information must be given, which is why in some countries written communication is also done.

Based on this background ethos, the expectation was that the PC would promote without any delay and hesitation the practice of always telling the truth, even knowing that that 'always' is stated in a weak sense, because it is well known that in some very special situations the exception that leads to not telling may be justified. It must, however, be clear that in the first instance the rule prescribes loud and clear that the doctor must tell the truth, and that whether to tell it is no longer at his discretion. No! the doctor must always tell the truth, even if he may then, in specific cases, see such serious exemptions that justify the exception of not telling. But the situation is reversed with respect to before: the therapeutic privilege guaranteed the doctor wide discretion as to what to say and what not to say, so it was he who

evaluated without having to justify anything, whereas now it is the exact opposite, because the doctor must tell the truth and, possibly, provide articulate and solid explanations for having omitted this duty.

Because the situation outlined above is a widespread one, the expectation was that even the PC would strongly and unhesitatingly affirm the doctor's duty to tell the truth. Instead, the dedicated paragraph starts from the idea that 'the time of communication between doctor and patient constitutes time of care' to immediately say that as far as health is concerned '*the duty to provide information [...] is measured by the clinical and psychological peculiarities of these patients*'. Obviously, there are many different reasons why what is created is a "*very special communicative context*" that refers to a "more general cultural problem" related to medicine focused on healing instead of accompanying. Awareness of this situation leads one to say that "to ensure respect for the patients' right to be informed about their health condition [...] without compromising their emotional and psychological well-being and that of their family" the conditions listed must be respected, the first of which is that "both patient and family members do not embark on a PC pathway without first being fully aware of what this entails".

This clause is not easy to understand, but without dwelling on the point here, I note that when one goes on to examine the other clauses specifying what the PC pathway entails, one reads that communication must take place "with the patient and family in a bearable and progressive way. This does not mean concealing relevant information. On the contrary, the intention is to enable the patient to receive it in accordance with his or her ability to understand and process it'. It is astonishing that it is not specified from the outset that communication is to be done first with the patient and then, possibly, with the patient's consent, with the involvement of the family. We really do not understand why communication is to be 'with the patient and the family', except by referring back to the already seen and unacceptable thesis of patient-family as the 'sole caring entity'. It is still unclear in what sense communication is to be given "in a bearable and progressive manner [and ...] in accordance with his or her ability to understand and process it ". One wonders who it is that assesses the capacity for understanding, for if it were in the hands of the physician it would be a return to therapeutic privilege.

**Fourth: Compassionate care?** Lastly, I note that in the conclusions, and more specifically in the recommendations to "Health Organisations (Companies and Services)" the Opinion emphasises

"The importance of ensuring *Compassionate care* supported by Scientific Rigour'.

The recommendation raises many perplexities first for formal reasons, as it was not presented in the text where, as per established practice, it should have been explained first. Instead, it appears extemporaneously only in the conclusions without any clarification, but it does appear.

Moreover, because it is not clear what is meant by 'Scientific Rigour' written with capital R and S, and whether this expression has the same meaning or a different one from the same expression with lower case initials. This point should also have been clarified immediately because the fact that such rigour is required (which in fact should have been taken for granted!) suggests that in reality Compassionate care is often a kind of 'last resort' subject to misuse. Beyond the catchy name, such Cures make use of drugs whose efficacy has not yet been completed or that have been approved for diseases other than the ones in question. Given these conditions, it is well known that in Italy recourse to this type of Cures mostly involves disguised forms of therapeutic obstinacy on hopeless patients. The inclusion without any explanation and due clarification even of a recommendation regarding Compassionate care reveals how the PC model presented in the Opinion fails to detach itself from the received opinions stemming from Hippocratism.

This observation is important because it involves a more general observation: I have shown that other perplexities have arisen regarding the re-evaluation of the role of the family as the sole caring entity, and others because of certain affinities found between the ancient therapeutic privilege and the modes of communication proposed by the PC model under consideration. One wonders whether, after having taken up nature as a moral reference to reject the 'anticipation of death' and after having reaffirmed the difference between doing and letting it happen as an ontological difference, the proposed model of PC does not come to propose Compassionate care as a ploy to re-propose ancient theses about the continuation of care.

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