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Limits of and Alternatives to Conventional Medicine in the Context of Terminal Illness (e.g., Palliative Care)

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Abstract: This paper aims at analysing the evolution of palliative care in the international context and their role in the path of care for the patient and the family. Method: born in 1967 by Cicely Saunder, palliative care were aimed at assisting the terminally ill, accommodating both the needs of the patient and the family. Not only to be cured or healed, but to be taken care of. The paper examines the definitions of palliative care provided by the World Helth Organization. We observe that palliative care is not only an effective and timely response to the clinical, psychological, social and spiritual needs of the sick person and their family in an advanced and terminal stage, but an integrated care to support specialist treatment in the presence of an advanced disease picture; a space for in-depth study for the sick person and the family so that the sick person can consciously and freely choose the available treatment proposals, their limits and their consequences. A treatment path in which the transparency of the proposals is a condition for building a shared consensus with the patient and adequate communication with the family. Palliative care has acquired its own identity, its own role in the path of care for the patient and the family, pursuing the proportionality of therapeutic options and the support of the patient and the family without discrimination, with equity and equality.

Keywords: Defining palliative care; not cure but care, complexity; advance care planning; bioethics.

Introduction

Chronically ill women and men will experience different disease trajectories in their lives, depending on their health condition and diagnosis. All these paths will come to an end with an expected death according to at least 3 developments: a) a long maintenance of good functionality will be followed by a few weeks or months of rapid decline before death; b) a long period characterized by limitations, in which a gradual decline in functions occurs, interrupted by episodes of acute worsening, during which there is the risk of dying (the time of death remains uncertain); c) a decrease in one’s functionality over a prolonged period, in which the progressive disability and reduction of functions is not linked to the events causing death such as infections, trauma and fractures.

While historically the first case was attributed to cancer and the others to chronic diseases, in reality the new treatments of some types of cancer have changed the path of the disease, the development of which has become more similar to chronic disease.

The trajectories are complicated, however, given that often a chronic disease coexists with others, increasing the complexity of the patient's needs.

A correct understanding of the various developments in existing diseases therefore plays an important role in planning services.

Identifying people nearing end of life influences (Murray et al. 2013; Lynn & Adamson 2003) both the timing of delivery and the characteristics of services; reduces disproportionate care; recognizes that standardized care may not be valid and it is preferable to pursue models of care that assess the disease, its path and the sick person; limits the occurrence of unplanned events, which reduce the use of the emergency system, encouraging the adoption of assistance paths that reflect the socio-health condition and needs; plans a care that integrates the phase of the treatment of the disease to that of the symptoms, palliative care.

In most countries, palliative care services have mainly been provided to women and men with cancer. However, the growing prevalence of chronic diseases, coupled with an aging population has recognized that these clinical conditions can also benefit from such treatments.

The international consensus estimates a need for palliative care equal to 75% of deaths (Etkind et al. 2017; Krug & Kelley 2016).

Based on this premise, the elements for reading current needs, foreseeable developments and those to be implemented in order to ensure the assistance of those people living with a disease that has a poor prognosis will be developed.

I. Method

To offer the broadest international panorama on the development of palliative care, through international sources and research data.

II. Results

II.1. Historical Notes

Although the hospice movement originated in the 11th century, during the Crusades, by the Sovereign Order of St John of Jerusalem, what we now recognize as the modern hospice movement has its roots in 19th century in France, Ireland and the United States. Some historical dates are:

1843: a house for the dying is opened in Paris by the Association des Dames du

Calvaire, which was followed by the foundation of six other places for the care of the dying between 1874 and 1899, in Paris and New York.

1879: The Irish Sisters of Charity open the Hospice of Our Lady for the dying in Dublin, followed by others in Australia, England and Scotland, which still exist today and are run as modern palliative care units.

1900: Hawthorne Dominican Sisters founded St Rose's Hospice in Lower Manhattan and then another one in New York, followed by others in Philadelphia, Fall River, Atlanta, St Paul and Cleveland.

Although unrelated to each other, the leaders of these organizations shared a concern for the care of the dying, and especially the dying poor.

As it is well known, Cicely Saunders founded St Christopher's Hospice in London in 1967, which became a source of inspiration for other hospices. The founding elements on which Cicely Saunders was based were: clinical care, education and research.

Within a few years these principles were practiced in many other contexts: in specialist hospitalization units, but also in home and day care services.

In Canada, on the other hand, hospice palliative care developed to meet the needs of people with cancer in the 1970s. The palliative movement was born in 1974 with the creation of palliative care units in a hospital setting at the St. Boniface General Hospital in Winnipeg and at the Royal Victoria Hospital in Montreal.

In Italy, the Palliative Care movement began in the early 1980s, at the INT (National Cancer Institute) under the guidance of Vittorio Ventafridda. Contrary to what happened at the international level, home palliative care first developed in Italy, supported above all by the third Sector. The first hospice in Italy was established in Brescia in 1987.

II.2. Definitions and Characteristics

In 1990, WHO defined palliative care as follows:

> Palliative care is a series of therapeutic and assistance interventions aimed at the active and total care of patients whose underlying disease no longer responds to specific treatments. The control of pain and other symptoms and, in general, of the psychological, social and spiritual problems of the sick themselves is fundamental. The goal of palliative care is to achieve the best possible quality of life for the sick and their families.

The above definition was changed in 2002 as follows:

> Palliative care is an approach that improves the quality of life of patients and their families who are faced with problems related to life-threatening diseases, through the prevention and relief of suffering, through early identification and an impeccable evaluation and treatment of pain and other physical, psychosocial, and spiritual problems. They
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> - provide for the control of pain and other symptoms that cause suffering;
> - affirm the value of life and consider death as a natural process;
> - do not intend to hasten or postpone death;
> - integrate the psychological and spiritual aspects of patient care;

> - offer a support system to the sick to help them live as actively as possible until death.

The International Association for Hospice and Palliative Care (IAHPC) reformulated the general definition of Palliative Care in 2018 as follows:

> Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

Palliative care:

- Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based;
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care;
- Is applicable throughout the course of an illness, according to the patient's needs;
- Is provided in conjunction with disease modifying therapies whenever needed;
- May positively influence the course of illness;
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process;
- Provides support to the family and the caregivers during the patient's illness, and in their own bereavement;
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family;
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary);
- Can be provided by professionals with basic palliative care training;
- Requires specialist palliative care with a multi-professional team for referral of complex cases;

To achieve palliative care integration, governments should:

- adopt adequate policies and norms that include palliative care in health laws, national health programs and national health budgets;
- ensure that insurance plans integrate palliative care as a component of programs;
- ensure access to essential medicines and technologies for pain relief and palliative care, including pediatric formulations;
- ensure that palliative care is part of all health services (from community health-based programs to hospitals), that everyone is assessed, and that all staff can provide basic palliative care with specialist teams available for referral and consultation;

- ensure access to adequate palliative care for vulnerable groups, including children and older persons;
- engage with universities, academia and teaching hospitals to include palliative care research as well as palliative care training as an integral component of ongoing education, including basic, intermediate, specialist, and continuing education.

II.3. The Needs for Palliative Care

In Italy a joint SICP-FCP working group "Complexity and Networks of Palliative Care" produced in 2019 a review on the needs in palliative care, from which the following data emerge:

> - Gomez-Batiste et al. (Gomez-Batiste et al. 2012) estimated a need for palliative care present in 75% of all deaths/year, including all chronic pathologies with a developmental course and limited prognosis;
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> - The WHO-WPCA (WHO-WPCA 2014) on palliative care states that the incidence of the need for palliative care in the population can be calculated in Europe in about 560 deaths/year for every 100,000 resident adults; of this total number of people, again in Europe, 60% are affected by pathologies other than cancer and 40% by pathologies of neoplastic origin;
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> - In 2017, the publication by Gomez-Batiste and Stephen Connor (Gomez-Batiste & Connor 2017), defines an estimate of the prevalence, in the population of countries with high economic development, of patients with palliative care needs, of 1 - 1.4%. An estimate of the prevalence of the need for palliative care is also defined, present in 40 - 65% of people assisted in residential structures and in 40% of patients admitted to hospital.

In 2021, WHO states that only 1 in 10 people with palliative care needs receive such care today, and that, in 2060, also due to the progressive aging of the population, it is estimated that this need will double.

II.4. Clinical Aspects

Symptom management is an essential aspect of palliative and end-of-life care and five themes have been analysed (Baillie et al. 2018): pain (assessment, management and place of care); breathing difficulties (secretion management); terminal agitation (evaluation and sedation); nutrition (determination of the need and enteral feeding); and hydration (thirst, risk, artificial hydration).

Nutrition and hydration are a major concern, particularly for family members and caregivers. The study highlights the perceptions and experiences of patients, families and healthcare professionals working in palliative care, highlighting the need to improve care, communication and to carry out further research to determine which treatments are most effective.

Despite continued advances in palliative care, symptoms such as pain and shortness of breath remain a priority in the concerns of doctors, patients and families.

Caregivers interviewed also expressed concern that pain was under-recognized in people unable to communicate verbally, particularly people with dementia.

People interviewed showed concern about the place of care and questioned whether symptoms, particularly pain, would be better managed in the hospital or at home. A large survey in the UK showed a preference for the hospital setting and only 27% of respondents indicated domicile, despite 78% of respondents expressing a desire to die at home.

Symptom management, therefore, should be adequate competence in all care locations, to allow patients to stay and die in their preferred care location. The study advocates the need to implement improvements in patient care, supported by a solid scientific research base.

II.5. Psychological Aspects

According to what has been reported in the literature (Mateo-Ortega et al. 2018), an adequate psychosocial intervention can decrease the level of suffering in complex patients, obtaining the same result compared to non-complex patients, thus suggesting that patients with greater complexity could benefit from a specific psychosocial treatment.

The main objective of this study was the analysis of patients with advanced or end-of-life disease, especially those with high levels of suffering or distress.

A further aim was to demonstrate that interventions performed by experienced care teams could improve psychosocial symptoms, even among patients previously treated by a non-specialist care team.

The results showed that patients with higher levels of distress reported improvements in mood, anxiety and stress levels. With meaning-based group psychotherapy the perception of the meaning of life and well-being has improved, just as with dignity therapy the subjective perception of patients with depressive symptoms has improved.

The high percentage (60.3%) of patients classified as complex supports the need for specialized palliative care teams with experience in psychosocial interventions.

The condition of non-complex patients appears to remain relatively stable after psychosocial intervention and, above all, does not worsen over time despite disease progression.

Suffering is usually involved in the process of dying, and an expert psychosocial intervention seems to contribute significantly to keep the levels of suffering tolerable: in this sense, an increase in specialist teams should be evaluated so that more patients can benefit from it.

II.6. Social and Spiritual Aspects

There is no single definition with respect to the social dimension of the quality of life and dying: it includes social relationships, which allow people to have a sense of identity and give meaning to life. This dimension also includes emotional support and assistance in practical aspects, such as financial and information support. Sociability in incurable disease could be defined as the dimension of the human that is related to the way people establish and maintain relationships with others and which concerns the way in which values, norms, rules and roles are respected.

On the contrary, the spiritual dimension seems to have a clear definition. The EAPC Spiritual Care Reference Group defines spirituality as "the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred" (Nolan et al. 2011).

As reported in the literature (Lormans et al. 2021), five main need domains have emerged.

1) Being autonomous:
a. Need to be treated like a person;
b. Need not to lose control;
c. Need to continue life normally;
d. Need to take care of the financial aspects;
e. Need to be informed about one's own clinical picture;
f. Need to receive information about the future;
2) Being connected:
a. To maintain relationships;
b. To care for loved ones and be looked after by loved ones;
c. To communicate and be in contact with others;
3) Finding the dimension of meaning:
1. To accept and find meaning in illness;
2. Having had a life of meaning;
3. Need to be forgiven;
4. Need for completeness;
4) Positive look:
a. Hope;
a. Peace of mind;
5) Dealing with death and dying:
a. Addressing the issues of death and the process of dying;
a. Need to die according to one's own preferences.

A study (Balboni et al. 2013) shows that patients who receive high levels of spiritual support from religious communities are less likely to access palliative care and are more likely to receive aggressive medical interventions at the end of life and often die in intensive care units. These findings were more relevant among racial/ethnic minorities.

Conversely, for patients who received spiritual support from the care team, it was possible to deal with end-of-life discussions and there was less recourse to aggressive and intensive care at the end of life. These results suggest that a possible intervention among patients who rely on religious communities for spiritual support could be to integrate religious spiritual support with that of the treating team.

Religious congregations may not be aware of clinical and prognostic aspects and may not be able to address the issues of death and dying due to lack of expertise. Furthermore, within many religious traditions including Christian ones, most of the population sample analysed showed that there is a strong belief in miracles. Religious communities, then, to support their sick faithful, could emphasize and strengthen faith in a potential miraculous healing.

II.7. Complexity

People who express palliative care needs are heterogeneous and with very different underlying personal needs, both from a clinical and social point of view, which is why the overall situation is influenced by external factors, such as the living environment, the health system, the economic and human resources, the services available, both formally and informally (Pype et al. 2018).

Current evidence suggests that access to specialized palliative care services is only partially related to the requirements associated with such care, while more often determined by diagnosis, age, location and socio-economic factors (Pask et al. 2018).

Complexity is a relatively new concept, defined as the nature of patients’ situations and the magnitude of the resulting needs (Hodiamomt et al. 2019). Classifying patients based on the complexity of their care needs can guide the integration of services, advance care planning, planning of health services and economic and managerial resources, and defining specialist or basic palliative care needs.

A systematic analysis (Grant et al. 2021) assessed six complexity and needs classification systems, which develop and consider different aspects of care needs which show that their application has been limited. The HexCOM and IDC-Pal systems appear to offer the broadest determinations of complexity from an individual perspective.

As a result, more research will be needed to apply these systems to larger populations than those for which they were developed and to appreciate how they can integrate and impact on clinical care.

II.8. Discrimination

With respect to the issue of discrimination, this research analyses some types of people with palliative care needs: rural population, people in prison, LGBT, people with intellectual disabilities.

II.8.1. Rural Population

From a study (Schill & Caxaj 2019) it emerges that there is little literature on this subject. The authors analysed 22 articles referable to palliative care approaches adopted for rural populations in Canada, the United States, New Zealand and Australia. The conclusions reached by the authors are that

> culturally safe strategies invite decolonization of care through awareness of colonialism, racism, and discrimination. They invite commitment to building partnerships, power sharing, and decision-making in the delivery of care. Culturally competent activities may catalyze the adoption of a cultural safety framework; however, mislabeling of cultural competency as cultural safety may contribute to organizational inaction and a watering down of the spirit of cultural safety (Schill & Caxaj 2019).

II.8.2. People in Prison

Barriers to palliative and end-of-life care in prison can be divided into two areas: physical barriers and ideological barriers.

The most commonly identified physical barrier is the prison environment itself: prisons are noisy, with closed cells and management protocols that often prevent inmates from having equal access to care, aggravated by the lack of primary elements such as beds, linens, portable oxygen, etc. Drug administration also poses a number of problems.

Ideological barriers relate to stigma and prejudice, for example with respect to the decision to administer analgesic drugs to individuals labeled as having a history of drug abuse, even if it is over. Another obstacle is the potential conflict between care and safety, but public opinion can also be a barrier, as any investment of money or resources in improving palliative and end-of-life care for prisoners could be viewed negatively or as a secondary priority.

In conclusion, three main needs emerged (McParland & Johnston 2019):

1. Relationships (with friends both inside and outside the prison, and with family members) are of paramount importance to end-of-life inmates
2. Volunteers (and health workers) can forge close ties with prisoners in their care, but they can also experience great discomfort due to their work: actions must therefore be taken to support care workers
3. The regime and the physical environment of a prison create conflicts with the implementation of good practices in palliative care and this element must be considered for proper planning and provision of services for this population.

II.8.3. LGBTQ+ Community

Healthcare professionals and researchers have recently begun to pay more attention to the healthcare experiences of lesbian, gay, bisexual and transgender (LGBT) patients and caregivers (Cloyes et al. 2018). Organizations such as LGBT HealthLink and the National LGBT Cancer Network have made progress in raising awareness and promoting best practice recommendations for cancer care in the LGBT community. In 2017, the “LGBTQ-Inclusive Hospice and Palliative Care” practical guide was the first comprehensive guide aimed at giving healthcare professionals guidance on providing competent care to the LGBT community.

One of the main aspects to investigate is the sharing of information about one’s sexual orientation or gender identity. Some LGBT patients may feel this is a fundamental aspect of their identity and therefore important for any doctor to know, while others may feel that the doctor need not know. All healthcare professionals interacting with these patients should consider how best to sensibly and respectfully invite a patient to share this information. Indeed, it emerged that patients report a higher level of comfort after revealing to practitioners that they are LGBT particularly if they are given reassurance - through clear non-discrimination policies - that disclosure will mean a more informed, individualized and authentic response from of the care team.

The evolution of care models is therefore particularly interesting for LGBT patients, including communication processes, the perception of safety, acceptance and evaluation and respect for the definitions of family and spirituality that the patients themselves operate.

II.8.4. People with Intellectual Disabilities

The global prevalence of intellectual disability in adults is estimated to be around 1%. There is a consensus that intellectual disability is present when the following criteria are met:

- a significantly reduced ability to understand new or complex information and learn and apply new skills (reduced intelligence);
- a reduced ability to act independently (impaired social functioning).

A study (Cloyes et al. 2018) highlighted three aspects of particular interest in these subjects: physical needs, psychosocial and spiritual needs, information and communication needs.

- Physical needs. The most common physical need is pain management. Many health care professionals have described objectively observable signs or behaviours such as irritability, inactivity, loss of appetite, and sleep disturbances, rather than spontaneous complaints. They also described nausea, vomiting, fatigue, shortness of breath, constipation, delirium, urinary incontinence, and oral thrush.
- Psychosocial and spiritual needs. The importance of the family and the need for a social network were clearly expressed. Socialization, friendships and human contact are important. People with intellectual disabilities who are dying require daily routine mechanisms, ongoing activities (including the need to be busy), and important

relationships.

- Information and communication needs. People with intellectual disabilities are often not provided with information in a way that is accessible to them. This is important to enable them to understand the diagnosis, prognosis and symptomatic course of their disease. It is the responsibility of healthcare professionals to consider the differences in communication and the difficulties these people may have in understanding abstract concepts. People with intellectual disabilities often need help to express their views and participate in decision-making. They need honest and understandable communication in order to plan their care in advance.

II.9. Costs

From the literature and good clinical practice, it emerges that early care and a good model of assistance in palliative care allows for cost optimization, a reduction in improper hospital admissions and an improvement in the quality of life. In particular, the studies by Lori Yosick and KPMG Australia were analysed.

The first (Yosick et al. 2019) shows that patients who received “community-based palliative care” showed a statistically significant 20% reduction in total medical expenses ($ 619 per patient/month), a 38% reduction in ICU admissions, the 33% reduction in hospital admissions and a 12% reduction in hospital days.

The “community-based palliative care” model managed by nurses and social workers has therefore led to lower costs, fewer hospitalizations and days of intensive care, greater use of hospice improving assistance, quality of care and patient and families’ satisfaction.

III. Discussion

III.1. Integration

WHO has published “Public Health Strategy,” a guide to integrating palliative care into health systems. It identifies some decisive aspects: the development of adequate palliative care policies, an appropriate availability of drugs, specific health education, specialized training of dedicated professionals, and the activation of palliative care at all levels of care.

The international literature has described two necessary “levels of palliative care” (Gomez-Batiste & Connor 2017): a “palliative approach” implemented by all healthcare professionals who care for people with life-threatening diseases; and the “specialist” activity provided by specially trained personnel.

Age is often a source of inequalities in access to specialized palliative care services

(Burt & Raine 2006; Burge et al. 2008). The diagnosis of a life-limiting disease in young and middle-aged people can generate complex needs for palliative care, including psychological support and counselling for children; but it is easier to insert it. While, the presence of more chronic debilitating diseases determines a difficulty in defining the moment in which the patient becomes dying. This is especially true for people diagnosed with non-malignant conditions. In addition, there may be situations that hinder specialist care for the elderly. For example, the needs of those who die in hospitals or nursing homes are met by geriatricians and other “generalist” palliative care providers rather than specialized palliative care providers.

Palliative care services provide assistance not only to the person with a life-limiting illness, but also to their family and caregivers. This differs from other health services where the sick person is the sole recipient of care.

III.2. Self-Determination

The needs and preferences of the sick person, together with the understanding that the sick person should direct their own treatment, are central principles for palliative care.

The Council of Europe (CoE) and the World Medical Association (WMA) (Council of Europe 1997; World Medical Association 2011) have stated that patients should have the right to decide on their treatment but these decisions can only be made if the patient receives adequate information. Empowering the patient to participate in sharing in decision-making should be one of the care goals in palliative care (European Association for Palliative Care 2009) and the patient should be seen as part of the interdisciplinary team (Gomez-Virseda 2019).

Shared decision-making in which the patient is an active member of the process itself is a key factor for optimal palliative care (Virdun 2020). In palliative care, the autonomy of the sick person should be preserved, and the sick should be given the opportunity to engage in decisions that are not only health care (Houska 2016). Previous research had already ascertained that shared decision-making results in less invasive procedures, reduced healthcare costs, more informed and empowered patients with greater safety and better satisfaction (Castro 2016; Shay & Lafata 2015).

The EAPC and WHO state that palliative care pursues a team approach consisting of at least one nurse and one doctor, therefore interdisciplinary models of shared decision-making should include nurses among others (Lewis & Suacey 2016).

Advance care planning is the modality that allows sick people to reflect on their values and care priorities, to the point of expressing their preferences to be included in the care planning. Planning can establish a preferred care location; record a person’s wishes and values regarding the level of care, to ensure that care is suitable for the patient’s needs, and involves those close to him. And if advance care planning increases the concordance between end-of-life wishes and care, then planning is believed to improve quality of life.

Advance care planning is a continuous process, whose plans must be updated based on the evolution of the state of health, social and psychological circumstances. It is necessary to promote information for sick people, families and caregivers, and to make educational and training material available for professionals to encourage the adoption and implementation of advance care planning; this will lead to national development also in the legislative field.

III.3. Proportionality

A 2020 cohort study (Quinn 2020) showed a significant association between palliative care and less access to other levels of health care, including emergency, hospitalization and intensive care unit admission.

Differences in outcomes were then shown between specialist and non-specialist palliative care interventions (Ernecoff 2020). It is considered plausible that the standard of "usual care" is progressively incorporating the principles of palliative care, reducing the distance between specialist and non-specialist palliative care interventions. But the complexity of the non-cancer patient or patient with multiple comorbidities requires specific skills to satisfy the concept of proportionality of the care of which advance care planning is a requirement.

There is still a lack of reliable data in the literature to evaluate the relationship between the presence of advance care planning and the outcomes of the same (Brinkman-Stoppelenburg et al. 2014; Houben et al. 2014).

Differences need to be highlighted when comparing the care provided by the doctor with a palliative approach and that of specialized teams, on the one hand to understand how to be appropriate and proportional, and on the other to distribute professionals equally in order to satisfy the growing world needs.

Significant questions still remain regarding the optimal timing and care context of the different care models to be used to obtain the greatest benefits in the non-cancer area (Phongtankuel 2018). Indeed, patients with chronic diseases are often more likely to receive palliative care only near death.

IV. Concluding Remarks

IV.1. Health and Social Health Role

From the point of view of people in need of palliative care, the health system must be organized to direct patients to the services that best correspond to their needs; provide services in all care settings, to ensure that care is effective through teams with the right skills; and to promote the continuity and coordination of care according to the needs of the people who change and take place in the different levels of care.

This means that the healthcare professional must refer to palliative medicine specialists or be the one to undertake a palliative care training course. Palliative assessment includes medical settings (medical and psychosocial history, physical exam), symptom management, psychological, psychiatric and cognitive symptom assessment, understanding of the disease and care preferences (e.g., personal goals, expectations, understanding of development and risks with respect to the benefits of specific therapies), existential and spiritual interests, social and economic resources to meet the needs of people living with a life-limiting disease, their families and professional caregivers, as well as ensuring the continuity and coordination of transversal care.

Therefore, three groups of people are expected to be provided with palliative care.

1. People with predictability of needs: includes people whose needs are generally able to be managed through their own resources (including with the support of family, friends and carers) and/or with the provision of palliative care by healthcare professionals existing (including family doctors, community nurses, geriatricians, oncologists and other health professionals);

2. People with intermediate and fluctuating needs: includes people with an intermittent onset of worsening symptoms (such as pain, psychological distress and reduced function) that may not be planned and involve the emergency use of hospitals and other health services. People in this group could benefit from the advice of a palliative care specialist. They will also continue to receive treatment from their regular health professionals.

3. People with complex and persistent needs: This group includes persons with complex physical, psychological, social and/or spiritual needs that cannot be managed effectively by standardized care protocols. These people will require more continuous direct assistance from personnel specialized in palliative care, this should be achieved through partnerships and care models shared with healthcare professionals already responsible for care.

IV.2. Bioethical Role

Open communication between the sick person and the members of the care team and the family if the sick person so desires, is an essential requirement for the patient to participate in the decision-making process. Indeed, good relationships are based on mutual trust and getting to know each other (Belanger 2016; Bottorff 2016).

The role of health professionals in effective communication includes asking open questions, listening, giving the opportunity to discuss and receive clarifications. Different communication skills are required of professionals for communication to be effective. Patients may share their wishes and feelings non-verbal, and healthcare professionals need to be alert and sensitive to these messages (Robijn 2018). Similarly, the operator's non-verbal language affects the communication that the patient promotes.

Communication must also ensure that not only the patient receives an adequate amount of information to make decisions, but that healthcare professionals also have sufficient information to understand the preferences, needs and ultimately the choices the patient makes. Decisions are also influenced by the physical environment, privacy and time devoted to the communication process.

In the literature, palliative care is connected with moral problems which include: withholding of interventions, dignity (Guo & Jacelon 2014) and quality of care, respect for autonomy, palliative sedation and medically assisted death (Broeckaert 2011; ten Have 2014).

The need for training on the ethical aspects of palliative care is therefore a priority and a thorough understanding of the ethical context in which professionals operate is needed.

Providing adequate and effective training in the bioethical field implies being aware of the real-world experiences of learners to set the most effective aspects and paradigms, as it is known that the key to motivation in adult students is teaching material close to operational reality (Ahl 2006), therefore with the elaboration of the material of previous experiences one contributes to making learning profitable.

Furthermore, in the field of bioethics, understanding the real context of moral problems is a fundamental part of the analysis.

Therefore, identifying ethics training needs and designing specific programs for all those involved in the provision of palliative care is the basis of the specialist pathway in palliative care. Likewise, both education in clinical ethics and the development of research on the bioethics of palliative care must stimulate the evolution of skills in palliative care.

IV.3. Dissemination

It has been estimated that every year over 52 million adults worldwide are in need of end-of-life palliative care with a rapidly changing figure due to both the aging population and the extent of serious chronic diseases (Worldwide Hospice Palliative Care Alliance & World Health Organization 2020).

However, the provision of palliative care to remote communities becomes a challenge to be faced. Numerous publications show that telehealth is feasible and effective despite some challenges (Rogante 2016; Gordon et al. 2021). Telehealth interventions on the quality of life of cancer survivors significantly increased the quality of life compared to usual face-to-face care (Larson et al. 2019). Telemedicine has significantly improved caregivers' experiences and well-being in chronic diseases and remote hospices (Chi & Demiris 2014). Palliative care telemedicine-assisted home specialist had favourable outcomes compared to standard care in terms of slower functional decline and fewer health care visits and hospital admissions (Jiang et al 2020).

It was also found that the problems associated with virtual care – technological, ethical limitations and administrative barriers – can be addressed by involving and continuously incorporating the contribution of patients and health professionals in the design and delivery of these virtual treatments. While, ethical concerns related to equal access, participant recruitment and consent partly justify the lack of evaluative studies and their low efficacy given that patients in palliative care are considered very vulnerable and therefore mostly lack the equal opportunities to participate in clinical trials and contribute to the development of society, science and the future of palliative care itself.

Evaluating the effectiveness of palliative care assistance interventions in various disease conditions, age groups and social strata, as well as gender, would allow us to formulate new directions for care for patients with limited life expectancy.

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