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THE NEED FOR HEALTH LITERACY ON PALLIATIVE CARE

A NECESSIDADE DA LITERACIA EM SAÚDE SOBRE OS CUIDADOS PALIATIVOS

LA NECESIDAD DE ALFABETIZACIÓN EN SALUD SOBRE CUIDADOS PALIATIVOS

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ABSTRACT

Palliative care should be available to all people with chronic and life-threatening illnesses, but despite all the efforts of the Portuguese Association of Palliative Care and the National Commission for Palliative Care, there are still Portuguese people with palliative needs who do not have access to these.

One of the recommendations of the Strategic Plans for the Development of Palliative Care (PEDCP) is that the curricular unit of palliative care be integrated into all pre-graduate training courses in the area of health so that health professionals may be provided with basic training in palliative care.

In addition to this recommendation, palliative care should be incorporated into all levels of care to which the population has access in Portugal, Primary Health Care (CSP), Hospital Health Care (CSH) and Integrated Long-term Care (CCI), the greater the involvement of all stakeholders through collective and social action, the more effective this may become.

Thus, palliative care reduces the length of hospital stay, readmissions, therapeutic futility, the use of emergency services and intensive care, and, consequently, decreases health costs.

Therefore, this article aims to outline a health literacy plan for palliative care for the Portuguese population residing in Portugal.

RESUMO

Os cuidados paliativos são cuidados que deveriam ser disponibilizados a todas as pessoas com doenças crónicas e ameaçadores da vida, porém apesar de todos os esforços da Associação Portuguesa dos Cuidados Paliativos e da Comissão Nacional de Cuidados Paliativos ainda existem portugueses com necessidades paliativas que não tem acesso a estes.

Uma das recomendações dos Planos Estratégicos para o Desenvolvimento dos Cuidados Paliativos (PEDCP) é que seja integrada a unidade curricular de cuidados paliativos em todos os cursos de formação pré-graduada na área da saúde, para que se formem profissionais de saúde com formação básica em cuidados paliativos.

Para além desta recomendação, os cuidados paliativos deverão incorporar-se em todos os níveis de cuidados a que população tem acesso, em Portugal os Cuidados de Saúde Primários (CSP), Cuidados de Saúde Hospitalares (CSH) e Cuidados Continuados Integrados (CCI), sendo tanto mais eficaz quanto maior for o envolvimento de todos os intervenientes através de uma ação coletiva e social.

Assim, os cuidados paliativos diminuem os tempos de internamento hospitalar, os reinternamentos, a futilidade terapêutica, o recurso aos serviços de urgência e aos cuidados intensivos e, consequentemente, diminuem os custos em saúde.

Deste modo, o presente artigo visa dar a conhecer um plano de literacia em saúde sobre os cuidados paliativos, para a população portuguesa residente em Portugal.

RESUMEN

Los cuidados paliativos son cuidados que deben estar disponibles para todas las personas con enfermedades crónicas y potencialmente mortales, pero a pesar de todos los esfuerzos de la Asociación Portuguesa de Cuidados Paliativos y la Comisión Nacional de Cuidados Paliativos, todavía hay portugueses con necesidades paliativas que no tienen acceso a estos.

Una de las recomendaciones de los Planes Estratégicos para el Desarrollo de los Cuidados Paliativos (PEDCP) es incluir la unidad curricular de cuidados paliativos en todos los cursos de formación sanitaria de pregrado, de forma que puedan formarse profesionales sanitarios con formación básica en cuidados paliativos.

Además de esta recomendación, los cuidados paliativos deben incorporarse a todos los niveles de atención a los que la población tiene acceso, en Portugal la Atención Primaria de Salud, (CSP) la Atención Hospitalaria de Salud (SCH) y la Atención Integrada Continua (ICC), siendo tanto más efectiva cuanto mayor sea la participación de todas las partes interesadas a través de la acción colectiva y social.

Por lo tanto, los cuidados paliativos reducen los tiempos de estadía hospitalaria, las rehospitalizaciones, la inutilidad terapéutica, el uso de servicios de emergencia y cuidados intensivos y, en consecuencia, reducen los costos de salud.

Este artículo tiene como objetivo dar a conocer un plan de alfabetización en salud sobre cuidados paliativos para la población portuguesa que vive en Portugal.

INTRODUCTION

The World Health Organization (WHO) defines health literacy as the set of “cognitive and social skills and the ability of individuals to gain access to, understand and use information in ways that promote and maintain good health: it is the ability to make informed decisions regarding health, in the course of everyday life – at home, in the community, in the workplace, in the market, in the use of the health system and in a political context; it makes it possible to increase people's control over their health, their ability to seek information and to take responsibilities(1).

Health literacy, according to the report of the Institute of Medicine of the National Academies, is based on the interaction between individuals' abilities and their own health contexts, the health system, the education system, and social and cultural factors at home, at work and in the community. Therefore, the responsibility for improving health literacy levels should be shared between several areas(2).

According to the same author, another crucial aspect of health literacy is the establishment of knowledge networks between scientists and professionals at the operational level in order to gather evidence that supports policies and interventions capable of overcoming social barriers regarding health. These networks should include topics such as child development, working conditions, features inherent to globalization, determining influences of health, the health system as a social determinant, urbanism, social exclusion, and policies on the determinants of health(2).

Health literacy is important in all aspects of the populations’ health, but it stands as decisive for a new understanding, knowledge, and acceptance of palliative care by the population in a timely manner.

The various Strategic Plans for the Development of Palliative Care aim to provide timely and adequate access to quality palliative care for all citizens residing in mainland Portugal, including children and youngsters, as well as the efficient use of available resources.

This article aims to describe a health literacy plan regarding palliative care, for the Portuguese population residing in Portugal.

FRAMEWORK

Palliative care, according to the World Health Organization (WHO), is care that improves the quality of life of patients and their families, addressing the problems related to life-threatening illnesses, preventing and alleviating suffering through early identification and thorough assessment of pain and other physical, psychological, social and spiritual problems. For this definition to be fulfilled and for palliative care to be seen, in practical terms, as a human right, much remains yet to be done. However, the commitment of numerous associations and entities should be highlighted, including the European Association of Palliative Care (EAPC), the International Association for Hospice and Palliative Care (IAHPC), the World Palliative Care Alliance (WPCA), and the International Observatory of Human Rights (HRW) who worked together to promote access to palliative care as a human right(3).

In the same line of thought, in 2015, the World Health Assembly, in its 67th meeting, created an extremely important document entitled *"Strengthening of palliative care as a component of comprehensive care throughout the life course"*, which highlights the increase in the need for palliative care for the elderly, those suffering from non-oncological diseases, as well as pediatric palliative care; the integration of palliative care into the *continuum* of care, particularly primary health care, as a priority; in many countries the availability and adequate use of essential medicine in palliative care is still insufficient; the persistence of avoidable suffering, whether generated or not by controllable symptoms is fostered by the lack of palliative care; the need for ongoing training in palliative care for all health professionals and other caregivers; the existence of different models of providing cost-effective and efficient palliative care, as well as interdisciplinary teamwork, is vital for meeting the needs of both patients and their families(3).

With the assertion of palliative care as a human right, which should be accessible to all people, health systems tend to organize in order to respond to patients that need this type of care(3,4).

However, in Portugal, there is still a long way to go compared to other European countries, namely Spain, our neighboring country which has full coverage of palliative care accessible to all patients(3,5,6).

In Portugal, the pioneer of palliative care who founded the first internment unit for Pain and later for Palliative Medicine at Hospital do Fundão was Dr. António Lourenço Marques(3).

Subsequently, other palliative care services for cancer patients emerged, namely at the Cancer Institutes in Porto and Coimbra. In 1996, at the Odivelas Health Centre, the first domiciliary long-term care team was created, which included the provision of palliative care, and had a colossal success(7).

In 2004, the 1st National Palliative Care Program was published by the Ministry of Health. This document regarded palliative care as a key player in general health care, bearing in mind the ethical imperative of promoting and protecting fundamental human rights and being a social obligation in terms of public health(4).

The aforementioned program indicates that palliative care is developed at various levels and is carried out by interdisciplinary teams, providing for the creation of Palliative Care Units. The essential components of this type of care are: the relief of pain and other symptoms; psychological, emotional, and spiritual support; and support for the family both during illness and in mourning(7).

On June 6, 2006, the decree-law no. 101/2006 created the National Network of Integrated Long-Term Care (RNCCI), founding the collaboration of the ministries of Health and Social Security under the obligation of providing health care to people with disabling chronic diseases, as well as people with incurable, late-stage diseases and at the end of their lives(6,8). This legislation thus recognized the inalienable right to the provision of palliative care, institutionalizing services aimed at providing active and organized treatment and care to people with irreversible illnesses, with intense suffering, and in the final phase of their lives.

For palliative care to be provided and for the units mentioned above to work, it is necessary to train health professionals that are capable of providing excellent care in this area. So, training in palliative care covers all the multi-professional players in the teams, the beginning of master's degrees in palliative care at the Faculty of Medicine of Lisbon and also at the Catholic University of Porto and Lisbon(3,9) set the starting point for this training.

Yet, in order to enable access to palliative care by those who need it, on September 5, 2012, the Basic Law on Palliative Care, which secured the right and regulated the access of citizens to palliative care, defined the State's responsibility in terms of palliative care and created the National Palliative Care Network (RNCP) to operate under the supervision of the Ministry of Health, was created(10).

This Law also protects the quality of palliative care, the need for national coverage, as well as equal access and training of professionals. After the creation of said Law, the strategic plan for the development of Palliative Care for the 2017-2018 biennium, created by the National Commission for Palliative Care (CNCP), began to be developed.

This Plan distinguished palliative care into four levels of differentiation: the 1st level, which is called the *palliative approach*, the 2nd level of differentiation or *Generalist Palliative Care*, the 3rd level, where *Specialized Palliative Care* takes place, and finally, the 4th level, with the *centers of excellence*. In order to decide which level of differentiation patients need, the level of complexity must be taken into account, as not all patients need specialized Palliative Care(5).

The creation of RNCP guarantees equity in access to palliative care and that its coverage at a national level is as thorough as possible. The WHO estimates that, annually, more than 40 million people need palliative care worldwide and recognizes the efficiency and cost-effectiveness of various models of organization of Palliative Care in relieving this suffering(6). Thus, the development of these models of palliative care, fully integrated into national health systems and in the continuity of all levels of care, is considered by the WHO an ethical responsibility of each state(6).

Due to the increase in disabling and irreversible chronic diseases, it is imperative to find biopsychosocial and spiritual answers that promote the quality of life of both patients and their families. A public palliative care strategy is one that offers the population the most appropriate approach to their problems, taking evidence-based perspectives and procedures, as well as their cost-effectiveness and equity into consideration(6).

Thus, palliative care must be incorporated into all levels of care to which the population has access, in Portugal Primary Health Care (CSP), Hospital Health Care (CSH) and Integrated Long-term Care (CCI), being all the more effective the greater the involvement of all stakeholders through collective and social action. Regarded as essential to a quality NHS, palliative care must be provided in the continuity of health care to all people with serious and/or advanced and progressive illnesses who need it, whatever their diagnosis and age and wherever they may be(3,8).

Finally, palliative care reduces the length of hospital stay, readmissions, therapeutic futility, the use of emergency and intensive care services, and subsequently, reduces health costs.

The aim of this literacy plan, is to attain a society that fully understands what palliative care is, looking forward to the integration of the principles and philosophy of palliative care into all clinical services of the NHS, provided by all its teams in Portugal.

In order to achieve this proposed vision, the central mission will always be to promote access to palliative care for all patients who need it in mainland Portugal, as well as contribute to the full integration of palliative care at all levels of care in the NHS.

The values and principles of palliative care – which are **universality**, that is, this care should be available to those who need it, **equity**, so that there is equal access at all levels of the NHS, **quality**, palliative care demands a high scientific and human level, with a holistic approach to the needs of the person and their family, **autonomy**, the person with active participation in care, in the processes of communication and decision-making, guaranteeing the respect for their opinions, values and rights, **dignity**, that is, respect for the person until the end of their life and finally **humanization**, caring for the person in all their dimensions of health and illness with predominance in the principles of privacy, communication, autonomy, beneficence, non-maleficence and justice – are defended.

The **objectives** of this plan are to alert the population to the importance of palliative care; promote accessibility to palliative care; foster education and training throughout the life cycle focusing on literacy in palliative care; encourage scientific research in the field of palliative care.

STRATEGIC AXES AND GUIDELINES

The present plan is based on a set of guidelines for action and measures structured around three strategic axes, which focus on the implementation of interventions in health, social and other systems, through an intersectoral and multidisciplinary approach.

The **accessibility**, in which palliative care is expected to be available to all people, from the moment of the diagnosis of a life-threatening or debilitating illness.

The **training** that aims to mobilize civil society regarding palliative care, it is necessary to intercede with the youngest generations, hence it becomes necessary to insert the concept of the life cycle and knowledge about complex chronic diseases in school training as well as what the implications of them are in life. In addition to this training amongst civil society, it is necessary to have specialized training in palliative care. Training becomes necessary and crucial for setting up new teams/units, for developing skills in palliative care for multidisciplinary teams and for guaranteeing the different degrees of complexity of interventions.

Finally, **quality**, which is extremely important for the progressive founding of a system that contributes to ensuring quality and a better response to the needs of patients and families in palliative care.

With regard to the **plan's guidelines**, the following were established: awareness regarding early referral; articulation and involvement of civil society; the training of formal and informal caregivers; pre- and post-graduate training; and the quality of palliative care.

Awareness of early referral

It is intended that all people with a serious or incurable disease, in an advanced and progressive phase, residing in Portugal, have access to quality palliative care, regardless of their age, diagnosis, place of residence, or socioeconomic background, from diagnosis to mourning.

Thus, the RNCP was assembled under a collaborative and integrated model, in which specific palliative care teams take care of patients with more complex needs.

Patients, of low to intermediate complexity levels, will be accompanied by their doctor and family nurse, by the RNCCI teams/units or other therapeutic teams, ensuring the appropriate palliative approach to their needs, and may receive advice and support from specific palliative care teams (from communities and hospitals)(11).

Therefore, the intervention of palliative care teams in the three levels of health care existing in Portugal (Primary Health Care, Hospital Health Care and Integrated Long-term Care) is ensured and fast and flexible access to these teams, in order to create a “functional network” of palliative care is created, increasing and facilitating access to them and strengthening the palliative approach carried out by all health professionals(11).

The aim of encouraging awareness of early referral is to carry out actions among the population together with the different national and regional stakeholders that lead to the acknowledgement of the importance of early referral for palliative care in the quality of life of patients and their families; create training activities about the principles of palliative care; develop skills that increase the person's autonomy in managing their own care process(11).

It is also suggested that identification and referral of complex cases should be made at an early stage. To this end, it is urgent to promote the training of health professionals on the assessment of complexity as a way of referring the individual during the course of their illness(11).

It is also considered important to make legislative changes that value assistance to patients in palliative care and their family caregivers, in order to integrate patients in palliative care into the transitional regime for the issuance of a multipurpose medical certificate of disability; grant the right to remuneration (the amount of which will be calculated according to a reference compensation) to family caregivers; and a maximum period of 30 days per calendar year, consecutive or interpolated, to assist family members in palliative care(11).

Articulation and involvement of civil society

It is extremely important to bring awareness of the requirements and needs of integrating the concept of palliative care in society, as well as the promotion of social values of solidarity and citizenship, through the implementation of strategies and entities.

Compassionate cities are cities created according to the model of Kellehear *et al* 2018, that developed a model of person-centered care and the concept of compassionate cities for end-of-life patients. This concept focuses on the circle of care, that is, the person surrounds himself with these circles, which are a closer internal network, supported by a wider external network, the community, social and health services and local and national authorities(12).

A compassionate community makes it possible for a patient at the end of life to be more resilient, less exhausted, and for said patient to have a better quality of life at home(12).

Among the strategies implemented at this level, the measures that stand out are those aimed at encouraging the organization of compassionate cities through the creation of a mutual aid network; volunteering and education; spreading information about the concept of dying and living as natural events in life; developing social awareness, information and training programs in the areas of aging, advanced-stage disease, the end of life and the death process; involve citizens in supporting sick people and their families in the advanced stage of the disease; allowing the person with an incurable disease in an advanced stage to remain at home if they so wish, with the support of a palliative care team and supported by a compassionate support network(11-13).

For these measures to be implemented, it is essential to encourage the provision of written information that presents and substantiates the concepts/principles and objectives of palliative care; concepts/principles on social rights and on available support and projected directives(12).

In order to prepare the new generations for this health topic, it is crucial to raise the awareness of the competent authorities (namely the Ministry of Education) for the development of school programs with the main purpose of making children and young people aware of palliative care by providing knowledge and information about the life cycle and the disease and dying process.

The training

Training in palliative care enables citizens to make decisions in different disease contexts and to correctly use health services.

Training is consensually identified as the critical factor in the success of palliative care teams. In 2003, the Council of Europe, in a statement about the organization of palliative care, highlighted the need for structured educational programs in the training of all professionals involved in this type of care, in order to obtain adequate training to carry out their functions in a tangible way, judicious and culturally sensitive. Thus, not all professionals require the same level of training, differing according to the frequency and intensity of each professional's contact with patients in need of palliative care. Therefore, two levels of training can be defined, for different recipients: pre-graduate training and post-graduate training at level 1 (basic); level 2 (intermediate) and level 3 (advanced)(11).

Formal and informal caregivers

Improved comfort and well-being will occur when the caregiver understands the interventions and accompanies the team in providing care. Sometimes, the difficulty in communication, challenges in adapting the individual care plan and knowledge about the level of complexity of the intervention in palliative care can be a constraint during the provision of care.

Thus, training and creating a network of formal and informal caregivers is essential in order to minimize these difficulties. This network necessarily requires the training of these caregivers, so training plans and ongoing training actions must always remain in operation for all those who volunteer(11).

Simultaneously, investment should be made in training and education on palliative care and aging throughout the life cycle based on human rights, equality and non-discrimination. Literacy in palliative care should be promoted at all levels of education with the aim of encouraging healthy decision-making ability, on the other hand, action should be taken with the Ministry of Education to integrate palliative care into syllabuses and develop projects in concurrence with CNCP(11,13).

Education and training opportunities for formal and informal caregivers should also be encouraged/disseminated, by supporting the development of education/training programs aimed at formal and informal caregivers, such as health literacy, and making known, reflecting and discussing the Statute of the Informal Caregiver(11).

Regarding *pre-graduate* training, it is maintained that the teaching of palliative care should be introduced in pre-graduate training in Medicine, Pharmacy, Nursing, Social Work and Psychology. This training should include general topics about basic principles of palliative care, symptom control, communication, family and teamwork, which already happens in some curriculum plans of Nursing and Medicine courses. Therefore, the creation and continuity of a curricular unit of palliative care in the pre-graduate training of the aforementioned courses should continue to be encouraged, through articulation with the Ministry of Science, Technology and Higher Education (MCTES) in order to adapt the respective syllabuses(11).

Postgraduate training is the most demanding area as far as the preparation of palliative care teams is concerned. There are different levels of complexity of intervention in palliative care, so it is crucial to develop adequate technical skills for the exercise of palliative care.

There are three types of training typologies in palliative care: Level 1 (basic); Level 2 (Intermediate) and Level 3 (Advanced)(11).

Investment in postgraduate training in palliative care is also necessary, which is why MCTES/responsible entities should propose and expedite the expansion in postgraduate training in palliative care, through an increase in postgraduate courses, masters and doctorates in palliative care and, lastly, to promote a multidisciplinary approach in palliative care research(11).

The quality

In palliative care, evaluating the impact of care is much more complex than in other areas of health, as the main result is the improvement of the individual's quality of life. Patients are in a situation of great vulnerability and sometimes it is hard for them to communicate; caregivers and family can assess their own care, but their assessment has limitations regarding the patient's experience. Person-centered care is measurable, although its complexity may be marked by considerable subjectivity and the multifactorial nature of the care experience, which can affect quality of life(11).

However, it is important to establish standardized measures to assess the quality of care(14). Thus, the constitution and acquisition of quality indicators for teams and Palliative Care Units should not be ignored. To this end, the terms of reference for contracting the provision of palliative care in primary and hospital health care should be drawn up, namely with regard to the material and physical requirements that are necessary for the proper functioning of the teams, as well as the staffing and qualification of professionals and the definition of assessment indicators for palliative care teams to be included in program contracts, always in harmony with the competent authorities(14).

It is equally important to identify and standardize the referral criteria for palliative care, through the elaboration of norms for the referral of patients to palliative care teams, between palliative care teams, and from these to other teams that provide health care, standardizing thus the articulation between all care providers(11-14).

FINAL CONSIDERATIONS

Despite all the information and training in the area of Palliative Care, there is still an accentuated myth around it, which will have to be demythologized by increasing literacy. This literacy should be provided by health professionals, the media and educational institutions, and should be go together with educational actions and awareness campaigns where it should be clarified what Palliative Care is and for whom it is.

Palliative care should be identified as a medical specialty like any other, and as with any medical specialty, people may need it at any stage of their life cycle and at any time in their lives.

The National Commission for Palliative Care has prepared strategic plans for the development of palliative care every two years, and these plans have several priority axes of intervention, but taking into account the current socioeconomic circumstances, it is expected that some of their measures will not be put into practice, or that the execution of their various intervention axes will take longer than expected.

Regarding health literacy, several studies carried out in Portugal have shown an inadequate level of health literacy amongst the Portuguese population, with significant consequences for the results and for the use of health services, with an impact on health expenditure.

This plan is intended to contribute to increase health literacy on palliative care, so that it can reach all patients with palliative needs. The identification of palliative needs and early referral for palliative care will bring countless benefits to patients, their families and society in general, as it will contribute to reducing therapeutic futility and health expenses.

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MS: Study design, collection, storage and analysis of data, review and discussion of results.
FM: Study design, review and discussion of results.
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