PALLIATIVE CARE

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Due to demographic changes characterized by ageing of population and taking into consideration a large proportion of people aged over 65, also over 95, an increase of chronic patients with chronic diseases, oncological patients, patients with dementia or dying patients is to be expected. Changes in the family, with fewer members available for patient support, represent an additional problem. Numerous researches worldwide indicate that terminally ill patient are a neglected and devalued group in the modern health system. Death is considered to be a medical failure and life is extended by all means of high technology regardless its quality (1). Everything mentioned above requires a new approach and organization of a new health care model.

Modern definition of palliative care

When referring to the palliative care, we usually start from the definition of the European Association for Palliative Care and from the definition made by the World Health Organization (WHO) in 2002.

According to the definition of the European Association for Palliative Care:

Palliative care is active, total care for the patient whose disease does not respond to treatment. The most important is suppression of pain and other symptoms as well as of social, psychological and mental problems. Palliative care is interdisciplinary in its approach and involves the patient, the family and the community. Palliative care offers the most basic protection concept – taking care of the patient's needs wherever the patient is being cared of, whether at home or at hospital. Palliative care affirms life and considers death to be a normal process; it does not accelerate nor postpone death. It attempts to preserve the best possible life quality until the death (2).

Definition brought by WHO in 2002 is slightly different from the definition made by the European Association for Palliative Care and it changed the older definition which was limited to patients "whose disease does not respond to treatment" by expanding the volume of palliative care to patients and family "faced with the problems related to the fatal disease" and states:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (3).

Historical development of palliative medicine

Historical development of palliative medicine dates back to Middle Ages and it is connected to the development of hospices. First hospices were founded by crusaders in the 11th century. These were the places where travellers were taken care of, as well as the sick and dying who were coming to and leaving the Sacred Land (4). Hospices also existed in
Croatia (Dubrovnik) in the Middle Ages (1). In the 17th century, French minister St. Vincent de Paul founded Sisters of Mercy in Paris and opened a home for poor, sick and dying people. In Lyon (France) in 1842, the word hospice was used for the first time to describe a place for terminally ill patients (founder Madame Jeanne Garnier).

In the 19th century and at the beginning of the 20th century hospices are founded as institutions where people die. At this time in London, there is a famous Holy Trinity Hospice (National House for Dying) and St Joseph Hospice. In 1917, there was St. Francis Hospice in Rijeka and it is considered to be forerunner of the modern hospice (4).

Modern hospice was founded by Dame Cicely Saunders (1, 4). This professional nurse, social worker and medical doctor recognized and responded to, at these times, unnoticed needs of dying patients and their families by recognizing specific and unique needs of each individual patient and his/her family. St. Christooper's Hospice, which she opened in 1967, in London, was the first modern teaching and research hospice unit (1, 4).

The term palliative care was introduced in 1975, after Balfour Mount was confused by collection of various terms while searching for a suitable name for stationary unit in Montreal. In the French-speaking part of Canada the term “hospice” was used in a different context (5).

Today, despite differences in terminology and differences between national approaches to palliative care, common principles and values are recognised by palliative care professionals through their activities of hospice and palliative care (the values of the patient's autonomy and dignity, the need for individual planning and decision making and holistic approach) (5).

**Palliative care forms**

Palliative care forms can be defined in two dimensions – form of provided care and level of provided care (Table 1) (6).

In accordance with patient’s needs, a suitable form of the palliative/hospice care is offered (acute, extended, home care).

Palliative care can be provided at different levels and it is necessary to ensure at least two: palliative approach and specialist palliative care (5). Palliative approach to patients will be used only temporarily while providing services in different environments. On the other hand, specialist palliative care refers to multidisciplinary team of adequately trained doctors, nurses, social workers, priests and other experts deemed necessary to optimize the life quality of persons with fatal and exhausting chronic diseases (7).
Table 1 System of palliative care services with levels.

<table>
<thead>
<tr>
<th>FORM OF CARE</th>
<th>LEVEL OF PALLIATIVE CARE</th>
<th>Palliative approach</th>
<th>Specialist support to the general palliative care</th>
<th>Specialist palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute care</td>
<td>Hospital</td>
<td></td>
<td>Hospital team for the support of palliative care</td>
<td>Palliative care unit</td>
</tr>
<tr>
<td>Extended care</td>
<td>Home for elderly and disabled persons, Residential home</td>
<td>Volunteer service</td>
<td>Teams for home health care</td>
<td>Stationary institutions</td>
</tr>
<tr>
<td>Home care</td>
<td>General practitioners; teams with nurse for visits at patient’s home</td>
<td></td>
<td>Mobile teams for palliative care, institutions for daily stays</td>
<td></td>
</tr>
</tbody>
</table>

Source: Strategic development plan for palliative care in the Republic of Croatia for the period from 2013 to 2015 (draft)

Whom is palliative care intended to?

Palliative care should be available to all the patients suffering from life-threatening diseases. It should not be limited to the predefined medical diagnosis (5).

In all European countries it is common that the palliative care is mostly provided to the patients with advanced malign diseases. It is disregarded that those suffering from other diseases, such as neurological diseases, HIV/AIDS, or heart, lungs or kidney failure can have the same needs for palliative care as those suffering from malign diseases. Unfortunately, this attitude contributes to the fact that for those persons approach to palliative care is made difficult.

According to some estimations, there are more than 320.000 oncological and slightly lower number of non-oncological patients who require some form of palliative care in European region at this moment (5). It is possible that these numbers are even higher considering that the symptoms and need for palliative care are not often recognized. Apart from the mentioned, these estimations presume that general palliative care is well developed which is reality in only few European countries (5).

There is no specific time point during a certain disease when the patients will need palliative care in a way that Lynn and Adamson complexly presented in the Figure 1 (8). Most
of them need palliative care during the advanced stage of disease. However, some require palliative intervention for dealing with certain crises at earlier stages of their disease. This period can last a few days, weeks, months or years (5, 9). The transfer from curative to palliative care is often gradual and not marked by the precise point in time. The transfer is also in accordance with the change of treatment goals, from those to prolong life to those to preserve the quality of life, as well as in accordance with the need for finding the balance between the benefit and burden of the treatment (5).

![Figure 1: When should one start palliative care? (Modified according to Lynn and Adamson)](image)

Special attention needs to be paid to the palliative care of children. Although closely related to the palliative care of adults, it represents a separate area with specific requirements of palliative care for children with incurable and life threatening diseases. As opposed to the palliative care of adults, paediatric palliative care is characterized by a heterogeneous range of states and higher proportion of non-oncological patients. Palliative care for children starts immediately after the diagnosis has been made and continues regardless whether the child is taking the treatment for the disease or not. Along with the overall care for the child, the care also includes the family.

**Instead of conclusion**

“Every year, millions of people all over the world who live in the final stage of their disease go through unnecessary pain and suffering, not being aware of, or not having access to the care they need. Quality hospice/palliative care, aiming at satisfying the needs of a whole person, should and can provide the answer. This is the problem which influences
literally everyone on this planet- we would all like to live calmly and pleasantly until the end.“

Archbishop Desmond Tutu

Literature


2. European Association for Palliative Care. Definition of Palliative Care, 1998. Available at: www.eapcnet.org/about/definition.html.


Available at:


