CONTENT

EDITORIAL

Societal acceptance of chronic illnesses
Olăroiu M

ORIGINAL PAPERS

The rising longevity makes availability of palliative geriatric care for seniors in the Czech Republic an urgent issue
Wija P, Holmerova I

CLINICAL LESSONS

Mistakes in communication doctor-sever ill patient
Vrabie T

Introspection and self-evaluation are important for professionals in palliative care
Vajasdi E

COMMENTS, DISCUSSION

Facilitating growth and human development in the context of a serious and terminal illness
Petruţa L

Psychological coping mechanisms in patient diagnosed with incurable disease
Kovacs R

NEWS

The picture on the cover: Sunset as seen in summer Aquarel from Wim van den Heuvel, The Netherlands, (2011)
EDITORIAL

Societal acceptance of chronic illnesses

Marinela Olăroiu, MD, PhD, Editor-in-Chief of PALIAŢIA

The Editorial of the last issue of PALIAŢIA ended with an call for a change in culture: societal acceptance of chronic illnesses, incurable diseases, dying, and death is needed. This issue of PALIAŢIA starts with an analysis from Czech Republic showing that changes are going on – more or less implicitly – in the way societies take care for persons with incurable diseases and dying persons. The authors call for the availability of sufficient expertise and qualitative facilities to take care for the most vulnerable ones in our societies. In May 2014 WHO calls for measures that are crucial for the further development of palliative care: a public health approach (see NEWS in this issue).

Indeed, in an ageing world, the care for vulnerable old has to be reconsidered and the way societies have organised their long term care facilities needs a fundamental revision.

When reconsidering the care for persons with incurable, (progressive), diseases we have to keep in mind that various types of measures are need and that these have to be realised on an integrated way. Such an integrated reform of long-term care asks for committed leadership as WHO states.

This issue of PALIAŢIA underlines such an integrated reform by discussing the need for introspection of professionals in palliative care, by asking to understand each individual and to see his potentials when taking care for a human being, and by emphasising the need for good communication.

Good communication should not be limited to patient/family/professional, but also should include communication (and open discussion) between professionals themselves (what is their role in health care reforms?) and between professionals and policy makers. In that way, integrated reforms of (health) care for vulnerable citizens may be realised.
ORIGINAL PAPERS

The rising longevity makes availability of palliative geriatric care for seniors in the Czech Republic an urgent issue

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Abstract

The article presents data on the number of deaths in social and health services for seniors, on changes in place of death, and on proportion of deaths in selected health and social care facilities with focus on long-term care. Data from health and social statistics describe trends and changes in recent years. The analysis shows a rapid increase in the number of deaths in non-hospital institutional settings. This development presents challenges for the availability of palliative, qualified geriatric, and nursing care, especially in residential social care facilities.

There is clear argument for strong and effective support of outpatient and home care and social services to encourage ageing in place and to increase the availability of palliative and geriatric care in social and health facilities providing care to frail seniors across different institutional and home settings.

Key words: long-term care, seniors, dying, social and health services, location of death, palliative care, health statistics

Introduction

The Czech Republic globally ranks among the countries with the lowest neonatal mortality. Neonatal mortality rate is defined as the number of neonates dying before reaching 28 days of age, per 1,000 live births in a given year. The UN Inter-agency Group for Child Mortality Estimation ranked the Czech Republic on 18th place from 223 countries for which data are available in 2012 (1). The availability and quality of health care at the beginning of the life course (prenatal and neonatal services) is generally considered as very good. However, according to the report on palliative care (2) published by organization “Cesta domů” (“Homecoming”), the Czech Republic lags behind the development of palliative and end-of-life care both in terms of availability and quality to die at home. As a rich country in global context, the Czech Republic should aspire to belong among countries providing quality care in important final stage of life.

With rising life expectancy and continuing demographic ageing the need for comprehensive palliative care provided to seniors with frailty, disability, and multiple conditions is going to increase. The share of the oldest group of seniors at risk of reduced self-care capacity and functioning, including people with dementia, is going to rise fastest. This development requires improving the availability of various forms of palliative care for different groups of patients.
The health and long-term care is provided by health facilities such as hospitals specialized in acute and post-acute care and specialized facilities for long-term ill patients “Institutes for long-term patients” - health establishments for bed care providing specialised care, especially nursing care and rehabilitation to older persons and chronic patients. According to the law on health services (Law no. 372/2011) long-term hospital care is provided to “patient whose health cannot be substantially improved by therapeutic care and whose health is getting worse without continuous provision of nursing care”. Long-term and nursing care is provided also in assisted living facilities within social sector, usually in “nursing units” of “home for seniors” and “homes with special regime” (for people with dementia) operated according to Social Services Act (Act no.108/2006).

Long-term care in the Czech Republic is provided under very different conditions within social and health care facilities. For both social services and health facilities, there is different system of registration of providers, quality standards, system of financing, responsibility of state, regions and municipalities, sources and ways of financing. The coordination of health and social services thus varies dependent on respective health and social facilities and their level of cooperation. There is no obligation for municipalities to employ “care manager” at municipality level or to coordinate social and health services. The unclear division of competencies and responsibilities between social and health systems and levels of government are the key obstacles to provision of integrated seamless long-term care aimed at improving quality of life and prevention of functional decline and permanent “institutionalization”.

**Demographic situation in the Czech Republic**

According to population forecast for the period 2008-2070, published by the Faculty of Science, Charles University (3), the process of demographic ageing in the Czech Republic is expected to be more intense than in the most economically developed countries. During the next ten years it will be accelerated by transition of cohorts born in the 1940s and 1950s. The population aged 65 and over is going to be the only part of the population that will grow in number. The number of seniors aged 75 and over will approximately triple between 2008 and 2067 and increase from 0.69 million to 2.02 million. Census data showed that the number of people aged 95 doubled and number of centenarians (people aged 100 and older) tripled between in 2001 and 2011 (4). Between 1990 and 2010, the life expectancy increased by 6.8 years for men and 5.2 years for women. Life expectancy in 2012 was 75.0 years for men and 80.9 years for women (5).

**Research question**

In this article we analyse data on the number of deaths in selected social and health care facilities with focus on long-term care services for older people in the Czech Republic. Changes in place of death and on proportion of deaths in health and social care facilities are described with focus on long-term care. Data are derived from health and social statistics. Such an analysis is important to understand the need for palliative, qualified geriatric, and nursing care, in the Czech health and social care system in the context of rising life expectancy and the number of people dying with multiple conditions in specialized health and social care institutions.

We argue that trends towards shorter hospital stay and health care reforms has been translated into the higher numbers and shares of patients receiving care and dying in specialized care institutions, such as long-term care facilities in health system and homes for seniors operated under social system. This has not been adequately accompanied by adapting those facilities to health condition and social needs of persons in those facilities. Outpatient and home services enabling ageing in community are not available as well as palliative and geriatric care in facilities providing care to frail seniors in institutional and home settings.
Results
The analysis shows a rapid increase in the number of deaths in non-hospital institutional settings – specialized long-term health facilities and residential social care facilities. The proportion of deaths in the social care facilities in the period 2007-2012 increased from 4.7 to 6.4% and in specialized health care facilities from 7.4 to 8.2%. This development presents challenges for the availability of palliative, qualified geriatric, and nursing care, especially in residential social care facilities. Nevertheless it has not been reflected in health and social care legislation up to date as there are no personal or care standards for qualified health care provided within social care facilities for seniors.

Since 1996, when the first hospice facility with 30 beds was established, the number of inpatient palliative care facilities increased to 16 hospices in 2012 with the total capacity of 468 beds, which corresponds to 0.4% of the total number of beds in health care facilities. Of all 16 hospices, only one is established and operated by municipality, 5 hospices were operated by the church and 10 by "other private subject" such as NGO or other non-government organization (6,7).

In the last ten years ten new hospices were established. The number of hospices increased especially during years 2004-2006, when their number almost doubled from 7 to 13. Between 2000 and 2012, the number of beds in hospices tripled to 468 beds. Correspondingly, the number of hospitalized patients increased 2.8 times. According to the Institute of health information and statistics of the Czech Republic, in 2012, in total 35 physicians (FTE) and 196 health workers were employed in hospices (6,7).

During 2012, 4,050 patients were admitted in hospices. The average length of stay was around one month (32 days). Women make up 55% of these patients. In 2012, 3,258 people died in a hospice, which is three times more compared to 2000 (Figure 1). More than three-quarters of people were admitted to the hospice on the basis of a diagnosis of cancer (dg. C00-D48) compared to less than one tenth admitted due to stroke (dg. I60-I69 and I70). The costs of health insurance on hospice beds amounted to 5.32 million Euros (142 million CZK) in 2011.

Figure 1. Development of the number of deaths in hospice

The number of people dying in health facilities for long-term ill patients (LDN) has been stable over the past ten years

In 2012 there were 74 care facilities for the chronically ill (LDN) with a capacity of 7,204 beds, which corresponds to 6.8% of the total number of all beds in health care facilities, including hospitals (6). Of the 74 LDN 5 were directly managed by the Ministry of Health, one
by the Ministry of Defence, 13 by regional authorities, 8 by city or municipality, and 47 by another legal entity or churches.

During 2012, more than 42,000 patients were admitted in LDN and 8.3 thousand died in those facilities. Average length of stay in LDN compared to hospice is about double (55 days). Although the number of patients hospitalized in LDN between 2000 and 2012 increased by about 10,000, the number of deaths increased only slightly (Figure 2). The number of deaths per thousand admitted persons decreased from 300.7 in 1992 to 196.2 in 2012 (ÚZIS), while in the case of hospices it increased from 655.2 in 1997 to 804.4 in 2012. This may indicate a change in the structure of patients and change in the profile of these facilities.

Figure 2. The number of deaths in LDN

The number of people dying in long-term health and social care institutions is increasing

Growth in the number of seniors in social and health care facilities for seniors or chronically ill persons resulted in increased number of deaths in social and health care facilities. In 2012, about 17 thousand persons died in non-hospital health or social care facility, by 3.2 thousand (23%) more compared to 2007. The proportion of deaths in the social care facilities in the period 2007-2012 increased from 4.7 to 6.4% and in specialized health care facilities from 7.4 to 8.2%. Almost every fifth woman died in social care or special long-term care facility. Almost every 10th woman died in a social care facility. In opposite, the number of people who died in psychiatric institutions decreased by more than a half (55%) between 1992-2012, thus reflecting trends in deinstitutionalizations and decreasing number of beds in inpatient psychiatric institutions.

According to the Ministry of Labour and Social Affairs, who registers the number of users in residential social services for seniors, more than 12,000 people died in residential facilities for seniors and people with dementia in 2012, which is by one fifth more than in 2007. These statistics however does not correspond to factual location of death, which is recorded only by health statistics (8).

Most people in Czech Republic not only wish to live but also to die at home (9). However, in 2012, about three-quarters of people died in a hospital or other health or social facilities. In 2011 a total number of 56,073 patients died in hospitals (3.8% of all hospitalized patients in 2011). Over 42% of all hospital deaths were recorded in departments of internal medicine (13). The increase in proportion of people dying in non-hospital institutions illustrates the table 1 (below).
Table 1. The changes in proportion of deaths by location in 2007-2012

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>18.1</td>
<td>19.8</td>
<td>19.9</td>
<td>20.4</td>
<td>20.6</td>
<td>21.0</td>
</tr>
<tr>
<td>Hospital</td>
<td>60.5</td>
<td>60.1</td>
<td>60.1</td>
<td>58.9</td>
<td>58.9</td>
<td>58.3</td>
</tr>
<tr>
<td>Health institution</td>
<td>8.5</td>
<td>9.3</td>
<td>9.5</td>
<td>9.1</td>
<td>9.1</td>
<td>9.2</td>
</tr>
<tr>
<td>Street/public</td>
<td>1.9</td>
<td>2.1</td>
<td>2.0</td>
<td>2.2</td>
<td>2.1</td>
<td>2.0</td>
</tr>
<tr>
<td>Transport*</td>
<td>0.4</td>
<td>0.4</td>
<td>0.4</td>
<td>0.5</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>Social care</td>
<td>4.7</td>
<td>5.4</td>
<td>5.5</td>
<td>5.8</td>
<td>6.0</td>
<td>6.4</td>
</tr>
<tr>
<td>Other</td>
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<td>2.9</td>
<td>2.7</td>
<td>3.1</td>
<td>2.8</td>
<td>2.6</td>
</tr>
<tr>
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<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Source: Data of Institute of health information and statistics (ÚZIS, 2013)

* Deaths during transport to health care facility

The number of health staff has been decreasing during last years in social services. The total number of health workers in social services declined by 1,720 to 6,021 from 2007 to 2012, i.e. by more than one fifth. Of all health workers nurses made 83% (8).

Discussion

With increasing longevity the need for geriatric palliative care is growing. Age structure of patients in hospitals and primary care are aging as the total population. While 9.5% of all people died at the age of 80 years or more in 1930, in 2011, people aged over 80 years accounted for 43.2% of all deaths. In 2011 nearly 107 thousand people died in the Czech Republic, of which more than half (56%) were older than 75 years and a quarter older 85 years (13).

Variability in the place of death within the territory is determined mainly by availability of different types of health and social services (11). However changes in time reflect changes in structure of health care services and continuing trend of moving specialized care for seniors from hospitals to long-term care institutions (12). Differences between men and women in the place of death are also influenced by the different structure of causes of death as men relatively more frequently suffer from some acute conditions, and especially higher frequency of deaths due to external causes, such as traffic accidents, injuries, self-harm, which are more common in men, especially at a younger age.

According to WHO (11), most adults in need of palliative care are dying from cardiovascular disease (38.5%) cancer (34%), chronic respiratory diseases (10.3%), HIV / AIDS (5.7%), and diabetes (4.5%). With ageing population and rising prevalence of chronic diseases the need for palliative and long-term care facilities is expected to grow. The beginning of the use of medical or long-term care facilities is postponed to a later age. With increasing longevity the population of seniors is also becoming more diverse.

Older people have different and often more complex needs than younger patients. Seniors are also at increased risk of adverse events and iatrogenic effects and complications. Even minor health problems in older adults may have major psychological impact. Older people tend to show less of their needs and symptoms and physicians conversely to underestimate and inadequately treat pain, especially in non-malignant diseases, but also in cancer patients (10). Problems with acute illnesses often are often superimposed on physical, mental and cognitive impairment, economic hardship and social isolation (10). Since it is difficult to predict the course of many chronic diseases affecting the elderly population, palliative care should be based on the needs of patients and their families rather than on the prognosis (10). These show the need for more multidisciplinary and multi-professional collaboration and
links between geriatrics, long-term and palliative care, especially at community level, and the need for geriatric training in palliative and primary care (16).

However despite all these, treatment of pain and palliative care are less accessible for seniors, and particularly those with dementia, than for younger age groups. Dementia is fatal and incurable disease whose terminal stage lasts 2-3 years and affects about a quarter of the population aged 85 and over (11, 14).

According to WHO (10,11), palliative care has focused primarily on cancer patients with a clear prognosis, for that it has been successful in reducing suffering at the end of life. This led to the view that palliative care is important only to the last few weeks of life and may be provided only in specialized facilities. The time has come for palliative care to become regular part of overall health policies for older people and be an integral part of the services they receive (10,11). Effective care should be available in places and facilities where people live, grow old, and die – i.e. in hospitals, nursing home facilities, social services and our homes and communities.

Conclusion

The data of the Czech Republic show a rapid increase in the number of deaths in non-hospital institutional settings. This requires increased availability of palliative and geriatric care in services that are expected to meet complex conditions and specific needs of older and oldest populations. That is strong argument for effective and efficient support of integrated health and social services encouraging ageing in place.

According to our surveys and practical experiences, many seniors in Czech residential social care facilities, of whom at least a half suffer from some form of dementia and/or depression, are without proper pain relief and palliative and nursing care. Despite worsening of health condition of clients, increasing average age of residents, and rising share of people with 3rd and 4th degree of “dependency on care” (Note: The degree is based on medical assessment provided according to social services act as entitlement for care allowance), the number of health staff in those facilities is decreasing (8) and access of those facilities to funding from health insurance companies is fragmentary and hardly available as health insurance refuse to sign agreements with them and in some cases they accept to sign contracts with social care facilities only after legal action and court decision.

Palliative care should be an integral part of the health care. It represents humanistic mission of medicine to alleviate suffering and pain. According to the WHO, palliative care is an approach that improves the quality of life for patients and families facing life-threatening illness through the alleviation of suffering, early identification, assessment and treatment of pain and other problems of physical, psychosocial and spiritual nature (10). It is now a key priority and challenge to expand our view of palliative care to adapt it to the needs of ageing, frailty and multimorbidity and to increase the availability of palliative and geriatric care in social and health facilities across institutional and home settings.

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CLINICAL LESSONS

Mistakes in communication doctor-sever ill patient

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Communication in palliative care is a key issue to realise quality of care. Honesty and sincerity are essential for a good doctor-patient communication in chronic progressive diseases. For patients with such disease in advanced stage, communication is virtually the only form of treatment: information, realistic hope, preserve human dignity by alleviating physical and emotional pain, psycho-emotional, social and spiritual encouragement and family involvement in care patient. These are essential in helping patients adjust to a more limited lifestyle imposed by the disease.

Communication will not always be perceived as a desired message. This is because the one who receives the message plays through their own perceptions, which may differ from those who initiate the communication. Doctors should learn and continuously improve their communications skills. In the case of life-threatening diseases, especially in palliative care, human psychology should be understood. A smile and a handshake for a sick may do more than a thousand words.

Hippocrates was right: medicine remains the most noble profession. And I would add: that nobility is most needed in providing care palliative to those who need them.

Key words: communication, relationship doctor-patient, empathy, dignity, respect, understanding

(Full text in Romanian)
Introspection and self-evaluation are important for professionals in palliative care

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Abstract

The palliative care principle, i.e. a holistic approach, considers the patient and his family as a unity. Over time, the number of professionals in palliative care, dedicated to serve their neighbours, has increased.

Introspection and self-evaluation are important issues to become such a professional. Involvement in this medical field is a great privilege because it helps to look insight yourself and to discover yourself.

For those, who want to find out what palliative care is, it is important to look at these professionals, to ask them to go with us to "see the good in action."

Key words: self-evaluation, introspection, palliative care

(Full text in Romanian)
COMMENTS, DISCUSSION

Facilitating growth and human development in the context of a serious and terminal illness

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Abstract

Man is a whole composed of body and soul and to be cared for in its entirety. In treating a disease the first thing and most important is the correct diagnosis, physical and/or spiritual. None of them should be neglected because they have an impact on each other, knowing that a healthy body affects a weak soul or a strong soul affects a body weakened by disease.

Key words: soul, body, suffering, terminal illness

(Full text in Romanian)
Psychological coping mechanisms in patient diagnosed with incurable disease

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Abstract

The psychological mechanisms of coping in patients diagnosed with an incurable disease are a long and complex process. "Medical truth" should always be communicated with sensitivity. The way the diagnosis is presented is very important.

Emotional reactions of patients after receiving 'bad news' include a wide range. These reactions are dependent of the personality traits of patients, of the age and social support, of type of disease, location, status, symptoms and prognosis. They range from denial, anger, bargaining, to acceptance and adaptation.

Support and assistance should be bilateral between palliative care specialist and patient/family to help as much as possible. Psychotherapy could supported the family as much as the patient.

Key words: terminal illness, communication, support, psychotherapy

(Full text in Romanian)
NEWS

Hungarian Hospice Palliative Association Conference

The Hungarian Hospice Palliative Association held its biennial national conference in Zalaegerszeg 27-29 March 2014. The title of the conference was ‘We’re not alone’. There were 163 registered participants. There was a plenary session on pain management and various parallel sessions including treatment of physical symptoms, psychological issues, psycho-social care, and paediatric palliative care. Guest speakers from Austria presented an overview on Palliative care in the Austrian social care system.

Palliative medicine: a medical specialty in 18 European countries

During the 8th EAPC World Research Congress in Lerida (Spain, May 2014) the outcomes of a report of the EAPC Task Force on the Process of Specialisation in Palliative Medicine in Europe was presented. The study revealed that 18 out of 53 European countries have official specialisation programmes: the Czech Republic, Denmark, Finland, France, Georgia, Germany, Hungary, Ireland, Israel, Italy, Latvia, Malta, Norway, Poland, Portugal, Romania, Slovakia and the United Kingdom. Ten of these programmes have been started in the last five years.

Strengthening of palliative care as a component of integrated treatment throughout the life course

During the 67th World Health Assembly in Geneva May 2014 a report was presented describing the current status globally of palliative care and measures that are crucial to its development with a public health approach.
Most important were the recommended actions to support the extension and strengthening of services for palliative care at the country level. These actions include:
(a) formulating and implementing national policies that integrate evidence-based palliative services into the continuum of care, at all levels, of chronic life-threatening conditions, with an emphasis on primary care, and community- and home-based care;
(b) advocating for palliative care in efforts to promote universal health coverage and essential medicines policies, on the basis of the results of assessment and improvement of the quality and safety of palliative care;
(c) implementing and monitoring the recommendations in the WHO global action plan for the prevention and control of noncommunicable diseases 2013–2020 and ensuring its integration into universal coverage and essential medicines schemes;
(d) ensuring that education about palliative care (including ethical aspects) is offered to students in undergraduate medical and nursing schools and to health care providers at all levels, in accordance with their roles and responsibilities and as part of human resource development;
(e) ensuring adequate access to controlled medicines while minimizing opportunities for their diversion and abuse by aligning national and local regulations with WHO’s guidance in national policies for controlled substances;
(f) ensuring access to all aspects of palliative care (basic medical support and psychosocial and spiritual support to patients and families), under the supervision of trained health care professionals, as appropriate;
(g) establishing ethical guidance related to the provision of palliative care, in areas such as equitable access, respectful care and community involvement in policies and programmes; and
(h) working in partnership with different sectors to foster operational research in palliative care, including the development of cost-effective models of such care.
All these measures, combined with committed leadership, are considered necessary for effective and efficient palliative care.