

6.2 THE LABOUR MARKET CONTEXT OF THE INCREASING DEMAND FOR PALLIATIVE CARE*

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Rise in the proportion and number of patients with serious health-related suffering (SHS)

Average life expectancy at birth increased from 42 years in 1900 to 76 years in 2000 in Hungary and at the same time the structure of the most common diseases leading to death transformed completely. In the last decades, the rise in average life expectancy has been caused by the increase in the life expectancy of the population over 65 rather than the decrease in infant mortality. This contributes to the increase in the number and proportion of the elderly. The proportion of the population over 60 rose from 7.5 per cent to 23.5 per cent between 1900 and 2011. The share of those older than 65 was 20 per cent in 2018, which is foreseen to reach 30–35 per cent in 2050.

At present, one does not tend to die of a contagious disease or in accidents any longer but of chronic diseases such as cancer, cardiovascular or respiratory diseases, stroke, dementia and neuro-organic diseases. The increasing number and proportion of deaths caused by chronic diseases is common knowledge. However, it is less well-known that the number and proportion of deaths due to diseases involving serious (physical and mental) health-related suffering (SHS)¹ has also risen. This has been accompanied by a surge in the *number* of patients needing *palliative care* (which aims at mitigating suffering rather than treating diseases) and the *duration* of end-of-life palliative or hospice care. In the end stage of a terminal illness it is no longer possible to cure the disease. The aim is to alleviate or relieve suffering and support patients in reaching their end-of-life goals (*Hegedűs*, 2006). The average duration of the end-of-life stage was a few weeks in 1900. In just over 100 years, this period expanded to two to two and a half years on average.

The shift in public opinion and policy debate on the end-of-life stage substantially contributed to the increase in the demand for palliative care. The modern hospice movement, which started in the sixties of the previous century, changed the expectations and possibilities of an increasing proportion of patients, healthcare workers and geriatric nurses on the end-of-life stage globally (see for example *IAHPC*, 2019).

The Lancet report published in 2018 (*Knaul et al*, 2018) was a major milestone in assessing demand for palliative care and designing programmes to meet this demand. The working group “Lancet Commission on Global Access to Palliative Care and Pain Control”² organised by the project “Harvard Equity Initiative”³ in 2017 at Harvard University had developed a method

* We would like to thank *Ágnes Ruzsa* (Hungarian Hospice Palliative Association) for her expert guidance and help with writing the Chapter.

1 See: pallipedia.org.

2 See: Harvard University.

3 *Ibid*.

for estimating the annual number of SHS-related deaths globally and, based on the experience of several hundreds of specialist doctors, also the average duration of nursing tasks characteristic of the end-of-life stage in the various groups of diseases. Relying on health economists, they then prepared pilot case studies to estimate the costs that low- and middle-income countries selected from various regions would incur if they integrated palliative care according to Western-European standards in the system of primary healthcare. According to estimates of the Lancet report there were 56.2 million deaths globally in 2015. Nearly half of those who died had suffered from a condition involving SHS for an indeterminate period and leading to death.⁴ The report states that there is an enormous gap between high-income and low-income countries especially as regards relieving the pain associated with illness. Nevertheless, estimates indicated that the costs of a universal palliative basic care package are possible to be financed from only 0.03–0.25 per cent of the GDP in the countries considered (Ruanda, Vietnam and Mexico) (*Knaul et al*, 2018, p. 1421.).

Based on indicators of the quality of palliative care, Hungary is in the bottom end of the mid-range in Europe. In spite of significant improvements in the institutional and regulatory environment in recent years (*Csikós et al*, 2018, *Benyó–Lukács*, 2017), the country's position in international ranking is deteriorating. It is because several countries, including Eastern-European ones, have made more rapid progress than Hungary. It is particularly worrying that (similarly to the majority of Eastern-European countries) the increasing demand for palliative care will be accompanied by low capacities (*EIU*, 2015, p. 52.).

The quality of palliative care is determined more by the lack or spread of the palliative approach than the size of the GDP. The surveys and position papers of Hungarian⁵ and European⁶ hospice/palliative associations, foundations and universities play a crucial role in shaping attitudes about palliative care in Hungary (*Hegedűs–Farkas*, 2019, *Hegedűs–Munk*, 2018, *Arias-Casais et al*, 2019). European trends revealed by surveys in 2019 and prior were recently outlined by *Arias-Casais et al*, (2020). The results indicate that Hungary belongs to the group of countries which lag behind the targets for all three forms of care set by the WHO, in spite of their growth.

In order to have a more precise overview of the challenges facing Hungarian society, we estimated the changes in the demand for palliative care in Hungary between 1970 and 2018, using the mortality database of the Central Statistical Office⁷ and the methodology of the researchers at Harvard. Based on the estimates, the proportion of those in the annual mortality figures who died of diseases requiring palliative care increased from 38.7 to 46.9 per cent over this period (*Figure 6.2.1*). While the number of annual deaths rose by 9 per cent, the number of deaths associated with diseases requiring palliative care rose by 32.3 per cent over the same period.

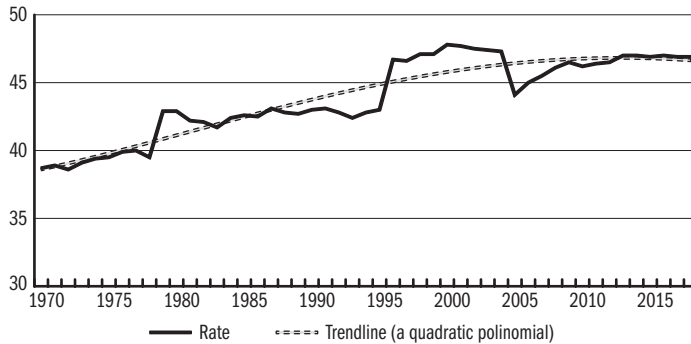
4 The International Association for Hospice & Palliative Care created [an interactive website](#) based on the results of the project, which also provides a breakdown of estimates by country. Global Data Platform to Calculate SHS and Palliative Care Need.

5 [Hungarian Hospice Palliative Association](#).

6 [European Association of Palliative Care](#).

7 See: [KSH](#).

Figure 6.2.1: Changes in the estimated proportion of patients needing palliative care within the number of deaths in Hungary annually, 1970–2018



Note: In 1976, 1995 and 2004 there were modifications to the International Classification of Diseases (ICD) and their impacts were not possible to eliminate entirely during transcoding.

Source: CERS Databank, CSO mortality data base, authors' calculation.

Changes in the composition of the most frequent diseases leading to death are presented in *Table 6.2.1*, which includes the ten most frequent disease groups involving SHS in 1970 and 2018. It is seen that malignant tumours and cardiovascular diseases occupy the first three places in both years. By 2018, injuries, poisoning, tuberculosis and birth defects had no longer been a leading cause of death. However, neuro-organic diseases common in old age (such as dementia, Parkinson's and Alzheimer's disease) and, to a large extent due to increasing alcohol consumption, liver diseases, have now been included.

Table 6.2.1: The ten most frequent disease groups with SHS leading to death in Hungary

1970	2018
1. Malignant tumours	1. Malignant tumours
2. Cerebrovascular diseases	2. Cardiomyopathy and heart failure
3. Cardiomyopathy and heart failure	3. Cerebrovascular diseases
4. Atherosclerosis	4. Respiratory diseases
5. Respiratory diseases	5. <i>Dementia</i> ^
6. <i>Injury or poisoning</i> v	6. <i>Liver diseases</i> ^
7. <i>Tuberculosis</i> v	7. Chronic ischemic heart disease
8. <i>Birth defects</i> v	8. Atherosclerosis
9. Chronic ischemic heart disease	9. Leukemia
10. Leukemia	10. <i>Neuro-organic diseases</i> ^

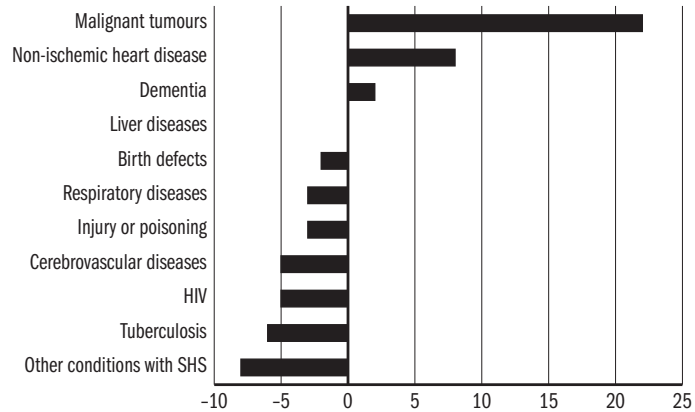
Note: Disease groups that were excluded or newly included in the ten most frequent disease groups involving SHS between 1970 and 2018 are in italics.

Source: CSO mortality database, authors' calculation.

The proportion of patients in need of palliative care is not significantly different from the average of countries included in the Lancet report. The estimated share of people who died of diseases requiring palliative care was 47

per cent in Hungary in 2016, whereas it was 45 per cent in the countries of the Lancet report. However, there was a significant difference in the *composition* of diseases leading to death in palliative care. The share of those who died of malignant tumours, chronic heart diseases and dementia is higher in Hungary than the average of the countries included in the Lancet report (Figure 6.2.2).

Figure 6.2.2: Difference between the proportions of patients who died with SHS in Hungary and the Lancet countries, 2016 (percentage points)



Source: Authors' calculations, based on CERS Databank, CSO mortality figures and Knaul *et al.* (2018).

Relying on the methodology of the Lancet report, it was possible to estimate the optimum duration, in nursing days, of palliative care of those who died in a given year. The estimated demand for care increased by nearly 50 per cent over the period concerned, since the proportion of conditions requiring lengthy palliative care increased among the causes of death. The number of deaths from SHS conditions increased by 132 per cent, the estimated duration of the cumulative demand for palliative care rose by 147 per cent and the maximum duration of palliative care increased by 153 per cent.⁸

Changes in the composition of diseases leading to death also had an impact on the structure of tasks in palliative care. In Hungary, nursing tasks related to pain relief, breathing difficulties and physical or mental fatigue expanded the most during the period considered.

These changes are in line with tendencies resulting from the shifts in the composition of diseases leading to death. However, most of the increase in the demand for palliative care is caused not by these but from the development of palliative care and the awareness and recognition of the right to palliative care. It is now acknowledged that the role of the healthcare system is not merely to cure but also to support patients during their end-of-life stage to reach their end-of-life goals and die with dignity. Society must not toler-

⁸ The duration of the *cumulative palliative care* is not equal to the actual duration of palliative care but to the sum of the estimated duration of the various forms of care. Since some forms of care are provided in parallel, this indicator is longer than the actual duration of the need for care. Its use is justified on the grounds that it illustrates the extent of the burden on the healthcare system. The duration of *maximum palliative care* is equal to the duration of the longest form of care multiplied by the number of deaths in a disease category. This is closer to the actual duration of care but is somewhat shorter (Knaul *et al.*, 2018).

ate patients and their families living the final stages of their lives (or a relative's life) in physical and mental agony. It is now also recognised that society is able to create the necessary institutional, human and financial conditions so that they are not forced to do that.

The labour market context of the increasing demand for palliative care

The expansion of palliative care presupposes that in the end-of-life stage the emphasis is shifted from treating the disease to achieving the palliative goals. This shift not only improves the quality of life of patients but, according to studies, it increases life expectancy and reduces the costs of care (*Higginson et al*, 2003, *Gardiner et al*, 2016). The spread of palliative care provided at home or in hospices eases the burden on the most expensive and labour intensive services of healthcare systems (*Dózsa et al*, 2013). In the following, two elements of the process are highlighted, which are especially important for matching labour market supply and demand.

Improving the key competences of workers in palliative care

Acquiring and developing the key competences of palliative care also require non-cognitive skills that are indispensable for achieving the goals of palliative care. These include conscientiousness, agreeableness, emotional stability, openness and extroversion (*Roberts et al*, 2015). Some of them are innate but can be continuously developed. Others are consolidated through parenting and formal education. Therefore the role of school education is not only to raise awareness of the palliative approach among youth but also to reinforce the non-cognitive skills needed for the effectiveness of palliative care.

Developing palliative care starts with raising awareness of the palliative approach and increasing its acceptance. Core values associated with palliative care include autonomy, dignity, quality of life and a holistic approach to life and death. In recent years, the WHO as well as international and European palliative associations prepared detailed analyses and guidelines to summarise key competences needed by staff working in the various fields of palliative care (*Ryan et al*, 2014). We herein focus on cooperation and communication skills, which are needed for teamwork.

Palliative care is a complex, multiprofessional task, which calls for close cooperation between family members participating in nursing, various professionals providing care and the patient. Several analyses found that the coordinated work of palliative teams belonging to different professions is considerably more efficient than traditional nursing based on separate care providers (*Higginson et al*, 2003). In recent years, the WHO compiled detailed handbooks with the aim of integrating the development of key palliative competences in education systems (*Radbruch et al*, 2010).

Setting up a decentralised institutional system that matches the needs of palliative care

Criteria of access to palliative care are crucial in the development of the system of institutions of palliative care. Only an institutional system with most of its elements regionally decentralised is able to attain the primary goals of palliative care. Patients prefer to spend the end-of-life stage of their life with their family or in a hospice (*Arnold et al, 2013*). Yet today they spend most of this period in hospital. This is, on the one hand, because there is a high share of elderly living in nursing homes or alone among those needing palliative care and, on the other hand, because family members do not have the skills and knowledge necessary for providing palliative care and they lack professional and financial support. In countries with a high proportion of patients who spend the end-of-life stage in their families, a carefully designed and decentralised system of institutions supports families in carrying out this task. This support also enables family members to find full-time or part-time employment (*Guerrierea et al, 2015*).

Therefore the development of the institutional system of palliative care has to be aligned with the regional characteristics of access and demand. The palliative care system has to have a structure that supports patients' home-based or hospice-based care in accordance with their disease and family conditions. This requires knowing the geographical distribution of patients needing palliative care and the transport conditions of regions as well as determining the appropriate geographical distribution of general and special palliative care institutions in order to provide for the conditions of home-based palliative care, where possible.⁹

The two-volume white paper of the European Association of Palliative Care on the standards of palliative care contains recommendations for European countries concerning the number and headcount of various levels of palliative services (palliative care wards, hospices or hospice wards, mobile palliative teams of hospitals, home-based palliative teams) proportional to the population as well as their geographical and temporal availability (*Radbruch et al, 2010*). In spite of recent developments, Hungarian palliative care institutions are not yet able to follow these recommendations (*Hegedűs–Farkas, 2019*).

⁹ The study "Access to palliative care in Hungary", launched in 2020 in the Institute of Economics of CERS, aims at assessing the geographical and social characteristics of patients in need of palliative care.

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