

Palliative Care Systems – International Comparison of the Czech Republic and Ireland – Lessons Drawing

Matěj Lejsal, Jiří Krejčí

Abstract:

Hospice and palliative care in the Czech Republic has been significantly practice-oriented from the very beginning. Gradually, the professional specialisation of physicians and the professional education of general nurses was added. The growing awareness and interest of the professional and lay public, including political representation, brings the need to embed palliative care in the system of individual branches of social policy as a fully-fledged part of this system. The aim here of comparing strategic documents and processes in the field of palliative care in the Czech Republic and Ireland through an overview study is to contribute to the 'lessons drawing' for shaping the further development of palliative care in the Czech Republic.

Keywords: palliative care, international comparison, Ireland, models, concepts, national clinical program, development, advocacy

In recent years, palliative care has received great attention in the Czech Republic, gaining its place in regional strategic documents, in the reimbursement mechanisms of public health insurance funds, and in legislation. Changes are often initiated 'from the bottom up'. Palliative care is essentially interdisciplinary care. Nevertheless, a number of changes take place in isolation in individual branches of social policy (health policy, education, social security).¹ Even if it is possible to follow partial efforts, for example, at the regional level, the Czech Republic does not have a unifying vision and a strategy for its fulfilment. Embedding palliative care as a systemic element in social policy, especially in health policy, can be seen as a process of large-scale change. It requires a shared vision of a number of actors, and the introduction of new elements into the system. These are mainly new services, new expertise, new financing tools. An integral part of the whole process is the setting of mutual relations between existing and new elements and the setting of related processes (transfer of information, financial relations) and their anchoring in legislation, training, and practice. An integral part is also raising awareness and interest in new elements among the professional and lay public. In policy-making, 'lessons drawing' is a legitimate tool which is, in various intensities, obtained abroad.² The Czech-Irish study compares three basic areas: access

1 Igor TOMEŠ, *Obory sociální politiky*, Praha: Portál, 2011.

2 Colin C. WILLIAMS et al., *Assessing the cross-national transferability of policy measures for tackling undeclared work*, GREY Working

to palliative care, strategic documents, and dominant players at the national level. The starting source was publicly available documents (policy papers, strategies, methodologies, profiles of organisations, see below) supplemented by semi-structured interviews with seven respondents. They were identified according to their profession (social workers, nurses, doctors, director) and type of organisation (in-patient hospice, hospital, umbrella institute, and provider of community palliative care). The basic areas of questioning regarded the system of palliative care, challenges in the development of palliative care, and advocacy.

This study should be one of the contributions to the process of finding and creating a unifying vision and strategy of palliative care in the Czech Republic. With regard to the diversity of the environment (especially cultural-historical and legislative), it describes the similarities and formulates recommendations for transfer of experience at the level of 'inspiration' which are based on the differences found. The comparative study compares three basic areas: access to palliative care, strategic documents, and dominant players at the national level. The study was carried out within the programme of the Faculty of Humanities of Charles University *Progres Q20 Kultura a společnost* from August to December 2019.

The Concept of Palliative Care – TALKING ONE VOICE

The development of palliative care in the Czech Republic encounters the absence of a unifying vision, or rather the existence of more ideas about care for a person in need of palliative care and its form. This image is formed not only by the Ministry of Health, the Ministry of Labour and Social Affairs, and individual regional authorities but also largely 'from the bottom up' by the providers and experts themselves who operate in associations or professional societies. Asociace poskytovatelů paliativní hospicové péče, Česká společnost paliativní péče, Česká společnost hospicové péče and Fórum mobilních hospiců are the main players in the development of palliative care in the Czech Republic. However, the direction of development is not uniform.³

The Irish experience shows that the ability 'talking one voice', that is, that most actors in a given segment know where they are going and what they want to achieve, allows more effective promotion of the interests of the group. Respondents mentioned in the interviews that a 2001 document⁴ was used to unify the vision for the development of palliative care in Ireland. The content of this document became a 'bible' for providers and key players. It is important to mention that the unifying element was not the content of this document, but it was the process of its creation. This document is not only expert opinion on the development of palliative care but largely a written record of the negotiation process of a wide range of key actors, experts, professional societies and umbrella organisations. Representatives of hospices, hospitals, oncologists, general practitioners, ministries, and foundations worked in the commission that drafted the document. Thanks to the broad support of this document among experts, it was subsequently adopted by the Irish Ministry of Health.

In its first part, the document focuses on a general description of basic concepts, levels of care and the need for specialised palliative care. A large part of the document is focused on the development of specialised palliative care. Each chapter has clear, measurable, and sufficiently specified

Paper No. 5, University of Sheffield, 2014.

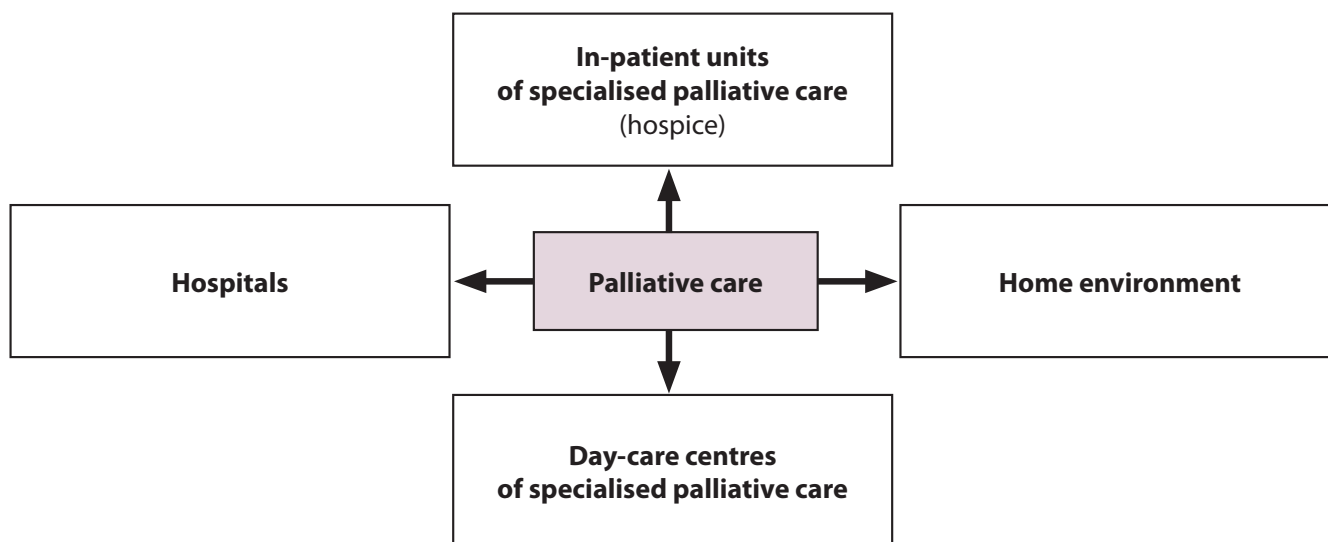
3 Ondřej SLÁMA, Aktuální výzvy pro paliativní péči v Evropě a ČR, Senát PČR (sympozium) 2nd October 2019.

4 © NAC, Report of the National Advisory Committee on Palliative Care (on-line), available at: <http://hospicefoundation.ie/wp-content/uploads/2012/07/Report-of-the-National-Advisory-Committee-on-Palliative-Care-2001.pdf>, cited 3rd May 2020.

objectives. For example, Chapter 6.3 recommends that there should be at least one in-patient specialised palliative care unit⁵ in each *region*⁶ (note: the role of this unit is mostly performed by in-patient hospices). Chapter 5.5 specifies that there should be at least one full-time palliative medicine doctor per 160,000 inhabitants. At the same time, the minimum of two such doctors in one region is set. The goals defined in this way enabled all representatives of key organisations to promote a shared vision not only because these goals were created together but also because they are concrete and based on the sufficient specificity of the defined recommendations.

The Four Pillars of Palliative Care

In Ireland, palliative care is provided in four settings – in the in-patient units of specialised palliative care, in hospitals (in the form of counselling), in the day-care centres of specialised palliative care, and in the home environment.



In-patient units of specialised palliative care are seen as an essential element of palliative care in every area. They are often the coordinators of care in the region, including hospitals and local communities. They work as a palliative care training centre for other health professionals in the region, usually providing expert advice and also conducting palliative care research.⁷

In the Czech Republic, in-patient hospices are closest (considering the form and content) to these in-patient units of specialised palliative care. The coverage of these facilities in the Czech Republic is similar to that in Ireland. In 14 regions, we can find 15 in-patient hospices, and two palliative care units in hospitals.

Palliative hospital care in Ireland is usually provided by a multidisciplinary counselling team that provides support to medical staff. The specialised palliative care team in Ireland consists of at least one doctor certified in palliative medicine, a specialist nurse, a social worker, and an administrative worker. The team of specialised palliative care often shows other healthcare professionals in the facility good practice in working with seriously ill patients. It also often offers education

5 © NAC, Report..., p. 73.

6 Ireland is divided into eight *health board areas* which form health policy in the territory. The number of inhabitants corresponds to one region in the Czech Republic (around 700 thousand inhabitants).

7 © NAC, Report..., p. 33.

and training in palliative medicine in the area. Studies show that the introduction of a specialised palliative care team in hospitals leads to an improvement in the quality of care for patients with end-stage disease.⁸

In the Czech Republic, counselling palliative care is a relatively new service provided in health care. The beginnings of its operation were supported by private foundations.⁹ Currently, the Ministry of Health is implementing a pilot project 'Podpora paliativní péče – zvýšení dostupnosti zdravotních služeb v oblasti paliativní péče v nemocnicích akutní a následné péče' to support the establishment of counselling palliative teams in hospitals. As in Ireland, their task is to support and facilitate, for example, management of symptom burden, formulation of treatment goals, discussion about treatment alternatives, or management of difficult communication with the patient or his relatives (due to, for example, diverging expectations of therapeutic options) in the form of consultation, or supportive intervention.¹⁰

In both countries, we can see that the ideas about the functioning of palliative care in hospitals do not differ in content, however, we can trace a different approach to the implementation of these changes. In the Czech Republic, short-term support has been created for a limited number of hospitals, although it is not yet clear what the care should look like in the future, how many hospitals will have a similar team, and whether its operation will be covered by health insurance. The Irish model points to a different approach. First of all, they defined the target state – in each hospital, counselling services are provided by a specialised palliative team led by a doctor.¹¹ Staffing of the palliative team is given, and its members are at least one palliative doctor, palliative nurse, social worker, and administrative worker.¹²

Day-care centres of specialised palliative care

Day-care centres providing specialised palliative day care are an important pillar in the system of care for patients with serious illness in Ireland. They are intended for patients who are not in the terminal phase of the disease and who are able to commute to the hospital (the service is, in most cases, connected to specialised palliative care units, i.e., hospices).

This form of care is practically unknown in the Czech Republic.¹³ According to zákon o sociálních službách (the Social Services Act), there are day-care centres providing 'out-patient services to people who have reduced self-sufficiency due to age, chronic illness or disability'.¹⁴ However, these services are not specialised palliative care. In order to fulfil the Irish vision, it would be necessary to provide, in addition to social services, also health services, especially the availability of a palliator, a nurse, a physiotherapist, or other professionals. Counselling palliative teams can also play an important role here. They could recommend these facilities to patients in the event of early intervention in a hospital environment. This type of service can be inspiring for existing Czech in-patient hospices.

8 Regina MCQUILLAN et al., The provision of a palliative care service in a teaching hospital and subsequent evaluation of that service, *Palliative Medicine* 10(3)/1996; © NAC, Report..., p. 80.

9 © NF Avast, Spolu až do konce (on-line), available at: <https://nadacnifond.avast.cz/spolu-az-do-konce>, cited 3rd May 2020.

10 © MZČR, Výzva k předkládání žádostí o dotaci v rámci Programu Podpory paliativní péče – zvýšení dostupnosti zdravotních služeb v oblasti paliativní péče v nemocnicích akutní a následné péče, 2019 (on-line), available at: http://www.mzcr.cz/Unie/obsah/podpora-paliativni-pece-nemocnicni_3984_8.html, cited 31st May 2020.

11 © NAC, Report..., p. 81.

12 © NAC, Report..., p. 82. The team is similar to Pilotní projekt MZČR (the pilot project of Ministry of Health of the Czech Republic) and the Irish NAC.

13 With the exception of the children's hospice hospital, which is operated by MH Ondrášek, see <https://www.mhondrasek.cz/cz/detsky-hospicovy-stacionar>.

14 Act No. 108/2006 Coll., On social services, §45 of the Act.

Home environment

In Ireland, the GP is responsible for the medical care of his patients. He works with other health care providers, hospitals, and nursing homes, as well as with community-based palliative care providers. However, clinical responsibility for the patient in Ireland remains with the GP. The community specialised palliative care team recommends medication and other aspects of patient care but the decision to implement these proposals is at the discretion of the GP. This model is different from the practice in the Czech Republic where the provider of mobile specialised palliative care is responsible for the care of patients (in the Czech context we are talking about *home hospitalisation*). The Czech model simplifies the work of the MSPP provider¹⁵ who is responsible for the quality of services and does not have to rely on the GP. At the same time, though, this approach creates tension between MSPP and GPs who often feel that the MSPP provider is intervening in their environment (this includes patients who are often accompanied by their GPs for a lifetime). In terms of the implementation of community palliative care, we could assume that the Irish model requires a higher degree of communication between subjects but it also increases the competencies of GPs (GPs can increase their competencies in caring for seriously ill patients when working with MSPP more closely). This model reduces the risk of conflict between MSPP and GPs when transferring patients into MSPP exclusive care.

In Ireland, similarly to the Czech Republic, community specialised care (or MSPP) services are provided often (but not exclusively) through teams which have been set up in existing specialised palliative care units (or in-patient hospices).

The organisation of specialised palliative care in Ireland relies primarily on counselling palliative care teams at hospitals and hospice centres which provide in-patient, out-patient and outreach care ('community care'). Cooperation in these services is, in many cases, facilitated by the simultaneous engagement of a palliative care doctor in all forms of palliative care service. The Irish model shows that specialised palliative care is primarily provided in two types of facilities – in an in-patient hospice providing palliative day-care centre and community palliative care services, and in hospitals with an established counselling palliative team. According to the respondents, the establishment of cooperation between these actors is an important element of the effective coordination of patient care. In Ireland, co-operation is usually supported in terms of staff (palliators working in hospitals also work in in-patient hospices) and spatially (in-patient hospices are usually built close to hospitals).

National Clinical Programme for Palliative Care

In 2010, the *National Clinical Programme for Palliative Care* was established in Ireland to ensure that patients with life-limiting illnesses and their families have easy access to palliative care suitable to their needs. The programme is coordinated by the national clinical leader, the national leader in nursing, and the programme leaders who work together to ensure that the programme's goals are met. In addition to this executive group, a multi-professional working group is also established to provide support to the executive committee in the process of programme implementation.

The individual operational objectives are identified in the document *Report of the National Advisory Committee on Palliative Care*.¹⁶

15 Mobilní specializovaná paliativní péče (Mobile specialised palliative care, MSPP) is a form of providing specialised out-patient palliative care in the home or in the alternative social environment with the continuous availability of medical and nursing care. This organisational model has the character of home hospitalisation, see <https://www.paliativnimedicina.cz/stanovisko-k-otazce-ambulantni-a-mobilni-specializovane-paliativni-pece/>, cited 3rd May 2020.

16 © HSE, Palliative Care, (Three year development framework – 2017-2019), (on-line) available at: <https://www.hse.ie/eng/about/who/>

In order to recapitulate the development of the implementation of palliative care in the health care system in Ireland, we should see two basic milestones:

1. The preparation of a document describing the desired target state (*Report of the National Advisory Committee on Palliative Care*) which was subsequently adopted by the Ministry of Health (2001);
2. The establishment of the *National Clinical Programme for Palliative Care*, the creation of the positions of *national clinical leader*, *national leader in nursing* and *programme leader* (year 2010) – people in these positions were implementing the programme.

In the past, Česká společnost paliativní péče (Czech Society for Palliative Care) developed a document *Strategie rozvoje paliativní péče v České republice* (Strategy for the Development of Palliative Care in the Czech Republic) for the period 2011–2015, followed by an updated version for 2015–2020; both proposals were rejected by the Czech government as unnecessary.¹⁷

In recent years, strategic documents have started to emerge at regional levels (e.g., South Bohemian Region,¹⁸ Vysočina Region,¹⁹ South-Moravian region,²⁰ Prague City Hall²¹), showing interest in the systematic development of palliative care in the regions.

At the national level, the signing of a memorandum from the Ministry of Health of the Czech Republic, health insurance companies, and the Czech Society of Palliative Medicine of the Czech Medical Association of J. E. Purkyně in cooperation regarding the systematic development of palliative care in the Czech Republic can be described as a breakthrough. The document does not describe the specific operational goals of the development of palliative care in the Czech Republic but it identifies the following areas of cooperation:

- pilot verification and analysis of specialised palliative care operations provided in acute and aftercare hospitals;
- pilot verification and analysis of reported home specialised palliative care;
- proposal of indication criteria for palliative care in the case of relevant forms of palliative care;
- quantification of the patient population meeting the indication criteria for palliative care;
- proposal of optimal and sustainable network capacity of providers of specialised palliative care;

cspd/ncps/palliative-care/resources/, cited 31st May 2020.

17 © ČSPM, Strategie rozvoje paliativní medicíny a péče v České republice v letech 2015–2020, Brno, 2015 (on-line), available at: <https://www.paliativnimedicina.cz/projekty/nf-avast/strategie-rozvoje-paliativni-mediciny-a-pace-v-ceske-republice-v-letech-2015-2020/>, cited 30th May 2020.

18 © Jihočeský kraj, Koncepce paliativní péče v Jihočeském kraji na období do roku 2023 (on-line), Available at: https://www.kraj-jihocesky.cz/sites/default/files/ku_usneseni/Zastupitelstvo/2018-09-06/Navrhy/261-ZK-18_Koncepce_paliativni_pece_v_Jihoceskem_kraji_na_obdobi_do_roku_202.pdf, cited 3rd May 2020.

19 © Kraj Vysočina, Strategie paliativní péče v Kraji Vysočina na období do roku 2020 (on-line), available at: <https://www.kr-vysocina.cz/paliativni-pace/ds-303865/p1=92885>, cited 3rd May 2020.

20 © Jihomoravský kraj, Koncepce paliativní péče v Jihomoravském kraji (on-line), available at: https://www.paliatr-vysocina.cz/wp-content/uploads/2019/10/paliativni_pece_krajske-setkani.pdf, cited 3rd May 2020.

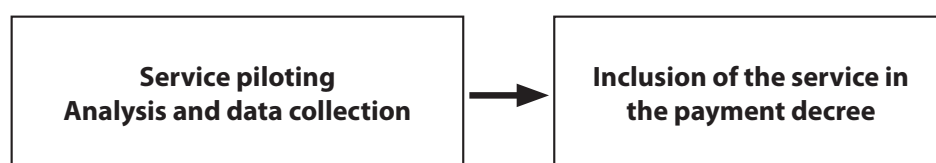
21 © MHMP, Analýza paliativní péče v hlavním městě Praha (on-line), available at: <https://paliativnicentrum.cz/projekty/analiza-paliativni-pace-v-hlavnim-meste-praha>, cited 3rd May 2020.

- analytical processing of available data and proposal of the optimal and sustainable capacity of the network of palliative care providers for patients aged 0-18;
- possible recommendations for changes of a legislative nature which would be identified on the basis of the analytical materials.²²

The role of the coordinator of this cooperation (according to a memorandum) belongs to ČSPM (Czech Society of Palliative Medicine). A comparison of the Irish and Czech systems shows a fundamentally different approach to the implementation of palliative care into the system. In Ireland, experts created a shared vision (vision of the future state) which was subsequently implemented by the state – see the following figure:



In the Czech Republic, the model of piloting new services, collecting data and possibly securing funding from public health insurance funds is used. The Czech Society of Palliative Medicine has a coordinating and professional role.



The Czech model can be perceived as very cautious, minimising the risk for health insurance companies and the Ministry of Health. These need to make sure (by piloting services) that even in the Czech environment palliative services can prove their benefits for patients and cost-effectiveness (in spite of the fact that foreign experience has already proven this approach to be beneficial for patients and for cost-effectiveness). This approach also brings great uncertainty for stakeholders: it is not clear in which direction the development of palliative care in the Czech Republic will go in the future. Although pilot projects may result in the setting up of funding for a given service, this is not guaranteed to providers of these pilot services.

It is questionable whether the ČSPM's mandate in coordinating the development of palliative care is not too weak, and whether (according to the Irish model) there should be an executive committee at the Ministry of Foreign Affairs responsible for implementing a comprehensive concept. This would then give providers some guarantee of stable development.

Access to Palliative Care – Graded Palliative Care, Approach vs. Performance

The European Association of Palliative Care Providers uses the concept of 'hospice and palliative care in levels' to specify palliative care.²³ When comparing the concept of palliative care in strategic

22 © MZČR, Memorandum o spolupráci na systematickém rozvoji paliativní péče (on-line), available at: <https://www.paliativnimedicina.cz/na-mz-bylo-podepsano-memorandum-o-spolupraci-na-systemickem-rozvoji-paliativni-pece/>, cited 3rd May 2020.

23 Originally, the palliative care scheme in levels has been used by Hospiz Österreich since 2004 – see: © ÖSTERREICH, Gesundheit.

documents between the Czech Republic and Ireland, one significant difference is obvious. In the Czech Republic, the concept of two-stage palliative care prevails, that is, general palliative care and specialised palliative care. Illustrative examples of actors are assigned to individual levels (and inter-levels).²⁴ Ireland uses the concept of palliative care divided into three levels, which is currently also used by the European Association for Palliative Care (EAPC).²⁵ This is a palliative approach, general palliative care, and specialised palliative care.²⁶ The reason for the decision to use the two-stage model, which is also mentioned by the EAPC, may be 'simplicity'. This was valuable (from the point of view of ČSPM ČLS JEP²⁷ in the phase of establishing palliative care, especially in the health care system and health services. The three levels of palliative care as recommended by the EAPC define these levels as follows:

- first level – palliative approach – the principles of palliative care should be appropriately applied by all health professionals;
- second level – general palliative care – the part of patients and families will benefit from the expertise of health care professionals who are not engaged in palliative care full-time but have additional training and experience in palliative care;
- third level – specialised palliative care – services of specialised palliative care whose main activity is limited to the provision of palliative care.

This structure is reflected in the demands on the competencies of professionals in various helping professions. At the same time, it forms expectations from services and legitimate demands on various actors. The two-stage model offers a clear structure for the medical professions, especially doctors. For other professions of the multidisciplinary team, the three-level model offers a clearer space for application, for example, outside the medical fields – in social services, etc.²⁸

The advantages of the schematic division are manifested in the area of competencies. At the same time, it turns out that the emphasis on a palliative approach increases the probability of early involvement of palliative care (emphasis on the social worker's competencies is shown in the ability to use general and specialised palliative care by professionals as a source of support for caregivers at the first level – i.e., counselling, training, advice, etc.).

The Irish system emphasises the counselling concept of specialised palliative care. This concept assumes that one of the competencies of professionals operating at the level of palliative approach (or at the level of general palliative care) is that 'They take into account the potential role of specialized palliative care services when supporting employees in other organizations.

Abgestufte Hospiz- und Palliativversorgung für Erwachsene. Aufl. Gesundheit Österreich, Wien, (on-line), available at: https://www.hospiz.at/wordpress/wp-content/uploads/2016/05/broschuere_hospiz-_und_palliativversorgung_1_12_2014.pdf, cited 30th January 2020.

24 The two-stage concept of palliative care is used in Věstník Ministerstva zdravotnictví ČR č. 14/2017 (the Bulletin of the Ministry of Health of the Czech Republic No. 14/2017) within the Methodological Instruction of the Ministry of Health of the Czech Republic for the provision of mobile specialised palliative care, pp. 23–24.

25 © Lukáš RADBRUCH and Sheila PAYNE, White Paper on standards and norms for hospice and palliative care in Europe: part 1, European journal of palliative care (on-line), available at: <https://www.eapcnet.eu/Portals/0/adam/Content/LmgAajW9M0Os7VYZs0ZXCQ/Text/White%20Paper%20on%20standards%20and%20norms%20for%20hospice%20and%20palliative%20care%20in%20Europe.pdf>, cited 30th January 2020.

26 © NAC, Report...

27 The Czech Society of Palliative Medicine of the Czech Medical Association of J. E. Purkyně.

28 Karolína HRDÁ, Matěj LEJSAL et al., *Paliativní péče v rezidenčních službách*, Tábor, Asociace poskytovatelů sociálních služeb České republiky, 2020, p. 88.

The aim is to ensure access to palliative care [at the level of palliative approach] for people with life-threatening illnesses.²⁹ This concept supports the availability of palliative care and, at the same time, it strengthens the effective use of specialised palliative care capacities. Such a concept precedes the perception of 'sharp interfaces' where the 'transfer of the patient/client' to the care of another professional, resp. subject takes place. Another element is, however, 'invited' into the spectrum of support and assistance services and professionals. Practice in the Czech Republic goes through the process of defining individual professions, services, and forms among themselves. However, the ensuring of higher availability of specialised palliative care can paradoxically cause more difficult access to routine health care.³⁰ The experience of palliative care providers at the palliative approach level³¹ confirms that the appropriate involvement of specialised palliative care in a counselling or shared care regime can be a highly effective way to ensure the availability of palliative care to a wide range of potential clients/patients. At the same time, it can contribute to the promotion of the concept of early palliative care.³²

Research, Organising, Advocacy³³

Palliative care is essentially multidisciplinary. Its holistic approach to human needs is reflected in the demand for coordination and cooperation of a wide range of helping professions and helping lay people. Things which in practice have a positive effect on the quality of life of the client/patient place high demands on the coordination of other related processes – research, organisation of palliative care providers, administration, and efforts to develop health and social care and security systems (advocacy). The coordination of these processes will ultimately affect the real availability of palliative care for the average person. To compare the environment of the Czech Republic and Ireland, the study focused on the institutionalised form of coordination, that is, the identification of entities that are (according to strategic documents and testimonials) active in the comprehensive coordination and facilitation of the research process, the organisation of palliative care professionals, and systems administration and development.

Research

The topics of research in palliative care in Ireland were conducted within professional areas, similarly as in the Czech Republic. A comparative study by Sonja McIlfatrick and Tara Murphy published in 2013³⁴ provided significant impetus for change. Following the documented absence of large-scale interdisciplinary research, the All Ireland Institute of Hospice and Palliative Care (AIHPC) was established.³⁵ The institute responded to the need for interdisciplinary cooperation

29 © Karen RYAN et al., Palliative care competence framework (on-line), available at: https://aiihpc.org/our_work/education/competence-framework/, p. 74, cited 20th December 2019.

30 The current system of financing specialised palliative care assumes that the mobile team of specialised palliative care will take responsibility for all health care. This condition can be counterproductive, for example, in geriatric patients, for whom curative care may be indicated in addition to palliative care. In his speeches, for example, MUDr. Zdeněk Kalvach points out this issue.

31 For example, the experience of the Sue Ryder Home for the Elderly, © Domov Sue Ryder, z. ú., (on-line), available at: <http://www.sue-ryder.cz>, cited 31st May 2020.

32 Ondřej KOPECKÝ et al., Úloha paliativní medicíny u akutních stavů, *Vnitřní lékařství* 6/2019, p. 449.

33 Advocacy is the activity of an individual or group. Its aim is to influence decisions within political, economic and social systems and institutions.

34 © Sonja McILFATRICK, Tara MURPHY, Palliative care research on the island of Ireland over the last decade: a systematic review and thematic analysis of peer reviewed publications. *BMC Palliative Care* (on-line), available at: <https://link.springer.com/article/10.1186/1472-684X-12-33>, cited 30th January 2020.

35 All Ireland Institute of Hospice and Palliative Care – © web organisation: <https://aiihpc.org/>.

in research and to the need for inter-organisational and inter-sectoral cooperation. It acts as a facilitator for the development of palliative and hospice care in the field of research and creates a space for connecting academics and educators, clinical experts, public administration staff and clients/patients and their relatives. It helps to create space for academic and applied research and supports the use of knowledge in everyday practice. A possible example of the results of the work is the document *Palliative Care Competence Framework*.³⁶ It defines the requirements for the competencies of employees of a wide range of professions (of those which are usually involved in the provision of palliative care). In the conditions of the Czech Republic, a similar entity is still lacking. An initiative of a similar nature is being developed by the Centrum paliativní péče (Palliative Care Centre), CPP.³⁷ A significant difference between AIIHPC and CPP is in the scope of activities but, above all, in the way of governance of both organisations. Representatives of all partner organisations (universities, palliative care providers, hospitals, professional societies, etc.) are involved in the management of the AIIHPC. CPP is a young³⁸ non-profit organisation that has a basic management structure based on the legal form of a registered institute.³⁹

Organising Professionals

Palliative care is based on multidisciplinary cooperation. The EAPC White Paper explicitly states that 'specialist palliative care services require a team approach, combining a multiprofessional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care.'⁴⁰ The appropriate way of organising teams, the system of education, the way of managing organisations that provide services of specialised palliative care, is given, among other things, by the form of providing the service. The palliative team in the hospital environment focuses on other factors than the in-patient hospice team or the field team. In addition to the internal environment of organisations and teams operating in the field of specialised palliative care, the external environment plays a significant role (legislation, funding systems, the system of education of future professionals, etc.). A suitable means for the development of organisations, good practices and for participation in the formation of the external environment is professional cooperation in the form of an umbrella network.

In Ireland, such an entity is the Irish Association for Palliative Care⁴¹ which was established in 1993 and brings together palliative care professionals and is a collective representative of the interests and needs of members at national and international level, with a number of permanent or ad hoc groups and committees. The unifying element is the topic of palliative care. The organisation complements the activities of other professional groups and associations.

In the Czech Republic, the situation is less clear. The agenda is scattered among several subjects – the Czech Society of Palliative Medicine of the Czech Medical Society of Jan Evangelista Purkyně (ČSPM, founded in 2008)⁴² and its specialised sections and working groups that bring together professionals in palliative care. Other entities are organisations that bring together mainly

36 RYAN et al., *Palliative...*

37 © Centrum paliativní péče, <https://paliativnicentrum.cz/> cited 31st May 2020.

38 Centrum paliativní péče (The Palliative Care Centre) was established in 2014.

39 The founder of the Palliative Care Centre is a natural person, the board of directors has three members.

40 RADBRUCH and PAYNE, *White...*, p. 286.

41 © Irish Association for Palliative Care – <http://www.iapc.ie/about-us/>.

42 © Česká společnost paliativní medicíny – <https://www.paliativnimedicina.cz/cspm/>.

organisations providing palliative care services, namely Asociace poskytovatelů hospicové paliativní péče (the Association of Hospice Palliative Care Providers, founded in 2005) and Fórum mobilních hospiců (the Forum of Mobile Hospices, founded in 2017). Internal inconsistency manifests itself both within the Czech Republic and in international cooperation.⁴³

Advocacy

The development of palliative care is closely linked to state policy in the areas of social security and services, health, and education. Individuals across the palliative care spectrum often make efforts to influence this policy at the local level, some at national level, some have an ad hoc initiative, others work on a long-term basis. A comprehensive mapping of the establishment of palliative care in the system of services and its comparison in Ireland and the Czech Republic goes beyond the scope of this text. At present, the environment differs mainly in the direction of developed initiatives. While in Ireland it is possible to trace the 'top-down' direction, in the Czech Republic 'bottom-up' initiatives predominate. The already mentioned *Report of the National Advisory Committee on Palliative Care*⁴⁴ in the introductory part emphasises the contribution of civil society to the development of palliative care which is followed by further efforts. It does not merely regard a kind of historical delay. It is not just about state policy, its acceptance of the institutes, tools and 'good practice' (which were created so far as a stable part of the system), and its further support of the development of existing and new tools, elements and methods. It is, amongst other things, about the fundamentally different legal systems of Ireland and the Czech Republic⁴⁵ which have a direct impact on the success of 'advocacy' strategies. Nevertheless, it is possible to be inspired here as well, especially in the area of non-legislative goals and procedures. Until now, initiatives that initiated a change in the legislative environment (for example, the enactment of hospice care in 2017) have been considered successful 'advocacy' strategies in the field of palliative care in the Czech Republic.⁴⁶ Partial legislative changes without a broader systemic context and without a link to the unifying vision may raise concerns or opposition of another part of the professional public (cf. conflicting opinion on the abovementioned legislative change prepared for ČSPM ČLS JEP).⁴⁷ In the Czech Republic, it has not yet been possible to obtain key actors for the topic of palliative care which would form a longer-term strategy in the field of health and social security, and to create an environment for systematic work based on data, negotiation, and involvement of key actors at the micro, mezzo, and macro levels. In the draft strategic document *Zdraví 2030* (Health 2030),⁴⁸ palliative care is mentioned to a limited extent, mainly as a set of measures (types of services, capacities, etc.). The change in the conditions for the development of palliative care

43 The contribution of MUDr. Ondřej Sláma focused on this issue. It was presented as part of the symposium Aktuální výzvy pro paliativní péči v Evropě a ČR (Current Calls for Palliative Care in Europe and the Czech Republic), organised by Centrum paliativní péče (Palliative Care Centre) on 2nd October 2019 in Prague.

44 HSE, Palliative...

45 Roughly speaking, Ireland uses the Anglo-American system of law which, among other things, uses common-law. This brings into the legal order the principle of using precedent and custom in decision-making. The Czech Republic operates in the regime of continental law in which public and private law is strictly separated and which, at the same time, presupposes a written form of law. A clear comparison of legal systems is offered by © Václava LUKEŠOVÁ, Právní systémy současného světa se zaměřením na srovnání kontinentálního a angloamerického právního systému (on-line), available at: <https://is.cuni.cz/webapps/zzp/download/150024372>, cited 1st June 2020.

46 Zákon č. 290/2017 Sb. (Act No. 290/2017 Coll.), Amending zákon č. 372/2011 Sb. (Act No. 372/2011 Coll.), o zdravotních službách (On health services) which contains the new § 44a (Section 44a).

47 An opinion prepared by lawyer MUDr. Mgr. Dagmar Záleská questions the legislative change, the full text of the opinion is available online: https://www.cesadomu.cz/sites/default/files/stanovisko_k_ss_44a.pdf, cited 3rd May 2020.

48 © Ministerstvo zdravotnictví ČR, Zdraví 2030 – Strategický rámec rozvoje péče o zdraví v České republice do roku 2030 (on-line), available at: <https://zdravi2030.mzcr.cz/zdravi-2030-strategicky-ramec.pdf>, cited 6th May 2020 – author's note: palliative care occurs on page 36, it is completely absent in the chapter about science.

is not only in their quantitative strengthening, legislative regulation, or the volume of financial resources. This is explicitly stated by Dr Tony O'Brien, Chairman of the National Advisory Committee: '... Over the years to come, the success or failure of this report will not be judged solely by the number or diversity of our specialist palliative care programmes, nor by any set of pre-determined statistics documenting our activities. The success of this report will be judged by the extent to which we all learn to recognise and respond to the complex and challenging needs of our palliative care patients and their families. For the future, I hope that this report will ensure that all health boards are in a position to provide a level and a quality of service that both reflects and defines best international practice. Our patients and their families require and deserve nothing less.'⁴⁹ It can therefore be concluded that without a change in attitudes towards the advocacy process, without a shared vision and clear goals, not only it will not be possible to use synergies to push for change but the efforts of part of the professional spectrum may, on the contrary, be weakened or exhausted by the efforts of another part.

Success in 'advocacy' is determined, among other things, by the involvement of the necessary resources – networks of contacts, people, information, and finance. When monitoring the origin of a number of current strategic initiatives and system documents, it was possible to trace an entity in Ireland and one in the Czech Republic which gave support to many of them during their creation. In Ireland, it is the Irish Hospice Foundation.⁵⁰ In the Czech Republic, Nadační fond AVAST (the AVAST Endowment Fund) can be described as a similar entity.⁵¹ A common feature for both entities is that they are not palliative care providers themselves, nor are they professional associations. In both cases, the primary instrument of influence is financial support for initiatives with the potential for a significant impact on palliative care, that is, the development of palliative care and changes in public policies in connection with relevant findings, research results, and pilot verification. The Irish Hospice Foundation is a body which was set up for this purpose. The programme is run by representatives of the professional community. It is a foundation, that is, an entity designated for 'permanent service of socially or economically useful purpose'.⁵² Its purpose was specified by the founder. The Irish Hospice Foundation thus supports projects based on a broader consensus of the professional public. The AVAST Endowment Fund is a corporate endowment fund, and its administration is in the hands of the founding corporation. This has a right to appoint a board of directors – the fund's statutory body. There is also a significant difference in the way of obtaining financial resources, which are subsequently distributed by these entities. In addition to the revenues from the foundation's assets, the Irish Hospice Foundation actively raises funds in the public space. In this way, it contributes to the strengthening of awareness and interest in the topic of palliative care. In some cases, though, it also competes in the process of attracting donors with other entities (e.g., palliative care providers). The AVAST Endowment Fund distributes financial resources given by the founding corporation. Considering the state of development of palliative care in the Czech Republic (newly emerging providers, insufficient legislative entrenchment of palliative care services, etc.), it can be said that the current form and volume of support represents an extremely important impetus for the development of the whole field in the Czech Republic. Despite these differences, the two entities use highly participatory techniques and procedures to identify topics suitable for support.⁵³

49 © NAC, Report..., p. 5.

50 © Irish Hospice Foundation – <https://hospicefoundation.ie>.

51 © Nadační fond AVAST – <https://nadacnifond.avast.cz/index>.

52 Act No. 89/2012 Coll., občanský zákoník, §306 (Civil Code, §306).

53 Over the past 5 years, NF AVAST (the AVAST Endowment Fund) has invested over CZK 150 million in supporting the development

Summary

When comparing the systems of the Czech Republic and Ireland, it is possible to find a number of parallels and, at the same time, one can obtain great inspiration. For a number of reasons (e.g., different legal environments) it is not possible to just copy individual steps. It is possible to be inspired in many ways. The comparison itself and the effort to understand the described differences can serve for the development of the whole field. The embedded table captures different viewing angles when comparing systems.

	IRELAND	CZECH REPUBLIC
The degree of unification of the vision (<i>'talking one voice'</i>)	Report of the National Advisory Committee on Palliative Care, 2001 Palliative Care Services – Three Year Development Framework 2017–2019 – refers to the previous document The Palliative Care Glossary of Terms ³ Palliative Care Needs Assessment Guidance ⁴	Koncepce paliativní péče v ČR (The Concept of Palliative Care in the Czech Republic). Working material for professional and public discussion, 2004 (ČSPM – Czech Society of Palliative Medicine) Národní program paliativní péče (National Palliative Care Program), 2015 (ČSPM) Paliativní péče v České Republice 2016 (Palliative Care in the Czech Republic 2016) – Situation analysis (ČSPM) Koncepce hospicové péče (Hospice Care Concept), 2017 (APHPP – Association of Palliative Care Providers) Strategie paliativní péče v Kraji Vysočina na období do roku 2020 (Palliative Care Strategy in the Vysočina Region for the Period up to 2020), 2017 Koncepce podpory rozvoje paliativní péče v Olomouckém kraji (Concept of Support for the Development of Palliative Care in the Olomouc Region), 2018 Koncepce paliativní péče v Jihočeském kraji na období do roku 2023 (The Concept of Palliative Care in the South Bohemian Region for the Period up to 2023), 2018 Koncepce rozvoje paliativní péče v Praze (The Concept of the Development of Palliative Care in Prague), 2020 Koncepce paliativní péče v Moravskoslezském kraji 2020–2025 (The Concept of Palliative Care in the Moravian-Silesian Region 2020–2025), 2020
Approach to the development of palliative care	From shared vision through goals to realisation: Shared vision – goals – strategy – implementation of system tools – development of services and system elements	From partial visions and practice to legislation: Partial visions – experiments and pilots – integration into the system

of palliative care in the Czech Republic. It uses participatory techniques to a large extent in the preparation of programmes and in the selection of supported activity projects.

Organisation of specialised palliative care	Hospitals In-patient specialised palliative care facilities (hospice) Community care – Mobile specialised palliative care, Out-patient palliative care (hospitals, ambulances)	Hospitals In-patient hospice Mobile specialised palliative care teams Out-patient palliative care
Internal division of palliative care	Three-level model (palliative approach – general palliative care – specialised palliative care)	Two-level model (general palliative care – specialised palliative care)
Approach to the role of specialised palliative care	Counselling (specialised palliative care is added in its counselling role to regular services, it solves what is not in the possibilities of providers of general palliative care)	Control-performance (specialised palliative care takes over the management of the patient's case and the corresponding care services)
Professional organisation	Research: All Ireland Institute of Hospice and Palliative Care (AIHPC) Individual entities: Irish Association for Palliative Care Providers: none Advocacy (lobbying): Irish Hospice Foundation	Research: none Individual entities: Czech Society of Palliative Medicine of the Czech Medical Association of J. E. Purkyně Providers: Association of Hospice Palliative Care Providers (2005) Forum of Mobile Hospices (2017) Advocacy (lobbying): NF Avast, smaller foundations and endowment funds, individual 'umbrella' organisations, individual providers (Cesta Domů and others)
Advocacy	Top-down approach (The central strategy is developed and applied in professional circles, in local governments and by individual providers and experts.)	Bottom-up (sub-initiatives are promoted by differently formed streams of interest, without systematic coordination, without a shared vision and common goals)

The basic source of inspiration for the Czech Republic can be the process of creating and the content of a National Advisory Committee report published in 2001. It is a result of an interdisciplinary dialogue commissioned by the Ministry of Health. It is still a recognised vision, and a plan for palliative care in Ireland. A similar basic document is missing in the Czech Republic, although the existence of a similar document is also recommended by the EAPC.⁵⁴

In Ireland, palliative care is supposed to be an additional 'consulting' element in the service system. In the Czech Republic, it is often perceived as a defined (by time, needs, responsibilities, or

54 RADBRUCH and PAYNE, White...

expertise) phase or stage of providing services. The counselling nature partially removes barriers to accessibility (destigmatises – emphasises quality of life, eliminates the need for ‘hard criteria’ for ‘transfer’ to palliative care, or ‘taking back from palliative care’). Acting outside the public administration and practice of palliative care research (AIIHPC) and supporting the development and innovation of palliative care (Irish Hospice Foundation), together with a functioning single professional organisation (which is not just an interest group of organisations or service providers) effectively supports and facilitates participation of all actors on the future of palliative care and its shaping (users, professionals, researchers, academics, and policy makers).

Contact***Matěj Lejsal MSc, MA***

Charles University

Faculty of Humanities

Department of Management and Supervision in Social and Health Care Organisations

Pátkova 2137/5, 182 00 Praha 8 – Libeň

matej.lejsal@fhs.cuni.cz

Jiří Krejčí MA

Charles University

Faculty of Humanities

Department of Management and Supervision in Social and Health Care Organisations

Pátkova 2137/5, 182 00 Praha 8 – Libeň

jirikrejci@centrum.cz