Gaps in end-of-life care and lack of support for family carers in Poland and Central Eastern Europe

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Abstract: The growth of life expectancy in Central Eastern Europe and increase in the number of older people in that region are the consequences of changes in the 1990s period, connected to transition from the communism into a market economy. Central Eastern Europe is already facing consequences of fast ageing and insufficient development of state health care and social services. Those result in gaps in the provision of end-of-life care and overburden of family caregivers. This essay addresses gaps in end-of-life care, showing the development of hospice-palliative care on one side, and highlighting main problems with long-term care on the other. There is scarce support for informal caregivers and lack of cooperation between health and social care. End-of-life care is over medicalized in hospice-palliative care and hardly existing in long-term care. Dying is more a social than medical event, and as such, it should be cared for by compassionate communities, encouraging cooperation of professionals with family caregivers and society. Unfortunately, to date, there is no adequate cooperation in social dimension of end-of-life care in most of Central Eastern Europe. The social dimension of end-of-life care has to be recognized and empowered with the health promoting palliative care and introduction of compassionate communities in Central Eastern Europe.

Keywords: compassionate community, end-of-life care, family care, health promoting palliative care, hospice, informal care, integration of care, palliative care, social work, volunteering

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Introduction

The world's population is ageing and life expectancy in the West has been growing since the 1960s, but this trend was only noticed in Poland and Eastern Europe after the 1990s.1 This recently observed dynamic increase in the number of older people in Poland and their percentage in the population is a new phenomenon. This process has already been associated with challenges and will be one of the most important policy issues in the coming decades in Poland and other countries in Eastern Europe.² The economic trends from the 1990s show that Poland and all ex-socialist countries in transition from Eastern Europe entered a profound crisis in the initial phase of the conversion into a market economy order. It was a time of intense changes in social structure.³ The upturn of life expectancy in

Central Eastern Europe (CEE) in the 1990s, after a period of stagnation or even decline, is one of the main events in European population history of the late 20th century. Although this started at different points in time, improvements in prevention and treatment of major diseases appear to have played a major role in all these countries. Other factors, such as changes in alcohol consumption, diet and road traffic safety, have, however, also made important contributions in some East European countries.⁴ People are living longer, but what about the end of their lives in this part of the world? Do they have adequate access to palliative care?

The hospice movement in Poland was initiated in the 1970s and will be described in more detail later in this article as hospice-palliative care (HPC). Correspondence to: Piotr Krakowiak Uniwersytet Mikołaja Kopernika w Toruniu, Torun 87-100, Poland. pkrakow@umk.pl



The following words describe the achievements of the hospice movement, rooted in the solidarity of various professionals, who, as volunteers, started these initiative years before the fall of the Berlin wall and the democratic changes in CEE.

More than 400 palliative and hospice centres, thousands of employees and volunteers forming interdisciplinary teams caring for the terminally ill and their families, and many thousands of people who have benefited from this care – such is the outcome of the over 30 years' existence of the hospice movement and palliative medicine in Poland.⁵

Other Eastern European countries were not so lucky and only after the democratic changes of 1989 was the development of HPC possible in the various countries under Soviet influence. All of these HPC initiatives, in CEE, have been, for many years, dedicated to cancer patients only and connected exclusively to oncology, with limited or no cooperation with long-term care (LTC) and care institutions for elderly in local communities.

In the 21st century, there are new challenges, and an analysis of demographic changes in Poland and Eastern Europe will be presented in this critical essay. The discussion about the tradition of familyoriented care for the elderly and people towards the end of their life will highlight the main challenges for these societies. Among these challenges is the problem of a lack of cooperation and adequate inclusion of informal caregivers into integrated care.6 The successes of HPC in Poland will be presented, but the existing division between end-of-life care (EOLC) for cancer and nononcological patients both in institutional and home care will be highlighted. The deficiencies in coordination of care and limited cooperation between health and social care professionals will be explained. Good practices of inclusion of family carers from the United Kingdom will be presented, as the growing demands of EOLC in Eastern Europe require integration and better cooperation between professionals and informal caregivers from families or non-kin carers from communities and volunteers.7 Knowing how important informal care is in EOLC, first good practices regarding family carers in Poland will be presented. The need for the integration of EOLC and the inclusion of family carers will be discussed, based on the concept of compassionate communities (CC) as a public health approach to the EOLC. The concept of health promoting palliative care (HPPC) will be presented as a possible model for reducing gaps in care and implementing changes, to move forward towards the integration of health and social care, and the involvement of the local communities in a public health approach to EOLC.

Demographic changes in Poland and Eastern Europe and their social consequences

The population processes taking place in Poland in the last 30 years, observed in Europe since the 1960s, are sometimes referred to as the second demographic transition, characterized by a decrease in the number of births and marriages, a delay in the average age of childbirth and entering into marriage, and an increase in the number of divorces and informal relationships. The effects of these transformations in CEE are intensified by foreign migrations.8 Issues regarding inequalities connected to global care chains, and transnational care provision, where certain forms of care, like care at a distance and delegation of care to migrants, are important, but will not be discussed here, having been described in a recent paper regarding migrants and their ageing parents.8 According to the Eurostat forecast, after 2024, the segment of people aged 65+ in the structure of the Polish population will be 20%, and after 2060, will exceed 33%.10 These European data are confirmed by Polish research with indications that the need for services for this age group will grow rapidly.11

CEE is changing fast and different levels of democratization attained by the post-communist countries in the first decade after the fall of the Berlin Wall have had an effect on their levels of health, noticeable since the 2000s. Levels of democratization of these countries seem to have had a protective effect on the health crisis suffered as a consequence of the abrupt disruption of the communist regimes.¹² Countries in CEE, in the approaching decades will face the dramatic consequences of an increased proportion of aged people, aggravated by the inadequate development of state social services, health care and LTC systems; and by low levels of private savings.8 The increase in life expectancy, which should be considered one of the greatest achievements of 20thcentury medicine, coupled with a significant drop in birth rates, has already led to significant changes in demographics.¹³ These changes have currently had a big impact on politics in Poland, and they will become the cause of many challenges in social, economic and health issues.2

A similar situation has occurred in other CEE countries, richer in 'the silver generation' and poorer in the young people, as the population of the whole region changed after mass labour migration, facilitated by the accession to the European Union after 2004 and 2007 enlargements.¹⁴ The question now is whether the familial model of care for the elderly, which has been traditionally present in these countries, will continue.

Family-oriented multigenerational care for elderly people in Poland and CEE

Care is a phenomenon, tailored by social actors and embedded in social contexts, played out in relationships. CEE and Poland are still seen as the stronghold of multigenerational families, traditionally caring for the older generation both in home settings and actively assisting fragile members in caring institutions.8 In Poland, care for a dependent person is provided by the family, because for centuries a 'system' of mutual care for grandparents, parents, children and grandchildren requiring care has been in operation. Family carers are the first to relieve suffering, ensure health and social safety, and improve the quality of life for those in need. 15 At the beginning of the 21st century, a Polish family is still expected to help in need, which results from the tradition of a sense of moral duty or gratitude for help and love received before. Values such as tradition, intergenerational solidarity or reciprocity construct the obligation to personal care provision for elderly and disabled in the familial model of care.8 In 2010 in Poland, older people were asked about whose help they could count on in the event of illness, and most indicated their immediate family. Only a small number expected help from social workers, carers and community nurses.¹⁶ Most (64%) indicated that they would want to stay in their own apartment and count on family help. For 15% of respondents, living with children or extended family would be a good solution, 8% would like to live in their own apartment and benefit from paid help, and 3% from free care. 17 The familial model of care, still prominent in Eastern Europe, places the family as the first and by default most important caregiver for elderly, disabled and those dying at home. But such care has to take into account international and internal migrations, which have left many old people alone. The majority (83%) of dependent people in Poland benefitted in some way from different forms of family care¹⁸; however, both the dependent people and families also admit that

this task can be challenging.⁶ According to the forecast, by 2030, the number of informal carers in Poland will decrease by over 50%.¹⁹ So what will family care look like in the coming years? In what way will both demographics and changes in families affect the care systems in Eastern Europe?

Within one generation, the traditional model of family has changed dramatically. The contemporary picture of an East European family is not dissimilar from a sample of those from the West. The traditional house, which was inhabited by several generations simultaneously has mostly gone. The elderly can count on care benefits only if they live alone or when the family is unable to provide adequate care. Only in crisis situations in Poland will someone be helped by government institutions.²⁰ What will happen if the old system of family care does not work anymore, and there is little or no alternative proposed by local government or society? Researchers of societies in Poland and other countries of CEE emphasize that changes in the structure of families and households will affect the reduction of the caring potential of families to provide care to their old, dependent and disabled members. Population ageing has far-reaching social and economic consequences.²¹ The shift from informal to formal care is expected to affect all of Europe, but especially CEE. According to Eurostat, from 2019 if currently 10% of the dependents receiving LTC receive care at home, in future only 10% of dependents will receive home care and 90%, institutional care.22 Since Poland has well developed HPC, delivered mostly in home care settings, should there be concern about these predictions?

Successes in EOLC provision for cancer patients by HPC in Poland

The contemporary hospice movement in Poland was established in 1981, but it had been preceded by years of effort on the part of numerous people institutions. These included Hanna Chrzanowska, a nurse and lecturer of the Jagiellonian University, and Cardinal Karol Wojtyła, the metropolitan of Cracow (future Pope John Paul II). Chrzanowska took up the initiative of home nursing care of the terminally ill, and Wojtyła appointed a group of people tasked with finding adequate means of helping people at the end of life. Another was Cicely Saunders, known for her friendliness towards Poland and the Polish people.⁵ She visited Poland several times, and her

visits were important moments in the establishment of hospice care in Poland.²³ This history is described in detail in the book *In Solidarity*. *Hospice-Palliative care in Poland*, available online.⁵ Recent papers regarding HPC in Poland have acknowledged British influence, and Dame Cicely Saunder's personal friendship towards Poland,²³ while others have shown the problems of walls and barriers to the care system in Poland and Eastern Europe.²⁴

According to the European Association of Palliative Care (EAPC) Atlas 2019, Poland was one of the first Eastern European countries to have a national Palliative Care (PC) programme. With its 587 PC services in the country and 1.5 services per 100,000 inhabitants, Poland scores highest in Eastern Europe and is one of the best PC providers in the whole of Europe.²⁵ Traditionally the most developed among all types of PC services is the home care model. With 404 mobile teams for adults and 66 teams for children, Poland's PC successfully covers the whole country. Only a few European countries have a paediatric hospice home care programme, but Poland is fortunate to have such a service.²⁶ Since 1998, palliative care has been fully implemented into the health care system, and the role of professionals, psycho-social and spiritual care, and volunteers is recognized as an important part of HPC teams. Poland has helped other CEE countries in establishing or developing palliative care. The international courses organized by Jacek Łuczak in Poland, with lecturers from Poland and Great Britain, played a large part in that development. They were highly popular among Polish and foreign guests. The sessions were attended by professionals from Poland, and then also by physicians and nurses from most Eastern European countries.23

The involvement of volunteers in HPC looks also impressive in Poland.²⁷ Apart from different ages, creeds and backgrounds of groups helping HPC in Poland, there has also been an innovative project involving prisoners who are trained and included in the caring team as hospice volunteers.²⁸ Social education about end-of-life issues and knowledge about HPC is widespread in Poland, mainly because of a series of nationwide campaigns under the heading of 'Hospice is also life' (*Hospicjum to też życie*). These are launched annually with public and private media support.²⁹ In Poland, home care is especially appreciated. The belief that dying people should rather be at

home dominates among Poles. Hospice house or palliative care unit – in their opinion – is the right solution only in exceptional situations.³⁰ As well as being in first place in Europe for the percentage of HPC home services,²⁵ with many countries like the United Kingdom struggling with de-institutionalization, one could simply say that the HPC in Poland is a success story and a model for others. However, there are a few problems showing that EOLC is not equally distributed and not available for all in Poland and other CEE countries.

Gaps and lack of cooperation in EOLC in Poland and CEE

A recent audit of the Supreme Audit Office in Poland (NIK) showed that only 10% of HPC patients in Poland are dying from diseases other than cancer. Others have no access to HPC, although Polish legislation has been adapted to requirements of the World Health Organization (WHO), making HPC available to all people at the end of their life. Therefore, the NIK recently ordered an amendment to the regulations aimed at ensuring access to care for those who needed it, regardless of the disease.³¹ Data from the international project which compares the effectiveness of palliative care for elderly people in care or nursing homes in Europe and aims to advise policy-makers on optimal palliative care practices show that palliative care knowledge among Polish and Italian nurses and care assistants working in LTC facilities is deficient.32 There is also evidence that the integration of palliative care in LTC services in Poland is minimal if not non-existent, especially when compared with West European countries. Researchers of LTC urge that national policies focusing on enhancing palliative care development in LTC facilities are needed to ensure optimal levels of care.33 After the above mentioned audit of the NIK, the Ministry of Health in Poland stated that there was a lack of coordination and integration, and especially a lack of cooperation with social services, mainly LTC and other social economy entities. The level of implementation of individual care plans, the recognition of the problems of family caregivers, the level of social assistance and the lack of cooperation with LTC institutions was also seen as unsatisfactory.31

Thus, not all people in Poland who need it have access to appropriate EOLC. The reason, among others, is a narrow list of diseases – mainly cancer.

Those 'happy islands' of well-funded HPC, almost entirely for cancer patients, are totally different from the situation of people at the end of their life suffering from diseases other than cancer. The EOLC in LTC is generally poor both in institutions and in home care.7 This is confirmed by HPC specialists who state that in Poland, general standards of HPC are not adjusted to LTC. Specialist HPC services by law are excluded from LTC facilities. If a patient is referred to LTC, he or she cannot receive HPC from the specialists in this field.²⁵ HPC has been developed under the umbrella of oncology and consequently enjoys much higher funding than any other kind of LTC. As it is well-financed and promoted, HPC is attractive to patients and families. In addition, HPC is free of charge for families, with optional donations only, while LTC is expensive and complicated. Based on the analysis of costs, applications have been repeatedly submitted to the government for changing the reimbursement amount of HPC services and have been accepted ensuring continued funding.³⁴

In addition, there is hardly any cooperation between HPC and the social work sector where most of LTC is located. The number of social workers involved in HPC in Eastern Europe is significantly lower than in Western Europe, as confirmed by experts gathered by EAPC, studying Core competencies for palliative care social work in Europe: an EAPC White Paper-parts 1 & 2.35,36 Social work training programmes, allowing entry into HPC interdisciplinary team practice are needed as well as practical ways of promoting the core competencies of the Social Worker in HPC in Poland and Eastern Europe.³⁷ Experts from the World Bank warn that in Poland, horizontal coordination between the health and social sectors is complicated by the high level of decentralization. They have proposed key strategies to create and promote horizontal and vertical coordination. The weak coordination between the health and social sectors is one of the central issues that will need to be addressed. A combination of actions including meaningful involvement, respect and inclusion, communication and information, transportation and mobility, and health and well-being could bring about a new paradigm for the community.³⁸

The recommendations of these economists are similar to the principles presented in the Ottawa Charter, which has been the conceptual basis of CC as a public health approach.³⁹ Caring, holism

and ecology are essential issues in developing strategies for health promotion. Therefore, those involved should take as a guiding principle that, in each phase of planning, implementation and evaluation of health promotion activities, women and men should become equal partners.40 The Compassionate City Charter describes a compassionate city as a community that recognizes that care for one another at times of health crisis and personal loss is not simply a task solely for health and social services but is everyone's responsibility.41 These concepts, as well as the development of CC40 and the HPPC are still absent in Poland and Eastern Europe,²⁵ will be presented in the next part of this essay. Cooperation between HPC and LTC is crucial for the improvement of the quality of EOLC for all. The empowerment of family caregivers seems to be equally urgent and important in Poland and other CEE countries. How can those who care for their loved ones at home be provided with the support they need?

Learning from the UK experience to empower and include family carers in EOLC

Carers UK is the largest organization in the Kingdom supporting carers. European professionals and family carers can find inspiration and example in the milestones of this organization's development. This movement started in the United Kingdom in 1964, when Mary Webster shared her story of being a womencarer, drawing attention to the practical difficulties, the isolation and often financial hardship that women carers were experiencing. In 1967, the Dependent Relative Tax Allowance was introduced.42 In 1992, the book Carers: research and practice, edited by Julia Twigg, was published. She highlighted that 20 years previously no one would have even thought about family caregivers as a subject of research.⁴³ In 1996, the first ever legal recognition that carers in the United Kingdom have needs in their own right was introduced; 15 years later, the Equality Act was introduced; and in 2012, new rights were announced for most carers.⁴² Those historical facts briefly mentioned above are presented in detail in a book regarding that matter.44 Reflecting on Carers UK's recent document However, caring affects you, our vision for 202145 will help to prepare the next steps in order to unify efforts for a less lonely future for family carers.

The current activities of Carers UK have inspired the first steps towards inclusion and empowerment

of family caregivers in CEE. The Hospice Foundation in Poland has conducted nationwide campaigns regarding family caregivers, aimed at broadening social awareness and practical support of caregivers.^{5,7} The attention of the Polish Ombudsman was drawn to the matter of family care, resulting in the first response of the government in 2019 when the first ever Polish Government document was issued with descriptions of respite care, approving the programme titled Respite Care Program - 2019 edition. 46 For the first time in Poland, public money has been assigned and distributed for the respite care programme for family caregivers. The first steps have been taken, but Poland is at the beginning of its aim to include family carers in the integrated care system, and the problem of the growing population of old and dependent people is at an early stage of the social discourse.⁴⁷ Other countries in Eastern Europe are often still struggling with full implementation of PC into the health system,²⁵ lack funding for basic care, have limited resources and can do nothing for family carers. Courage to reform the system and improve the EOLC for all is the first step. Recognition of the familial tradition of care in the region and support for family carers modelled on the basis of good practices developed in Western Europe are the urgent social challenges of the day, and even more of tomorrow in Poland and CEE.

The daily struggles of family carers in home care in Poland have been described by them in first books unfolding their struggles,48 and some research has already been conducted in Poland. 5,19 There are publications regarding families in Eastern Europe stating that caring for elderly family members is perceived as a sign of love, respect and familial duty. Yet, caring for elderly parents could put pressure on the sandwich generation caring also for their children. Research recommendation for Eastern Europe's family policy states that governments should provide social protection by financially compensating the caregiving process and contributing to intergenerational solidarity.⁴⁹ The whole region of CEE shows many similarities to the challenges described above. It is true that while the distinction between family and formal care countries in Europe is not based on geography, in general, Northern countries belong to formal care countries, while Southern and Eastern countries are family care countries.⁵⁰ Poland, despite the actions already taken, is at the beginning of its way to include family carers in the integrated care

system, especially in home care.^{6,47} The problem of the growing population of old and dependent people is, lately, a more frequent part of the social discourse in CEE. Poland with those just initiated actions could again be the leader of changes, as it was over 30 years ago with beginnings of HPC and solidarity of care.²⁴

The need for integration of EOLC and inclusion of family carers: CC and development of EOLC social work in Poland

Is it possible to work together with those who are dving and their families in Poland? Together with the medical aspects of care, there is an urgent need for better psychological and spiritual care, as well as for social care. The social dimension of care has been part of the modern interdisciplinary hospice team in the world and in Poland since the beginning, but social work seems to be omitted from Polish HPC.37 It might be surprising for HPC team members in Poland to know that a person with life-limiting illness spends only about 5% of their time with nurses, doctors, specialists and the full range of hospice services. According to Allan Kellehear, a Professor in Community Health with an interest in Palliative care, as much as 95% of time is spent alone, with family carers, friends and in the community – not engaged with medical professionals. For those facing death in home care, this time alone can breed feelings of isolation and loneliness, worry and despair, as dying is more a social than medical event.⁵¹ As such, care should be provided by CC, which include and empower family caregivers, and involve the whole society and local communities in the joint effort to provide support and care.

The First International Conference on Health Promotion was held in Canada in 1986, and culminated in the Ottawa Charter for Health Promotion.⁴⁰ Since the 1990s, the WHO has been advocating a public health approach to palliative care and an idea initiated in Australia, the Compassionate City Charter has since gathered support on an international scale.⁴¹ This Charter was developed, applying the Ottawa Charter for Health Promotion to palliative care.⁵² The CC is one that identifies all-natural cycles of sickness and health, birth and death, and love and loss which occur every day within the orbits of its institutions and regular activities.53 The CC movement is a social model of palliative care, rooted in community development processes. In a CC, it is everyone's responsibility to care for

each other during times of crisis and loss, and not simply the task of health professionals. The development of CC promotes quality EOLC designed to meet the individualized needs of the dying as well as their caregivers.⁵⁴ CC values a top-down (whole systems) approach, which extends health services to community settings such as local government, workplaces and schools; and a bottomup (health promoting) approach, which demystifies caregiving, dving, death and grieving through social, educational and cultural sectors, to affect the greatest degree of change. Much literature regarding the development of the CC is available, but Canada could be a good example for other countries.⁵⁵ The historical development of the public health approach to EOLC in Canada presents many successes and problems as a public health approach to palliative care has been successfully introduced there since 2011.56

Societies in Eastern Europe and Poland need to adapt to fast demographic changes, be open to the concept of CC, to the HPPC, and start to develop a social model of care.⁵⁷ There is a large quantity of available literature and many examples of good practices: there are even toolkits ready for adaptation,⁵³ in order to develop the HPPC and CC in Poland and other CEE countries. One of the commitments to health promotion urges all nations to reorient health services and their resources towards the promotion of health; and to share power with other sectors, other disciplines and most importantly with people themselves.⁴⁰ As professionals are currently trying to build the practice of supporting family caregivers, there is a chance to involve local communities and unite the efforts of HPC and LTC. Families experiencing social transformations are often in crisis with its formal and traditional functions. Changes take place dynamically, hence one should agree that today the family model can change from generation to generation.⁵⁸ The authors of the recommendations of the European Association for Palliative Care (EAPC) regarding family carers in palliative care drew attention to the changes that the family and its definitions undergo. They adopted the definition of the National Institute for Health and Clinical Excellence, which includes formalized relationships, but also those that are defined by patients as relevant and important.^{59,60} How will those widely defined families cope with caring for their loved ones at the end of their lives? Each of them – whether traditional or modern - will need support in carrying out care tasks. This is particularly evident

in the case of people working professionally, caring for a long time and deprived of the regular support of others. Both the lack of legal regulations, as well as the almost non-existent support and respite care can lead to overloading with care, sometimes leading to exhaustion and caregiver stress syndrome, especially in the case of those performing the function of the main family guardian.⁵

In the compassionate model of care, the social dimension of care and involvement of local communities play important roles, and social workers could help. Unfortunately, to date there is no adequate training for social workers dealing with the end of life issues in Poland and most CEE countries.³⁷ In home care settings especially, the impact of social work practice with patients and their carers is important. Despite years of good practice in Poland, medically driven HPC governance in the Ministry of Health in 2008 has excluded social work from HPC teams, through failing to make this compulsory and not paying them under the health care system. Social workers were often dismissed when teams became short of financial resources, resulting in the lack of a social dimension in EOLC.7 Social work is crucial for the patients, but even more for family carers, both during the care and also for those grieving and bereaved.37 The role of social workers in end of life and bereavement care is widely recognized, 35,36 yet not implemented into the system of training of social work specialists in Poland and other CEE countries. As part of empowering family caregivers, creation of the curriculum for EOLC Social Work could be an answer to the urgent need of unification of HPC, LTC and development of CC in Poland and Eastern Europe.

Conclusion

The impact of demographic changes in Poland and Eastern Europe, and changes to the familial system of care for the elderly and dying urge the necessity for action in EOLC. The success of HPC in Poland simultaneously displays many shortcomings and gaps in EOLC for all who need it. The lack of support for informal carers in particular, and the need for integration of EOLC seem to be urgent. The concept of CC as a public health approach to the EOLC has been presented as a possible model for changes. Both empowerment of family caregivers and development of end-of-life social work could be the way forward

towards the integration of health and social care, and involvement of the local communities in a public health approach to the EOLC.

The HPPC approach⁵⁷ has still to be introduced in CEE. Then, it would be possible to create CC and develop the social dimension of EOLC in Poland and other countries in the region. Moreover, good practices of inclusion of family carers and their implementation in Poland could also help to promote it, with an understanding of the familial model of care which needs empowerment and inclusion. Having as a guide The Ottawa Charter for Health Promotion, 40 documents regarding informal caregivers^{59,60} and the EAPC White Papers regarding social work in EOLC^{35,36} and various recommendations, practical actions are needed in order to develop the social dimension of EOLC. Only this level of change will help to overcome the barriers between social and health systems, allow inclusion and support of family carers, and help to reduce existing gaps in care. Working together can change the existing, insufficient and deeply fragmented EOLC system in Poland and other CEE countries.

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