OECD Health Policy Studies

Time for Better Care at the End of Life

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Foreword

The policy priority attributed to end-of-life care is too low given its impact on society. Care needs are changing with the rise of chronic diseases so that there will be more people dying often after long periods lived with chronic or debilitating diseases such as organ failure, cancer and with dementia (which is rising particularly rapidly). Currently, 80% of deaths happen among those aged 65 and above, and 50% of deaths occur among people aged 80 and above. Close to 7 million people needed end-of-life care in the OECD prior to the COVID-19 pandemic, in 2019, but with the share of people 80 and above doubling by 2050, many of whom living with chronic conditions, this number will rise to 10 million by 2050.

End-of-life care refers to the provision of palliative care in the last stages of life – which entails physical, emotional, social, and spiritual support – while also including curative care provided at the end of life, such as actions intended to sustain or prolong life. Rather than focusing on improving quality of life, life-prolonging measures are sometimes continued near the end of life. This is due among others to a lack of palliative care services, especially at home and in communities, but also to the ethical and other challenges of deciding the appropriate timing to discontinue treatment.

This report reviews end-of-life care policies across OECD countries, along the following policy dimensions: accessibility, people-centredness, quality, financing, and governance. It examines different policy solutions ranging from providing sufficiently trained staff across at the person's home and in long-term care homes, to improving knowledge of professionals about conducting conversations on care preferences, ensuring quality standards, and strengthening funding models and governance. The key findings of the report are that:

- Too many people receive sub-par care in their last days or months of life. Access to services is often insufficient and unequal, especially at home.
- Professionals often fail to discuss choices that provide people a dignified end of life, and their care preferences are rarely recorded.
- Care provided at the end of life often fails to alleviate people suffering and limit unnecessary treatments.
- Costs at the end of life are high for both the public purse and families, while not necessarily delivering quality of life, and there are questions about, which different care models could improve outcomes for patients while reducing costs.
- Putting end-of-life care higher in the policy agenda and implementing a more comprehensive set of policies would make the end of life a more meaningful and humane experience for people and their relatives, and improve the outcomes achieved for the resources invested.

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Executive summary

Across OECD countries, timely **access** to adequate end-of-life care to relieve symptoms for those with terminal illnesses such as pain, breathlessness, and distress, named as palliative care, is low, with less than 40% of those in need receiving care. Despite a preference to die at home, half of deaths happen in hospital, often due to lack of in-home and community-based support. Provision of palliative care to provide comfort and improve quality of life often happens at a late stage in the process because mechanisms to ensure timely access are scarce. Less than a third of the OECD countries have national programmes to monitor the time span between referral and delivery of end-of-life care services. Finally, the COVID-19 pandemic has brought to stark prominence the reality of overwhelmed health systems which struggled to provide end-of-life care and the necessity for systems to be scalable and adaptable in the face of emergencies.

Care delivered does not always reflect the **wishes of the patient** and **quality of care** is still too often poor for people at the end of life. Conversations on health status and care possibilities at the end of life are less frequent than they should, and the voice of patients and their relatives is still too often left out of decisions concerning care: only one-quarter of patients and professionals write advance directives on people's wishes. Holistic care is not always available, and people do not always receive adequate symptom relief, with 10% to 25% of people who died at the age of 65 or older receiving too little pain medication, too little help breathing or too little help with anxiety. Alongside the under-treatment of their symptoms, people receive aggressive treatment that is not likely to provide comfort, prolong life or be cost-effective: this is the case for around one-third of older patients who are hospitalised at the end of life. Fragmented systems undermine effective end-of-life care delivery and contribute to patients often experiencing multiple transitions across settings near the end of life. There is also insufficient measuring and benchmarking about the quality of end-of-life care across countries. More than one in four OECD countries do not have programmes of audit and evaluation to monitor quality at the end of life.

Care at the end of life also suffers from **funding** deficiencies and lack sufficient **evidence-based policies**. Public social protection systems provide partial coverage of expenses incurred to alleviate the symptoms of end of life in a third of OECD countries, leading to high out-of-pocket expenditures and strong reliance on family members. More importantly, public funding mainly covers services provided in hospitals, which likely influence the place of death and contribute to increase public spending. In OECD countries, hospital expenditure ranges between 32% and 67% of end-of-life care expenditures. Research in end-of-life care is insufficient and data infrastructure to provide a full picture of end-of-life care across multiple services and settings is still weak. Less than 30% of OECD countries have a national research agenda and less than 16% a local research agenda on the topic.

Such shortcomings call for greater policy priority and measures to improve end of life care.

First, addressing staffing shortages is key to improve **access** of care through expanding the knowledge on end-of-life care across different professionals and care settings. Besides training more health professionals with expertise in managing end-of-life care, incentivising end-of-life care in the preferred settings of care will be helpful. Australia has shown that nurse-led models are effective to facilitate access, especially in sparely populated areas, for example. New Zealand created regionally managed clinical networks to combine primary-care teams with support from specialists, thereby improving the availability of trained staff in non-hospital settings, especially in primary care and in long-term care. Time targets and guidelines can also help ensuring timely access to care by optimising care pathways. Ontario, Canada is using automated tools to perform screening while the United States sets timelines for needs assessments.

More information on end-of-life care among health care staff together with better evaluation are crucial to ensure that **people's wishes** are respected, and that **quality** of care improves**.** Improved training for health care workers can help to foster communication and involvement of patients and their families in the decision-making regarding their loved ones' health. Health care professionals who received training on end-of-life care are less likely to provide overtreatment and aggressive care at the end of life. Canada and the United States have developed training and guidance for health care professionals to support them to have open communication with people at the end of their life. Multidisciplinary teams able to provide holistic care and ensuring end-of-life care services in the patients' preferred settings are important steps towards comprehensive care centred on patients' and their family's needs. In England, guidelines encourage multidisciplinary teams work and underline the crucial role played by advance care planning and electronic records sharing within the multidisciplinary team, to ensure care co-ordination. This needs to be accompanied by greater public discussion on death and dying to improve people's knowledge and to reduce stigma around end-of-life care, such as public campaigns undertaken in France. Further to training, decision-making processes at the end of life should also be improved, including through closer involvement of people at the end of life and their relatives. Better quality standards to monitor and evaluate quality of life also allowing for international comparisons will be key. In Australia, the Palliative Care Outcomes Collaboration provides a framework intended to be integrated into regular clinical assessment.

There is room to prioritise the **effective distribution of resources** in end-of-life care and promote the design and implementation of **more evidence-based policies**. Improving payment systems that encourage the provision of more cost-effective services would also be paramount to ensure that end-of-life care is high-quality and financially sustainable. In particular, early access to palliative care services can both improve quality of end-of-life care and provide a better use of resources. Evidence from Belgium, Canada and the United States shows that access to palliative care out of hospital settings reduced use of intensive care units, medication, and overall health expenditures. The field lacks a strong focus on the use of research and data to inform policy making. It would benefit from promoting funding and developing institutional capacity to increase research projects on end-of-life care in areas where knowledge remains limited, such as timeliness of access, models of care delivery, and cost-effectiveness of interventions. Belgium, Ireland, France, and the Netherlands, for instance, have developed strong organisations supporting palliative care research. The availability of linked and timely data would facilitate international benchmarking and support to policy making around end-of-life care. Sweden has the Swedish Register of Palliative Care for that purpose while Ireland has indicators to measure accessibility of care.

1

Assessment and recommendations

This chapter provides a definition of end-of-life care (EOLC), introduces the OECD framework for assessing EOLC, summarises key challenges in the provision of EOLC and policy options to improve them. It shows that while the need for EOLC is growing, access to care is still limited and unequal across and within countries. The lack of awareness around death and dying among professionals and patients hampers the provision of people-centred services. Furthermore, people at the end of life would benefit from high-quality EOLC that addresses all symptoms and avoids under- or over-treatment. While services have proven cost-effective, particularly in community settings, public financing is often partial and geared towards hospital settings. Informal or family caregivers would also benefit from more public support. The governance of EOLC shows room for improvement, as the pandemic has recently highlighted. Improving research, data and quality indicators would inform policy making and align EOLC services with people's needs.

Introduction

Before the COVID-19 pandemic, close to 7 million people died every year in OECD countries and increasingly people die in old age. Realising that the end of life is near can be a devastating experience for individuals and their families. There are many ways to help people plan and die with dignity. End-of-life care (EOLC) help improve quality of life through relieving pain and other symptoms but also through helping address mental, emotional, and social needs. Such services are also a relief for relatives and friends, who often provide care, by giving emotional and practical help. Yet too often people are unable to access the care and support they need and that is in line with their wishes.

This report sets out policy challenges in end-of-life care, highlights examples of best practices in the provision of end-of-life care and brings together these findings to set out a framework for ensuring better end-of-life care. This report shows that, while many people want a peaceful end, without pain or distress, with loved ones and in familiar surroundings, this is not always the reality. People often do not die at home, which is the preferred place of death, because of lack of appropriate services and poor care co-ordination. Access to end-of-life care services is unequal across and within countries and leads to very different experiences at the time close to death. Many people experience unnecessary pain and other symptoms, and they are not always consulted or treated with dignity. Overtreatment and undertreatment at the end of life can occur simultaneously and there is a great use of resources that do not necessarily improve the quality at the end of life (Sallnow et al., 2022[1]). Out-of-pocket expenditure is substantial during the last year of life and places a high burden on the family of the dying person.

The COVID-19 pandemic has brought to stark prominence the reality of death. Across countries, overwhelmed health systems struggled to provide quality care and visiting restrictions reduced the responsiveness and people-centredness of care (Marie Curie UK, 2021[2]). In some countries, end-of-life care during the pandemic was not sufficient, particularly in long-term care (LTC) facilities, and regarding emotional support. In many countries, registering people’s wishes and recording advance care planning was delayed. In others, there was insufficient access to pain medication or oxygen. The pandemic has highlighted the need to improve such services and make health systems more resilient and able to provide adequate quality services.

Key findings

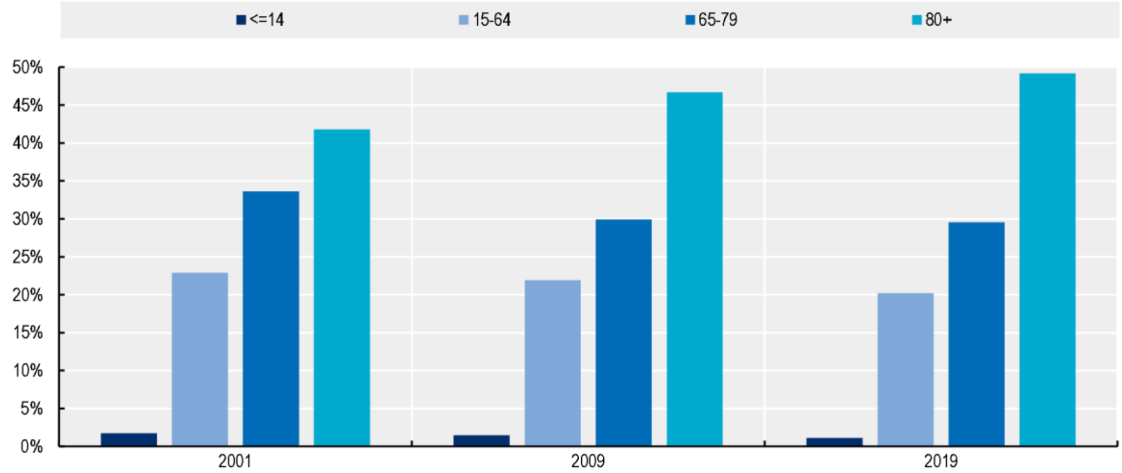
- **Gaps remain in access** to end-of-life care. Less than 40% of those in need of EOLC receive it across OECD countries. Addressing staffing shortages – including palliative care specialised doctors and nurses, primary care teams and long-term care workers trained in palliative care – and mechanisms for early screening for palliative care needs are a key factor to promote timely access.
- Currently, a lack of appropriate information for populations and communication between professionals and patients to care make end-of-life care **insufficiently people-centred**. Fewer than one in two adults in OECD countries report having some knowledge around EOLC. Communication on health status and care possibilities at the end of life occur less frequently than they should: less than half of people have such conversations with their doctor. Campaigns, improved training on communication and the use of multidisciplinary teams can contribute to a more people-centred care. Further to training, decision-making processes at the end of life need also to be improved, including through closer involvement of people at the end of life and their relatives.
- **Quality of care is still too often too poor** for people at the end of life. Alongside the under-treatment of their symptoms, people receive aggressive treatment that is not likely to provide comfort, prolong life or be cost-effective. This is the case for around one-third of older patients with advanced irreversible diseases who are hospitalised at the end of life. People can experience high levels of distress, depression, and anxiety at the end of life, yet only half of the surveyed countries include psychologists within EOLC multidisciplinary teams. There is also insufficient measurement and benchmarking about the quality of end-of-life care across countries. Less than two-thirds (63%) of 24 OECD countries have quality standards, and those which do exist are rarely binding or internationally comparable. Better quality standards to monitor and evaluate quality of life, also considering international comparisons will be key.
- End-of-life care services are **not always appropriately financed**. While palliative care services have been shown to be cost-effective for health systems, public social protection schemes provide only partial coverage of expenses to alleviate the symptoms of end of life in just a third of the 21 surveyed countries, typically for some services such as opioids and other forms of pain management, for nutrition support and for medication to alleviate vomiting and nausea. Public funding of end-of-life care services is more predominant in hospitals, which likely influence the place of death and have an upward impact on public expenses. There is room to improve payment systems for end-of-life care services to improve value for money. Early access to palliative care services especially outside hospitals can both improve quality of end-of-life care and provide a better use of resources.
- Finally, EOLC is **not always well-governed and evidence-based**. Improving co-ordination of services and the adaptability of health systems to increase access to end-of-life care services in case of extra demand due to emergencies. Besides increasing health workforce capacities, improving the use of advance care planning (ACP) and the availability of specific supplies in different care settings would allow carers to be better prepared for such events. Research in EOLC is insufficient and the data infrastructure to provide a full picture of end-of-life care across multiple services and data sets is still weak. Less than 30% of OECD countries have a national research agenda and less than 16% a local research agenda on the topic. Only 9 OECD countries collect data on EOLC that is integrated into other health and social systems. Countries could maximise the use of the wealth of available data by developing links across different datasets.

Population ageing and disease trajectories mean that end-of-life care needs will continue to rise.

End-of-life care refers to care provided to people who are in the last 12 months of life and receive palliative and curative care (Box 1.1 reports a more detailed definition of end-of-life care). This appears to be the timeframe most commonly adopted in definitions of end-of-life care (Hui et al., 2014[3]; Seow et al., 2018[4]) and this time period provides the opportunity to have Advance Care Planning discussions (Alliance for the Care of Dying People, 2014[5]; IKNL/Palliactief, 2017[6]) (for a definition of Advance Care Planning see Chapter 3). EOLC is considered to be the terminal stage of palliative care, provided in the very last period of a patient's life (Cherny et al., 2003[7]; Helsinki University Hospital, 2020[8]). In addition to this, this analysis encompasses the actions intended to sustain or prolong life.

An ageing population will result in a growing share of the population likely to die from conditions that require end-of-life care. Because people are living longer, a growing share of the total number of deaths occur in the older population (Figure 1.1). Previous OECD analysis has highlighted the fast rise in the population aged 65 and over across OECD countries. The increase has been particularly rapid among the oldest old – people aged 80 years or older (OECD, 2019[9]). In 2001, 42% of deaths occurred in people over 80 years old, and by 2019 this had increased to 49%. With the proportion of people over 80 years old expected to double from 5% in 2017 to 10% in 2050 (OECD, 2019[9]), the number of people who will need access to quality EOLC across the OECD is likely to further increase.

Figure 1.1. Trends in share of deaths by age group in OECD countries, 2001, 2009 and 2019

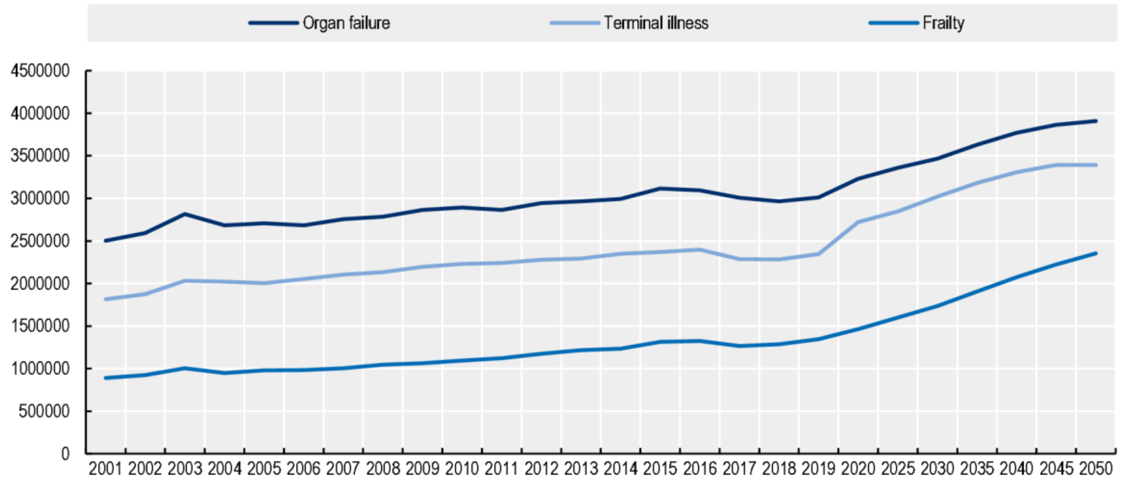


Source: (WHO, 2022[10]).

Figure 1.2 shows the estimated projection for the number of deaths that are likely to require palliative and EOLC for each of the EOL trajectories (organ failure, frailty, and terminal illness) up to 2050. According to these projections, the total number of deaths from diseases that would benefit from palliative and EOLC is forecast to move from 7 million in 2019 to close to 10 million in 2050. Annex 1.A provides data and methodological description of the projections. With such a high number of people affected by diseases that require EOLC, and an expected increase in the demand for these services in the coming years, EOLC is becoming a global public health priority.

Figure 1.2. Deaths from organ failure, terminal illness and frailty will increase until 2050

Projections of number of deaths requiring EOLC for each death trajectories until 2050



Note: The data include 33 OECD countries. Greece, Ireland and Türkiye are excluded for insufficient data.
Source: WHO mortality database (WHO, 2022[10]), UN database for mortality projections (United Nations, 2019[11]), (Qureshi et al., 2018[12]) for the definition of the EOLC death trajectories and (Etkind et al., 2017[13]) for the percentages of pain prevalence.

Box 1.1.What is end-of-life care?

There is no universally shared EOLC definition and a degree of heterogeneity exists on the timeframe to provide EOLC services. This report takes a broad interpretation and conceptualises EOLC as the care provided to people who are in the last 12 months of life. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; or d) life-threatening acute conditions caused by sudden catastrophic events (Leadership Alliance for the Care of the Dying People, 2014[14]).

In addition to the time frame, the definition of EOLC concerns the services and support provided. The EOLC concept utilised in this report refers to the terminal stage of palliative care, provided in the very last period of a patient's life, as well as including some elements of curative care and help with mobility limitations. In essence, it means that the focus is on palliative care which entails physical, emotional, social, and spiritual support with a particular emphasis on symptoms management such as pain but also emotional support and mental health care and bereavement care for families.

With respect to curative care, the report provides evidence of avoidable hospitalisations, emergency care and the care provided in intensive care units (ICU), among others (Wentlandt and Zimmermann, 2012[15]). In relation to life-sustaining care for individuals with life-threatening diseases and at the last stage of life, it is often profoundly difficult to make treatment decisions as survival probabilities are difficult to estimate. At the same time, life-prolonging measures are sometimes continued near the end of life, rather than focusing on improving quality of life due to a lack of other services. Decisions on commencing, as well as withholding and withdrawing treatments, are addressed in different ways across countries because of variation in legal frameworks and practices, as well as funding for certain treatments. This report's definition of end-of-life care does not include euthanasia, but a table in the Annex summarises which countries do include euthanasia within end-of-life care policy.

A framework for assessing end-of-life care

The OECD drew on national action plans and strategies for palliative and end-of-life care to identify key principles for evaluating the performance of end-of-life care in countries, identifying best practices and evidence-based strategies. In 2020, an expert workshop convened to discuss such framework, its key principles, and the best ways to measure them. In the future, countries wishing to improve end-of-life care should pay more attention to the five priorities which can help improve end-of-life care performance. Such priorities are outlined in the OECD's framework illustrated below so that end-of-life care becomes:

1. **Accessible**, that is, individuals have access to well-staffed, well-distributed, equitable, and timely end-of-life care.
2. **People-centred**, that is, individuals, their relatives and informal carers are informed, collaborate in key decisions, and receive inclusive care.
3. **High quality**, that is, individuals receive appropriate, comprehensive, and accountable care that provides comfort.
4. **Appropriately financed**, so that individuals and their families can afford care that is adequate, effective and whose burden is fairly shared.
5. **Well-governed and evidence-based**, that is, individuals receive care that is integrated and adaptable. They benefit from research-based and data-driven decision making in the end-of-life care planning and provision.

Table 1.1. Key principles of the OECD's framework for end-of-life care

Accessible	People-centred	High-quality	Appropriately financed	Well-governed and evidence-based
Individuals and their support networks have access to well-staffed, well-distributed, equitable and timely end-of-life care	Individuals and their support networks are empowered to take a central role in assessing and articulating their needs, and can access inclusive care that meets those needs	Individuals receive appropriate, comprehensive, and accountable care that maximises their quality of life	Individuals and their support networks can access sustainable, affordable, and effective care that does not place an undue burden on their support networks	Individuals receive care that is integrated within the national social security system and is adaptable in case of emergencies. They benefit from evidence-based decision making in the end-of-life care planning and provision.
Well-staffed: People have access to sufficient staff having adequate competences in palliative care and end-of-life care	**Informed:** People, relatives and informal carers are empowered to make informed decisions about their care through the provision of information on the services and support available to them	**Appropriate:** People receive adequate symptom control and care that is in line with their preferences and appropriate to their circumstances.	**Adequate:** Health and social services required to provide end-of-life care are sufficiently and sustainably financed.	**Adaptable:** Health systems can continue to provide high-quality end-of-life care during unexpected shocks and end-of-life care
Well-distributed: People can have access to services in their choice of setting, especially in the community	**Collaborative:** People, relatives and informal carers have timely and focused conversations with professionals to collaboratively plan their end-of-life care and support.	**Comprehensive:** Care is delivered through workers that work together in an interdisciplinary way, considering the psychosocial and spiritual needs of the person and their family.	**Fairly shared:** Care provided in the home places minimal burden on relatives and informal carers.	**Integrated:** Care is fully integrated into the wider health system and across all care settings.
Equitable: People receive effective care irrespective of their socio-economic background.	**Inclusive:** People, relatives and informal carers take a central role in determining their care according to their needs, values, and preferences. Care is provided in a considered and culturally appropriate manner	**Accountable:** Clear standards exist, and services are monitored, inspected, and regulated to ensure they meet these specifications.	**Effective:** End-of-life care services prioritise cost-effective interventions and delivery models that improve care quality	**Data-driven:** Governments implement a strategy for end-of-life care data with a minimum dataset.
Timely: People receive effective care when they need it.				**Research-based:** Governments and other stakeholders support end-of-life care research.

1.1. Removing barriers to access EOLC remains a priority

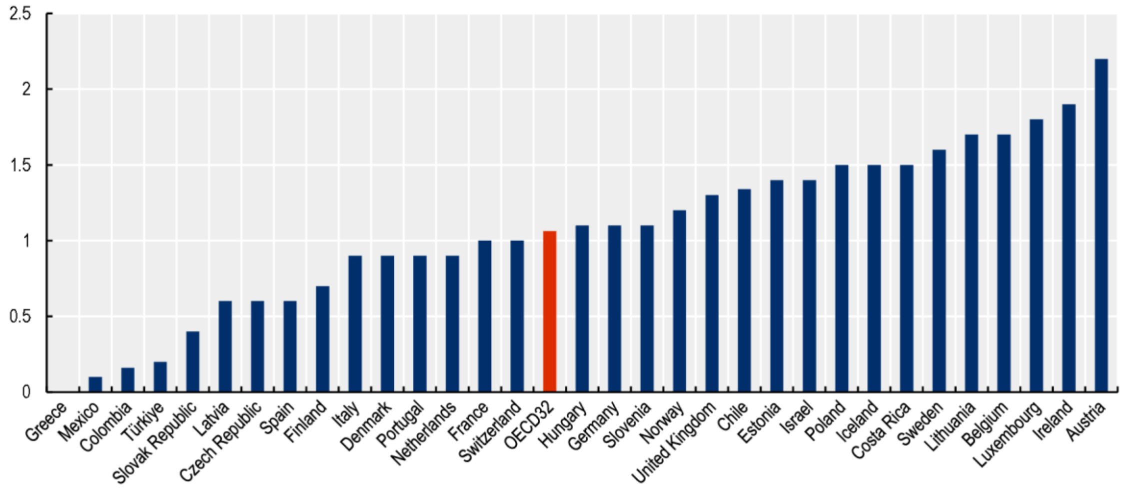
1.1.1. Access to end-of-life care is insufficient due mainly to staffing shortages

Palliative care services are not yet available to all patients with serious chronic illness, and challenges in accessing end-of-life care are prominent across all OECD countries. Across OECD countries for which data was available, less than 40% of those dying in need of palliative care services receive such services. Within European countries, Austria, Estonia, Greece, Hungary, and Latvia report a lack of timely access to palliative care services for people in need (Palm et al., 2021[16]).

There is a lack of palliative care specialists across countries. To address a patient's more complex needs, a multidisciplinary specialist team with extensive training in palliative care is typically suited. The European Association for Palliative Care recommends two specialised palliative care services team per 100 000 inhabitants (Centeno et al., 2016[17]) while the OECD average was 1.1 in 2017. In Europe, countries like Austria and Ireland appear to be better equipped in terms of the availability of palliative care teams, having close to two specialised palliative care teams per 100 000 population in 2017 (Figure 1.3). In Latin America, Chile and Costa Rica stand above the OECD32 average. On the other hand, Greece, Colombia and Türkiye show the lowest numbers.

Figure 1.3. Palliative care specialised teams in OECD countries with available data, 2017

Palliative care services per 100 000 inhabitants



Source: (Arias-Casais et al., 2019[18]) for Europe and (International Association for Hospice and Palliative Care, 2020[19]) for Latin American countries.

To ensure adequate access to end-of-life services, countries would need to make further efforts to train and recruit staff. While specialisations on palliative care for physicians are available in most OECD countries (75%), around one-third of countries still report that undergraduate medical school curricula do not include mandatory training on palliative care. Furthermore, while palliative care is increasingly included into medical and nursing school's curricula, there is high variability over the way countries embed it into the curricula. Palliative care is not always mandatory, and it is rarely mandatory *per se*, but often combined with other subjects (Arias-Casais et al., 2019[18]). France has set the objective to make palliative care training available in all health sector degrees and Australia also has several national and local initiatives to expand training on end-of-life care (Department of Health - Victoria, 2022[20]; French Ministry of Health, 2022[21]).Forecasting current and future care needs and enhanced workforce planning would provide a better idea of staffing needs and gaps. The United States, for example, has forecasted that given future needs, the number of physicians entering a palliative medicine fellowship training would need to increase from 325 to 500-600 per year by 2030 (Lupu et al., 2018[22]).

It is also important to provide adequate on-the-job training on end-of-life care to regularly develop and improve the skills of professionals in this area. Most countries (83%) already report on-the-job training. However, in only 29% of countries it is mandatory for staff working in the field of end-of-life care. Some efforts are already in place across OECD countries to improve the availability of continuous training for the health care workforce. To ensure quality training, France is planning to develop on-the-job training and to evaluate its quality through the monitoring of indicators and surveys of satisfaction (French Ministry of Health, 2022[21]), while England (United Kingdom) is improving the quality of end-of-life care training thanks to the use of technology, offering remote training sessions that reduce travel time and increase access to training (King's Fund, 2011[23]). Sweden also provides a guide and free online training on palliative care for all health care staff and other interested stakeholders. The United States have training centres to support the organisation and provision of on-the-job training (CAPC, 2022[24]; Skillsforcare, 2022[25]).

Besides training more, retention strategies are also critically necessary to ensure that palliative care health professionals do not leave the sector due to burnout, insufficient compensation, or poor leadership. In Canada, 38.2% of palliative care physicians reported a high degree of burnout and workplace interventions to reduce stress can prove useful (Wang et al., 2020[26]).

1.1.2. Significant inequalities remain across socio-economic groups at the end of life

Socio-economic background has been found to influence the way people experience the end of their life. In fact, while people with lower socio-economic background might be more in need of end-of-life care, due to higher prevalence of disease, disability and health risk factors, evidence from the United States, Canada and the United Kingdom shows that they are less likely to use palliative care, more likely to use acute hospital care and more likely to die at the hospital (Davies et al., 2021[27]; Simon et al., 2016[28]; Walsh and Laudicella, 2017[29]). OECD analysis of survey data confirms that people with higher education levels and in urban areas are also more likely to receive end-of-life care in many European countries, Korea, and the Unites States.

The reasons behind such outcomes are not yet well understood but evidence points to people from lower socio-economic background facing barriers to access end-of-life care. Geographical accessibility might differ because service availability favours more advantaged areas (French, Keegan and Anestis, 2021[30]). Other reasons might be related to health literacy, knowledge about services and higher communication difficulties with health care providers about choices and preferences.

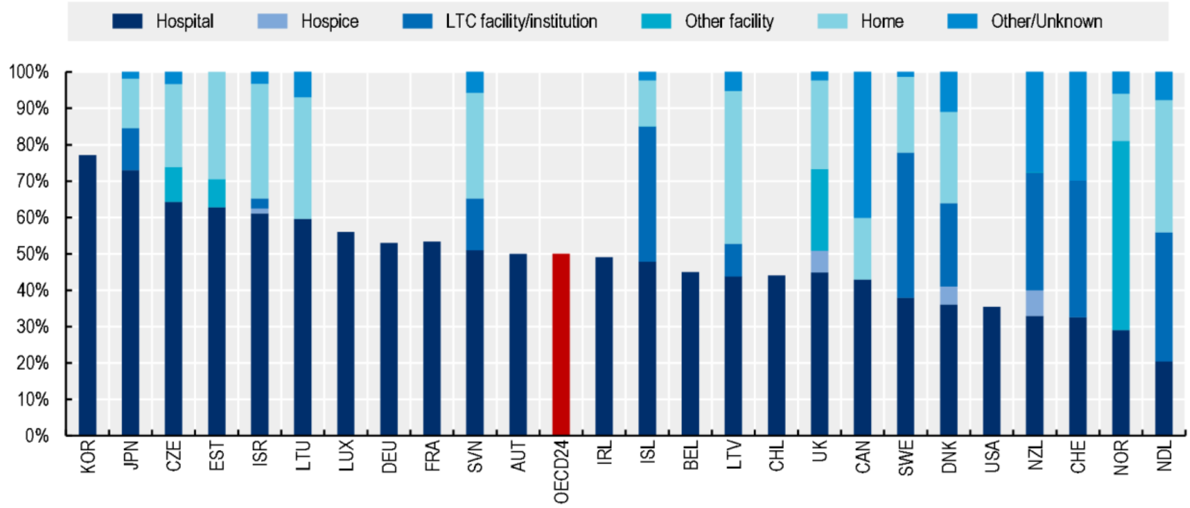
Some countries have placed special emphasis on reducing inequalities in access to end-of-life care. Currently, while more than 50% of the 24 OECD countries surveyed have policies to ensure equity in the access to EOLC, such policies are often quite general and do not define concrete measures to ensure equitable access to care. In Canada, on the other hand, the federal government has recently sought to address geographical disparities through higher funding. The federal government plans to invest CAN 26 million to incentivise professionals to work in rural areas, which are often underserved. The investment aims at forgiving student loans for physicians and nurses who practice in rural and remote areas (Department of Finance Canada, 2022[31]). In England (United Kingdom), people from a lower socio-economic background can obtain access to an adequate care package within 48 hours from referral thanks to a Fast-Track Funding (NHS, 2021[32]). Only half of the surveyed countries exempt people with low income from co-payments while Austria, Denmark, Germany, Luxembourg, Norway, and Sweden set a ceiling for co-payments (OECD, 2019[33]). Involving people with diverse socio-economic backgrounds in research and policy making could help tailor policies on people's needs (Rowley et al., 2021[34]).

1.1.3. People prefer to receive end-of-life care at home, yet 50% die in hospitals

End-of-life care can be provided in a variety of settings, including hospitals, in people's home, in a nursing home or in a hospice. One challenge is that the place of end of life is often poorly aligned with people's preferences, often because of lack of services. While most people prefer to die at home,[1] this rarely occurs, and when it happens it might not necessarily be a good death, because of lack of adequate services. In some cases, people at home are not able to receive end-of-life care services appropriate to their needs. While in Australia, Canada, New Zealand and Iceland, deaths in institutional care are common, representing more than one-third of deaths, across OECD countries, hospitals are still the predominant place of death, accounting for more than 40% of deaths and up to 77% in some countries. (Broad et al., 2013[35]). Figure 1.4 shows the percentage of people dying in hospital or in other settings in 2019 or the latest year available for 24 OECD countries. Japan, Korea, and the Czech Republic appear among the countries with highest share of people dying at the hospital, as opposed to The Netherlands, Norway, Switzerland, and New Zealand, where hospital deaths are rarer.

Figure 1.4. Half of the deaths across OECD countries happen at the hospital

Share of deaths by place of occurrence, 2019 (or closest year available)



Source: (OECD, 2021[36]) and OECD secretariat.

Further efforts are needed to expand access to end-of-life care at home and in non-hospital settings, such as long-term care institutions. Non-specialised care providers are often ill equipped to provide quality end-of-life care. Evidence showed that general practitioners who received training on identifying and planning palliative care are more likely to recognise people who need such services and to provide holistic palliative care (Lam et al., 2018[37]; Thoonsen et al., 2019[38]). In many countries, staff in long-term care facilities do not reach the 40% threshold in terms of staff´s palliative care training and more efforts are needed to prevent that older people are transferred to hospitals from nursing homes at the time of death (Arias-Casais et al., 2019[18]).

Training in end-of-life care should target better primary care professionals and long-term care staff, while finding innovative ways to co-ordinate with specialist support. Several countries are already transforming the provision of end-of-life care towards a model of palliative care where hospital, community, primary care, and specialist palliative care work together to provide integrated care. Canada, Ireland and New Zealand, for example, have increased the number of health care professionals with end-of-life care knowledge in a variety of settings (CIHI, 2018[39]; HSE, 2019[40]; Koper, Pasman and Onwuteaka-Philipsen, 2018[41]). In Australia, there is positive evidence of nurse-practitioner-led models in palliative care in rural areas. New Zealand decided to create regional managed clinical networks (MCNs) to link primary care professionals to specialists in case of need. Ireland is working on a model of palliative care where hospital, community, primary care, and specialist palliative care providers are supported to work together to provide an integrated care (HSE, 2019[40]). Australia and Germany have also made use of technology and training for generalists to ensure out-of-hours care at home (Health Research Board, 2019[42]; Victoria State Government, 2012[43]). In England, an innovative model of training was piloted and rolled out across nursing homes using a team from hospital including a palliative care consultant, a palliative care nurse consultant, a palliative care matron and three clinical nurse specialists to train and support nursing home staff (EJPC, 2020[44]).

1.1.4. Too often, people are unable to access appropriate end-of-life care when they need it

End-of-life care needs are often recognised late, delaying referral. Even when referral is obtained, the time span between referral and access to services can be lengthy, leading people to access the services they need only at the very end of life, in the last month before death. Countries are putting in place measures to prevent late identification of needs, but further efforts are still required to ensure that people have access to timely end-of-life care.

Ensuring timely access to adequate care is particularly crucial for people at the end of life but recognising when someone is reaching their end of life might be challenging, causing delays in diagnoses. Further delays take place between referral and actual access to end-of-life care services. Estimates from the United Kingdom report that 40% of referrals happen in the last 30 days of life (NIHR Dissemination Centre, 2018[45]). OECD analysis has also highlighted that more than half of the people receiving palliative care services only receive them in the last month of life. Supply constraints (e.g. insufficient specialists) and stigma from the patient side also represent barriers to timely access to EOLC.

OECD countries rarely monitor whether EOLC is provided in a timely manner and policies to ensure timely access are rare. Only Ireland, Italy and Norway provide national indication on the preferable timing for access to EOLC and only 7 countries have policies in place to monitor whether access to EOLC is timely.

Policies are in place in some countries to allow for early identification of needs and access to EOLC services, but they need to expand to achieve truly timely EOLC for all. Canada and Italy have programmes that have proven successful in providing people with the most appropriate care. Canada developed an Early Identification and Prognostic Indicator Guide to support providers, while Italy implemented a model of early identification of patients with palliative care needs through integration between primary care and home palliative care (Arianna Working Group, 2018[46]; CIHI, 2018[39]). The United Kingdom has monitored regional key performance indicators (KPIs) on timely access to EOLC services.

When the need of end-of-life care is recognised, referral should be fast to ensure that people who need care can receive it as soon as possible. Across OECD countries, EOLC services can be accessed mostly through referral from a GP or specialist (92%) or emergency department (69%). Virtual referral through digital health services is available in 31% of countries. Several examples of policies to improve referrals are available across the OECD. Maximum waiting times, regular evaluation, and assessment of waiting times and the introduction of fast-track pathways for people at the end of life are all in place in some OECD countries such as Ireland, the United Kingdom, and the United States (NHS, 2021[32]). Other measures that countries could develop include the early integration of end-of-life care in the care of people with life threatening and life-limiting conditions, by improving the links between different settings of care and types of care provided. Such policies have proven successful in improving the quality of people's life (Kaasa and Loge, 2018[47]; Vanbutsele et al., 2018[48]).

1.2. Towards more people-centred end-of-life care

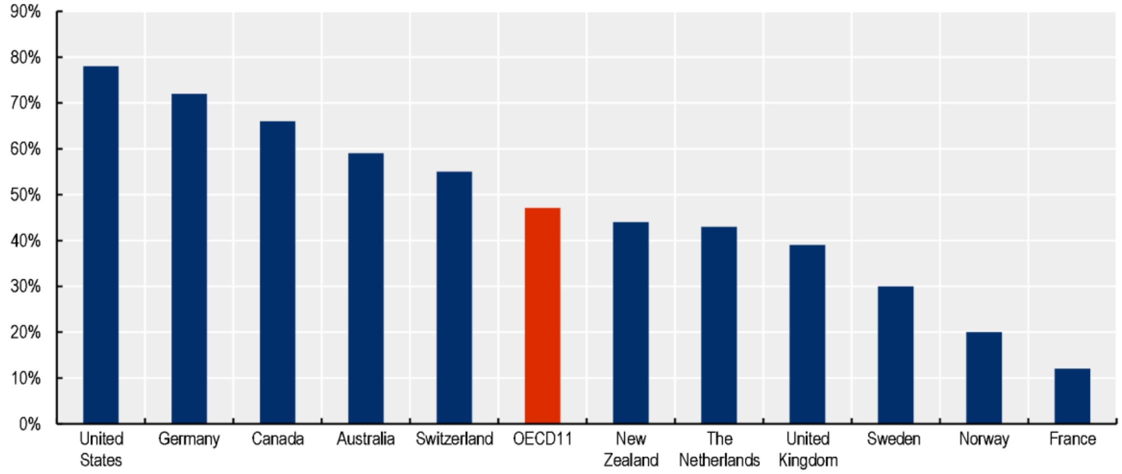
1.2.1. Improving communication around preferences for end-of-life care helps people make informed decisions about the end of their lives

A truly people-centred end-of-life care entails that people at the end of life and their relatives participate in the care choices at the end of life. Having conversations around care preferences and formal expressions of their wishes for end-of-life care is useful to make sure that people's wishes are respected when they approach death. This is particularly important for people who are affected by dementia or other cognitive diseases, who might not be able to express their wishes in their last period of life.

Only one in two people have conversations around end-of-life care preferences in surveyed countries. Despite the importance of having conversations on end-of-life care preferences, this is seldom discussed preferences as reported in Figure 1.5, although there is high cross-country variability.

Figure 1.5. On average, less than half of older people had conversations on their care preferences

Share of people aged 65+ who discusses care preferences if they become unable to make decisions for themselves



Note: Data refers to people aged 65+ who had discussion with someone including family, a close friend, or a health care professional.
Source: (Commonwealth Fund, 2017[49]).

Barriers to conversation on end of life include difficulties to find the right moment to start conversations on the clinician's side and poor understanding of end-of-life care on the patients' side (Bamford et al., 2018[50]; Swerissen, 2014[51]). Health care professionals also often report insufficient knowledge of the instruments available to register patients' care preference. Within LTC facilities, the lack of adequate space and low staff ratios further reduce the opportunities to engage in end-of-life care conversations (Harasym et al., 2020[52]).

Most OECD countries (77%) have some form of regulation that requires people at the end of life to designate an attorney for decision-making, namely choosing a relative who will make decisions on their end of life should they become unable to express their wishes. Nevertheless, the use of such instruments for decision making at the end of life is still limited and hampered by the biases mentioned above, and even where such tools are in place, they are not always followed.

Providing clinicians with training around end-of-life care and specifically on conversation and decision making at the end of life would reduce the communication barriers arising from stigma and disinformation. Results from Japan show that clinicians who received training on EOLC are more likely to have conversations and involve people at the end of life in the decisions regarding their end-of-life care (Tamiya, 2018[53]). Canada, Japan, and the United States are examples of countries already providing specific training on conversations at the end of life. In some cases, such training also includes specific guidance on EOLC conversations with people from diverse ethnic and cultural backgrounds (NHCPO, 2021[54]).

Enhancing multidisciplinary conversations would also improve the end-of-life experience. Clinicians who are informed about their patients' history and their previous contacts with other professionals would be better able to reduce discontinuity of care and repetition of information during the conversations with their patients, which usually cause stress, higher costs of care and more aggressive care (Hafid et al., 2022[55]; Sharma et al., 2009[56]).

Finally, to ensure that EOLC conversations contribute to better quality of life for people at the end of life, countries could include questions regarding conversations within Patient Reported Experience Surveys (PREMS). According to OECD surveys, 7 out of 12 surveyed OECD countries currently include questions on EOLC discussion within PREMs. The measurement of communication's quality at the end of life prioritised to assess how people centred EOLC is.

1.2.2. End-of-life care services should become more inclusive

Less than half of the surveyed countries require consideration of cultural preferences when providing end-of-life care. Ethnic and cultural minorities represent a growing share of the population in a number of OECD countries, but they tend to receive fewer end-of-life care services and more aggressive care, compared to the general population (Ejem et al., 2019[57]). Language and communication difficulties, personal beliefs and cultural factors, mistrust towards the health care sector and bias and discrimination are all barriers to people-centred end-of-life care for ethnic and cultural minorities (Crist et al., 2018[58]; Isaacson and Lynch, 2017[59]).

The knowledge of health care professionals around such cultural and ethnic differences is still limited. Only 10 out of 24 OECD countries have developed some form of regulation to take cultural aspects into account in the decision-making process around the end of life. Translation of relevant information into other language and training among the health care professionals could ease communication and improve access to adequate care at the end of life for all people, regardless their ethnic and cultural background.

Inequalities in the way people experience their end of life also exist across gender, age groups, and diseases. OECD analysis shows that males and younger people receive more aggressive care at the end of life, with higher rates of hospitalisations in the last year of life in all seven surveyed countries and across all disease types. Younger people with cancer are more likely to receive chemotherapy in the last 30 days of life compared to older adults, in Denmark, Israel and Sweden and youth who wish to receive palliative care are less likely to access such services compared to older people with similar wishes (Parr et al., 2010[60]). On the other hand, patients with cancer are far more likely to receive palliative care services compared to patients affected by other diseases.

Social biases and stereotypes are among the drivers of such differences and mismatch between people's preferences and care received. Requesting palliative care might be perceived as a sign of weakness and of "giving up the fight against the disease" and might be less acceptable for some groups. Furthermore, the death of a younger person might be considered less acceptable than that of an older person for some (Parr et al., 2010[60]). Health care workers should be made aware of such social biases and stereotypes, and they should be supported in fighting such biases, to ensure that everyone can receive the most appropriate end-of-life care services, regardless of their gender, age, and disease.

1.2.3. Improving awareness of end-of-life care is an important step to promote knowledge of services

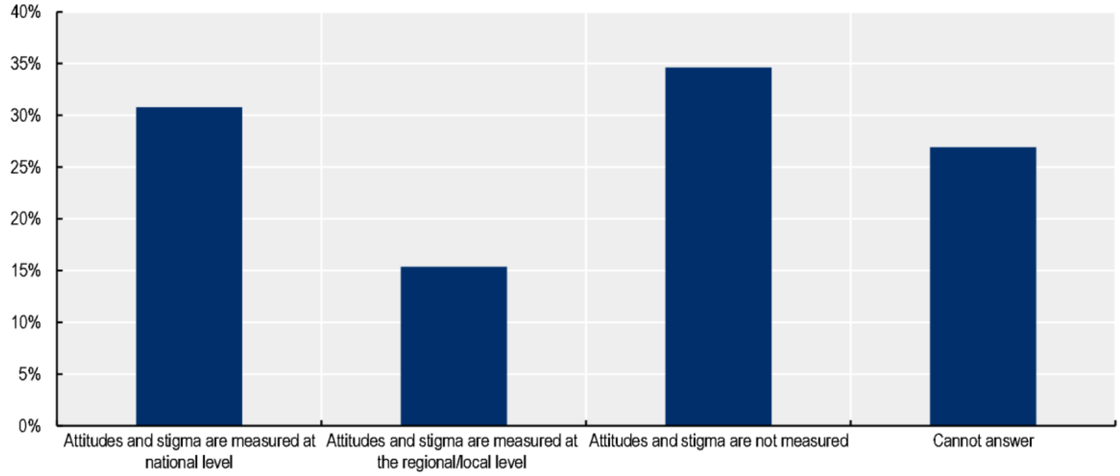
Stigma and taboo related to death affect the general population, reducing knowledge around end-of-life care services and the capacity of patients to request specific services. Insufficient information around EOLC makes it challenging to provide truly people-centred care, which entails the involvement of people in the decisions regarding their end of life. Campaigns to improve knowledge around end-of-life care and the role of other actors including patient and professional associations and groups of neighbours constituting compassionate communities (who provide support to patients and carers) can help making end-of-life care more centred on the person.

Evidence from most OECD countries shows that most adults in the general population have no or very limited knowledge around what services are available for people reaching the end of their life. Between 40% and 80% of adults across OECD countries are not able to provide a definition of end-of-life care or do not know what services are available to people reaching the end of their life. Even more noteworthy, significant shares of health care professionals (e.g. 17% of health professionals in Lithuania, 60% of nursing home and care home staff in the Netherlands) lack good knowledge around available tools to plan care in advance (Evenblij et al., 2019[61]; Peicius, 2017[62]).

Taboos around death, lack of conversations between health care professionals, patients and their close ones, and lack of funding are all recognised barriers to a wider spread of knowledge on end-of-life care. Despite this being a well-known issue, attitudes, and stigma around death and EOLC are not widely measures across OECD countries, with only 8 out of 26 OECD countries measuring them at the national level (Figure 1.6).

Figure 1.6. A third of the OECD countries surveyed do not measure stigma around EOLC

Share of countries that measure attitudes and stigma around EOLC



Note: N=26; Countries' answer to the question "Do you have any way of measuring attitudes or levels of stigma around EOLC or discussion on death?"
Source: (OECD, 2020-2021[63]).

Strengthening campaigns about end-of-life care would raise awareness and improve acceptance of EOLC services. Evidence suggests that being informed about end-of-life care also increases the likelihood of being willing to request and receive such services (Kleiner et al., 2019[64]; Lane, Ramadurai and Simonetti, 2019[65]). Better knowledge of EOLC among both the general population and health care professionals would also facilitate open conversations on the health status and care preferences for people at the end of life, allowing tailoring of care decisions on the person's preferences. Some countries have established programmes and campaigns to improve knowledge around palliative (83%) and end of life (72%) care, while more detailed campaigns on specific end-of-life care services are still rare. Awareness raising campaigns have proven effective. In France, for example, 84% of adults interviewed reported that information diffused through websites and social media was useful to learn about end-of-life care (Fin de vie soins palliatifs - centre national, 2019[66]).

A vital community can help improve the knowledge around end-of-life care, fight stigma and stereotypes and putting end-of-life care under the spotlight in policy making. Compassionate communities are building up across OECD countries. Made up of groups of people within the community providing support to people in need, also provide a measure of how much people are involved and engaged in end-of-life care decision making and services provision, their goal is to support people with limiting conditions and those who are at the end of life, as well as their loved ones, and they can foster their voices. Examples of compassionate communities exist in Belgium, Canada, Costa Rica, Germany, New Zealand, Spain, United Kingdom, and the United States (Compassionate Communities UK, 2022[67]; NHS UK, 2021[68]; Pallium Canada, 2022[69]).While compassionate communities often start as a local initiative, non-governmental organisations are playing an important role to foster the development of communities across the whole country.

Associations on end-of-life care can help spread EOLC knowledge across professionals and also bring the topic to the attention of policy makers. Most European countries have at least one national association on palliative care as of 2019 and in Latin America, Chile, Colombia, and Costa Rica have more than one, while Mexico has none (Arias-Casais et al., 2019[18]). The number of associations and lobbying groups devoted to end-of-life care also varies widely across countries, with Ireland and Canada showing the highest numbers across OECD countries whose data is available. Furthermore, Among OECD countries with data available, Luxembourg, Slovenia and Australia reported the highest numbers of national professional associations on EOLC.

1.3. Renewing focus on care quality

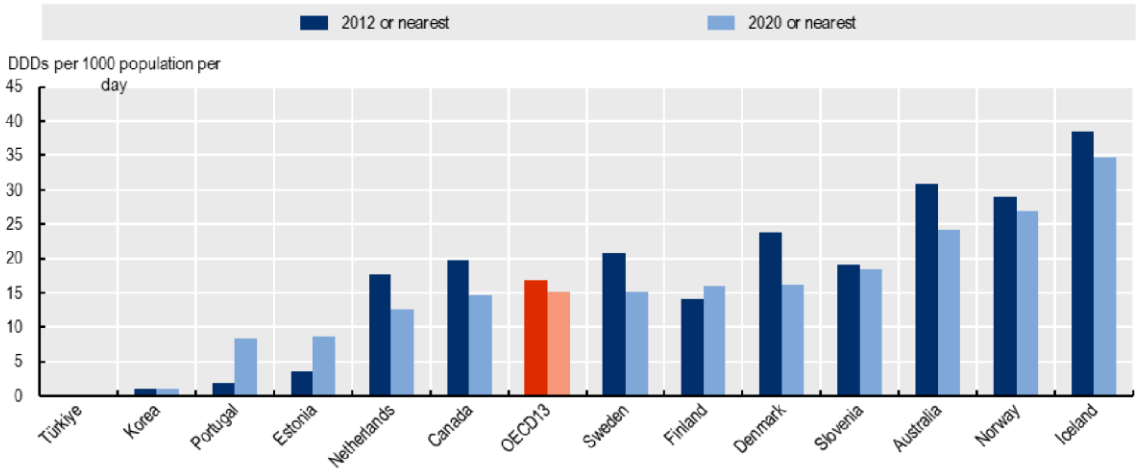
1.3.1. The end-of-life treatment that people receive is not always appropriate to their circumstances

When people are reaching the end of life, they risk experiencing suffering due to under-treatment of their symptoms. On the other end, some people are provided treatment that is not likely to provide any further curative benefit, resulting in overtreatment and aggressive care until the very end of life, which delays the use of palliative care. This is both inefficient and reduces the quality of life of people at the end of their lives.

The treatment of physical symptoms requires the use of pain-relieving medications, including opioids. Following concerns raised by the abuse and misuse of opioids in some OECD countries, the prescription of such medication fell between 2012 and 2020, although opioid overuse is still an issue in some countries (Figure 1.7). In Canada, the share of population using opioids fell between 2015 and 2017, but emergency department visits due to opioid poisoning and opioid-related deaths still increased in the same period in the provinces of Alberta, Yukon, and Ontario (CCSA, 2020[70]). In the United States, the national opioids dispensing rates decreased between 2012 and 2020, but some areas of the country still show particularly high rates (US CDC, 2021[71]). At the same time, pain relieving medications remain highly unequally distributed across countries, leaving some people's symptoms untreated, with older people appear to receive lower treatment for their physical symptoms compared to younger people (Dalacorte RR, 2011[72]; Fineberg IC, 2006[73]).

Figure 1.7. Opioid consumption has declined in most countries in the last decade

Opioids DDDs per 1 000 population per day for people aged 18 or older



Source: (OECD, 2021[74]).

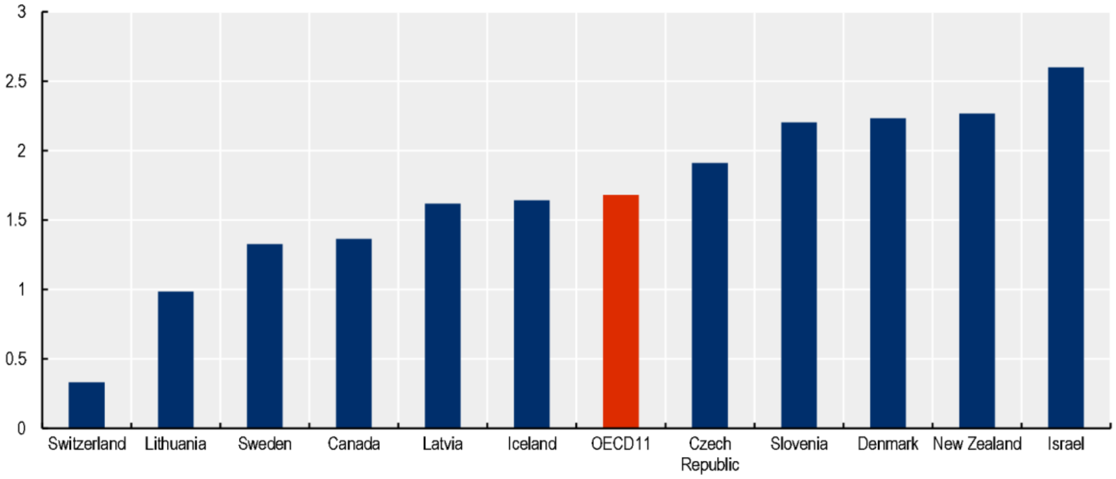
Reducing barriers to pain relief is of paramount importance to ensure that everyone experiences a good quality of life until the very end. Addressing this requires:

- Tackling barriers to pain relief medication include changing regulation. For example, in Canada, palliative drug programs have been put in place in several territories and provinces. In Australia, the position statement of Palliative Care Australia on Sustainable Access to Prescription Opioids for Use in Palliative Care also provides recommendations for a sustainable opioid management, to improve the access to such medications while minimising the risks linked to their use (Canadian Institute for Health Information, 2018[75]; PCA, 2019[76]; TGA, 2018[77]).
- Raising knowledge and skills among health care professionals, who report they lack adequate knowledge to safely prescribe opioids (Bhadelia et al., 2019[78]). Training has been shown to improve professionals' confidence to prescribe opioids and allowing some well-trained non-physicians to prescribe opioids increases the access to pain-relief. Evidence from the Netherlands and the United Kingdom showed that training is an effective way to support physicians to prescribe opioids appropriately (British Medical Association, 2017[79]).

People at the end of life also experience overtreatment, with more than one-third of older people hospitalised near the end of life receiving interventions unlikely to provide either survival or palliation benefit (Cardona-Morrel et al., 2016[80]). Figure 1.8 shows that hospitalisations in the last year of life are common in OECD countries and further OECD analysis has shown that people tend to be hospitalised more than once in the last year of life. Admissions to Intensive Care Units and visits to Emergency Departments are also common in the last 30 days of a person's life, particularly among younger people.

Figure 1.8. People are admitted to hospital on average 1.68 times in the last year of life

Number of hospitalisations during the last year of life, per death



Source: (OECD, 2021[36]).

Evidence on measures to reduce unnecessary treatment at the end of life is still emerging, but studies have shown that community-based palliative care is associated with less unnecessary hospital use at the end of life (Canadian Institute for Health Information, 2018[75]). Doctors who received training on end-of-life care are also less likely to choose aggressive care at the end of life, but family members can sometimes influence the professionals' choices, especially in the absence of written documents reporting the patients' wishes (e.g. living wills, do not attempt resuscitation, advance directives) (Piili et al., 2018[81]).

In some cases, wishes for continuing curative care and overtreatment come from family members of the patient. Disagreements can arise between professionals and family members which complicates decision-making on end-of-life care. Studies have shown that the use of ethics consultations is associated with lower use of aggressive care and shorter stays in intensive care units (Au et al., 2018[82]; Schneiderman, Gilmer and Teetzel, 2000[83]) Three-fifths of OECD countries have national guidelines to manage these situations of misalignment and around one-third have interdisciplinary ethics committees or employees assistants in most or all facilities to support health care professionals in complex decision-making (OECD, 2020-2021[63]).

1.3.2. There are considerable gaps still in measuring and monitoring the quality of end-of-life care

Good quality end-of-life care would require clear quality standards, clinical care guidelines and quality measures that can be regularly collected. In nearly two-thirds of OECD countries there are quality standards for EOLC services at the national level. Such standards typically focus on early identification of people who are reaching the end of their life, shared decision-making with patients and their relatives, symptoms and pain control, holistic care that includes support to patient's relatives, advance care planning, multidisciplinary and co-ordinated care provision. For instance in Australia the Commission on Safety and Quality in Health Care published standards that focus on two areas: i) process of care (i.e. patient-centred communication, share decision-making, care co-ordination, recognition of patients reaching the end of life) and ii) organisational prerequisites (governance, education and training, support to multidisciplinary teams, monitoring and evaluation) (Australian Commission on Safety and Quality in Health Care, 2015[84]). In the United Kingdom, the National Institute for Health and Care Excellence provides comprehensive quality standards for end-of-life care for adults, identifying 12 recommendations for high-quality end-of-life care[2]

(NICE, 2021[85]). Quality domains include identification of those approaching the end of life having advance care planning, receiving co-ordinated care and having access to 24-hour care support. Some countries, such as Germany and Ireland, also have quality standards for specific care settings. In Ireland, for example, the Hospice Foundation provides specific standards for end-of-life care in hospitals (Hospice Foundation, 2013[86]).

However, quality standards are not always mandatory or regularly monitored. Countries differ in the availability of audit and quality evaluation programmes and in their characteristics (e.g. whether they entail internal or external assurance and inspection). Three-fifths of OECD countries have audit or quality evaluations for end-of-life care, but they do not always cover all settings of care. In the United Kingdom, the National Audit of Care at the End of Life (NACEL) evaluates how hospitals perform vis-à-vis existing quality standards (NHS, 2022[87]). Similarly, the United States has a Hospice Quality Reporting Program for all Medicare-certified hospice programs that has quality reporting requirements for hospice providers and public reporting of quality measures (Centers for Medicare and Medicaid, 2021[88]).

Clinical care guidelines specific to EOLC provide clear guidance on the best care for people at the end of life and can represent a mechanism to avoid over- and under-treatment at the end of life. Across OECD countries, Norway, Denmark, and England have EOLC guidelines for several settings of care, while in other countries, EOLC guidance is included within clinical care guidelines for specific conditions (e.g. cancer). This can be a challenge if much end-of-life care was developed to care for people dying of cancer, but is not always fit for purpose for other conditions. Some countries such as Denmark and the Netherlands use other levers to drive service improvement in EOLC, including clinical quality programmes and payment systems that can drive care quality (Danish Ministry of Health, 2018[89]; Palliaweb, 2019[90]).

There is often a lack of nationally used sets of measures with benchmarking that applies across populations and settings. Quality indicators based on administrative and clinical data are also not widely in place. The most available outcome indicator is place of death, which is available in at least 14 OECD countries, followed by hospital admissions in the last year of life (in 12 countries), hospital 30-day readmission (9 countries) and visits to the emergency department in last 30 days of life (7 countries). Other indicators of poor quality, such as use of chemotherapy in the last days of life, as well as positive quality indicators such as the number of people using palliative care, recording advanced directives, or being referred to palliative care appear to be less widespread. Few indicators dealt with the organisational structure of palliative care. Moreover, not all domains of palliative care were covered to the same degree, with a notable underrepresentation of psychosocial, spiritual, and cultural domains. Finally, most indicators were restricted to one setting or patient group, often cancer patients (Daryl Bainbridge and Hsien Seow, 2016[91]).

Nearly half of the responding OECD countries (12 out of 25) held no system in place to monitor and evaluate palliative care experiences and outcomes such as patient reported outcomes and measures. In Australia and New Zealand, the Palliative Care Outcomes Collaboration collects patients' outcomes to measure quality of end-of-life care. The indicators measure responsiveness to urgent needs, pain management and timely commencement of palliative care, among other things (PCOC, 2022[92]). Other examples of national quality measures for end-of-life care are the measures in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey, Hospice Item Set (HIS) and the Bereaved Family Survey (bereaved family survey BFS) in the United States. Internationally comparable quality indicators are still rare, making cross-country benchmarking difficult, though some efforts are in place to improve international comparability. The Palliative Care Outcome Scale, the McGill Quality of Life Questionnaire (MQOL) and the Cambridge Palliative Assessment Schedule (CAMPAS-R) are examples of questionnaires collecting Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) on end-of-life care that aim to make such information internationally available and comparable.

1.3.3. Holistic care that addresses all the person's needs improves the quality of life for people at the end of life and their relatives

People at the end of their life have inter-related needs which are often not addressed sufficiently. When people reach the end of their life, they often face several physical, psychosocial, and spiritual needs, which require a holistic approach to be adequately addressed and managed. Psychosocial and spiritual support is key to ensure good quality of life until death for the dying person, as well as easing the grieving phase for the relatives. For instance, symptoms of depression increase in the last year of life and 60% of people have depression in the last month before death (Kozlov et al., 2019[93]). Nevertheless, surveys often report that both psychological and spiritual support at the end of life is inadequate, showing wide room for improvement (Evangelista et al., 2016[94]; McInnerney et al., 2021[95]; Thomas, 2021[96]).

Addressing all symptoms holistically entails that different professionals collaborate to take care of the person and their relatives at the end of life. Many countries are developing the use of multidisciplinary teams. England (United Kingdom) and France recommend the use of multidisciplinary teams within guidelines on end-of-life care. Canada makes regular use of multidisciplinary teams to provide end-of-life care, while Czech Republic started a pilot project in 2017 to implement multidisciplinary palliative care teams across the country. Ireland, Japan, and the United States have set up multidisciplinary training where professionals can learn together and exchange knowledge and experience. Despite the existence of multidisciplinary teams, the professionals included in such teams vary across countries, with psychologists and psychotherapists only included in 14 and 7 countries, respectively, across 27 OECD countries.

In addition, the death of a person is a mentally distressing moment for the relatives and carers. Patients' families also report declining mental health near the death of their loved ones. Between 7% and 39% of cancer patients' families experience grief disorders (Kustanti et al., 2021[97]). Follow-ups after death to help support relatives in the grieving and bereavement process and already exist in some countries, such as the Bereavement Support Line set up in Ireland.

1.4. Ensuring affordable end-of-life services

Public funding for EOLC is geared towards hospital settings and the lack of integrated funding streams reduce opportunities for early palliative care which has proved to be cost-effective. At the same time, out of pocket (OOP) costs are high in some countries for families because of partial public coverage of services. With EOLC needs expected to grow, there is a risk that this increases public expenditures heavily but also that families bear a great share of both the direct and indirect costs associated with providing informal care.

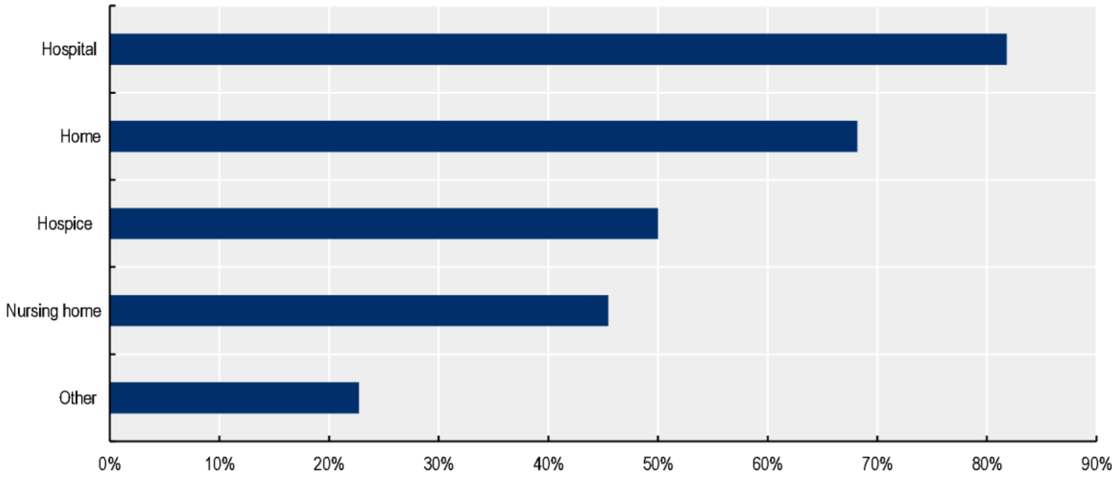
1.4.1. Publicly funded end-of-life care is available, but there are significant gaps

EOLC still heavily relies on hospital settings and can lead to the experience of death being more challenging in other settings, influencing the choice of place of care and death, but also, the overall spending. Funding for EOLC mainly typically comes from health and social security schemes, with health benefit packages being the most common funding system. Current EOLC funds mainly target hospital settings, with 82% of OECD countries having public financing mechanisms for EOLC in hospitals, while only half of the countries have similar mechanisms for hospice and fewer still for nursing home services (Figure 1.9). Studies highlight that 80% of the costs in the last three months of life were attributable to hospital acute care while the costs of palliative care were only close to 10% (Yi et al., 2020[98]). In contrast, palliative care, especially outside of inpatient settings, is correlated with higher patient satisfaction and lower overall health care costs (Public Health England, 2017[99]).

Incentivising home or community care and early access to palliative care services through more appropriate payment mechanisms are paramount. Finding ways to incentivise or removing negative incentives for care outside hospitals is important. For instance, in Victoria, Australia, each additional hospital admission attracts additional funding while this is not the case for community or home-based palliative care, creating a greater incentive for admissions to hospitals than for community-based treatment (Duckett, 2018[100]). Better pricing and reimbursement mechanisms can incentivise providers to promote palliative care (Duckett, 2018[100]; Groeneveld EI, 2017[101]). Bundled payments have been suggested as an alternative option to integrate curative and palliative care. The United States are moving towards value-based payments which might favour more palliative care and tested allowing paying for patients to receive hospice services as they continued to receive curative care (CSM, 2022[102]) while the United Kingdom has applied pay-for-performance systems incentivising GPs to identify and manage palliative care needs.

Figure 1.9. Public funding for EOLC mainly targets hospital settings

Share of countries having specific public financing mechanism for EOLC services in the following care settings

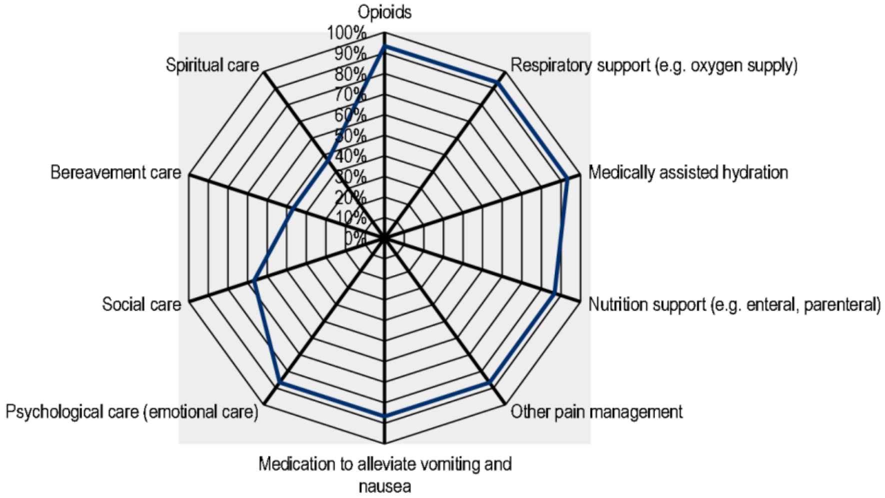


Note: N= 22.
Source: (OECD, 2020-2021[63]).

Affordability of services at the end of life remains an issue. In most countries, a plethora of EOLC services is publicly available or financed (Figure 1.10) but often require out-of-pocket payments that can be high. For instance, while most countries cover opioids and other pain management, in a third of countries this represents partial coverage, similarly to nutrition support and for medication to alleviate vomiting and nausea. Other services, such as spiritual care and bereavement, are not publicly funded in one-fourth of the countries. Even when they are funded, coverage is partial in 4 out of 10 surveyed countries. Complementary health services such as aromatherapy, relaxation, music therapy, art therapy and reflexology are less widely available, and their availability varies within countries.

Figure 1.10. Publicly available and funded EOLC services in OECD countries

Share of countries where EOLC services are fully covered (no out-of-pocket)



Note: N=10.
Source: (OECD, 2020-2021[63]).

In addition to specific end-of-life care services, care utilisation is high at the end of life, which raises the overall significance of out-of-pocket spending. For instance, data from the United States show that for 25% of households, the total out-of-pocket spending during the last 5 years of life exceeds total household assets and for 40% of the households it exceeds their financial assets (Kelley and al., 2010[103]). Out-of-pocket (OOP) expenses for end-of-life care are significant and there is a risk that gaps in public funding generate unmet needs or catastrophic expenditures. Often the largest single category of out-of-pocket spending is nursing home and hospital expenditures (French and al., 2017[104]). Insufficient public funding for EOLC is likely to exacerbate existing inequalities in the access to such services. Increasing demand for end-of-life care services will require governments to pay particular attention to affordability of these services for users. Some countries, like Korea, have introduced policies to limit out-of-pocket costs.

1.4.2. Heavy reliance on informal carers places a considerable burden on families

Informal carers play an important role in the provision of end-of-life care, but also bear a heavy direct and indirect financial burden related to the OOP expenditure for EOLC and the time invested in providing care, sometimes at the expenses of their job. While informal carers constitute a valuable support for people at the end of life, countries should support them adequately through the provision of financial and psychological support, legislation on work leave and training.

Informal carers face direct and indirect financial burden of end-of-life care. Among OECD countries, between 46% and 86% of people who die at the age of 65 or older received some informal care at the end of life (SHARE, the Survey of Health, Ageing and Retirement in Europe, 2020[105]). Family caregivers providing EOLC had either given up work, reduced hours at work, or used annual leave or sick leave to cope with the demands of caregiving. Providing informal care can be distressing and affect the carer’s mental health, leading to additional health expenses. Carers also face sometimes additional direct costs such as travel expenses and additional household costs. Total care costs met by informal caregivers are substantial, although they vary widely across countries, with estimates of caregiving ranging from 26.6% – 80% of total costs (Gardiner et al., 2014[106]).

Despite informal carers providing a substantial share of end-of-life care, not all countries provide support to informal carers. Only half of OECD countries provide financial support to informal carers. Better financial support to informal carers would reduce their burden, balancing the generosity of benefits with the size of eligible population, without trapping carers and preventing their labour force participation. While many countries have leave for care at the end of life, in many this is for a reduced period of time or unpaid. Belgium, Denmark, and France have generous paid leave for informal caregivers who are in the labour market.

In addition to financial support, counselling and training are often needed to reduce mental distress when accompanying a relative towards the end of life and improving the quality of care. In addition to being useful to the carers themselves, psychosocial support can have a broader societal financial impact, reducing caregivers' care utilisation and improving their productivity (KPMG, 2020[107]). Nevertheless, respite care, counselling, training, and other forms of support to informal carers are still inadequate in many OECD countries.

1.5. Strengthening governance and the evidence base for EOLC

1.5.1. The COVID-19 crisis has highlighted the importance of ensuring adaptability of systems to provide EOLC

The pandemic caught countries unprepared on several fronts. Staff and supply shortages impaired the delivery of care, while lockdowns and other restrictions caused loneliness among people living within facilities or at home with life limiting diseases. End-of-life care services were overwhelmed in the face of the COVID-19 crisis and people who were dying did not always have their wishes realised. This led to people often dying far from their relatives or at home without adequate care.

Despite most countries issuing guidelines for health care at the onset of the COVID-19 pandemic, only 6 OECD countries (Canada, Latvia, Luxembourg, Norway, Portugal, and the United States) mentioned palliative care needs and modes of delivery in their guidelines (Rocard, Sillitti and Llena-Nozal, 2021[108]).

Further shocks are expected to happen in the future and countries should prepare now to ensure better resilience of end-of-life care during future crises. In view of future crises, there is a clear need to adapt EOLC services based on the lessons learned during the pandemic. Including EOLC experts within task forces and issuing guidelines on EOLC resilience is the way to prepare the sector to future shocks. The use of shared decision-making tools such as advance directives and living wills can ease decision making in the event of a crisis. During the COVID-19 crisis, Canada, Ireland, France, the United Kingdom, and the United States issued guidelines on EOLC. The guidelines provided support to professionals transferring patients at the end of life across settings, providing supportive therapies for COVID-19, performing advance care planning and adequately supporting patients living with dementia (Comas-Herrera, Ashcroft and Lorenz-Dant, 2020[109]; Government of France, 2020[110]; OECD, 2020-2021[63]; Rocard, Sillitti and Llena-Nozal, 2021[108]).

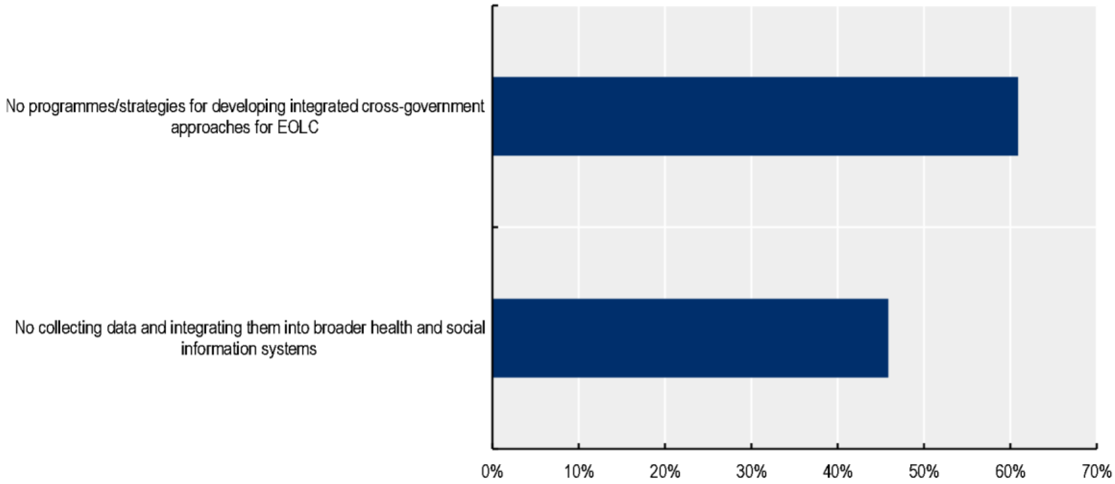
The COVID-19 pandemic has accelerated the recognition that all people working in health services should be competent in supporting those dying and their families. This requires alternatives to hospital admission with sufficient medical supplies for symptom management and staffing. To avoid staff shortages at home and in the community, in the future, countries need to find better ways of integrating specialist expertise within primary and community settings such as the long-term care sector. During the pandemic, Canada, Norway, Sweden and Slovenia developed training and support concerning EOLC for health care workers (National Competence Service for Aging and Health, 2020[111]; Pallium Canada, 2021[112]; Rocard, Sillitti and Llena-Nozal, 2021[108]).

Countries – such as Belgium, Canada, Sweden, and the United States – also made use of technology to improve care co-ordination, reduce the movement of patients across settings and facilitate contacts between patients and their relatives despite lockdowns and restrictions. Among OECD countries, 40% among the 25 surveyed countries used technology in EOLC already before 2020, while 24% introduced the use of technology in EOLC during the pandemic.

1.5.2. There is a need for better integrating EOLC into the broader health and social care systems

Across OECD countries, 60% of 23 countries surveyed do not have any programme to implement an integrated approach across different levels of government and nearly 50% of 24 countries surveyed do not collect and integrate data on EOLC into broader health and social information systems (Figure 1.11).

Figure 1.11. Most countries do not have well integrated EOLC



Note: Share of countries that replied “No” to the following questions: i) Do you have any national or subnational programmes/strategies for developing integrated cross-government approaches (i.e. across different levels of government and/or across ministries) to EOLC governance; ii) Is data about EOLC (e.g. access, outcomes, financing) collected through specific indicators integrated into broader health and social information systems?
Source: (OECD, 2020-2021[63]).

Some countries have initiatives for integrating end-of-life care into the health care system. Australia, Belgium, Northern Ireland (United Kingdom), England (United Kingdom), Italy and Sweden all have programs to improve the integration of EOLC. Integrating end-of-life care into primary care, for instance, allows earlier detection of patients who need EOLC and thus earlier provision of EOLC services. Shared electronic systems can facilitate co-ordination across services. Currently, around 60% of OECD countries have a system of secure electronic note sharing for EOLC, such as Australia, Costa Rica, and the United Kingdom. The Netherlands and Norway are currently developing electronic notes sharing and Australia is further improving the existing data availability.

When people reach the end of their life, they are often affected by multi-morbidities that require care from several different professionals, yet there is a lack of an integrated approach to end-of-life care across countries. People often need to repeat the same information to different professionals and might receive discordant opinions and inconsistent service standards. Disjointed services can also generate discontinuities in care when people are discharged from the hospitals. Lack of integrated end-of-life care leads to a hospital-focus in the provision of palliative care.

Interdisciplinary teams and case management would make end-of-life care more integrated in the health care system. Evidence from the Netherlands shows that the percentage of patients who die at home is higher and the number of hospitalisations in the last 30 days of a patients' life is lower when a case manager is involved offering advice and support (van der Plas AG, 2015[113]).

1.5.3. Countries need a stronger evidence and data infrastructure to monitor and improve end-of-life care

Policies on end-of-life care should be based on strong scientific evidence and thorough research. Nevertheless, more than half of OECD countries (56%) do not have a research agenda for EOLC at the national, regional, or local level, while public funding for EOLC research has fluctuated in recent years (OECD, 2020-2021[63]). In addition to low and fluctuating public funding, the number of funded projects has also been limited, with high variation across countries. The United States appear to have by far the highest number of research projects on EOLC, which are increasing over time, but they still represent a minority in comparison to other areas of research (American Cancer Society, 2021[114]).

Because of the limited research on the topic, gaps exist in the methodologies applied and the topics of focus. Studies are mainly observational and clinical trials only represent a minority of research projects. Improvements in end-of-life care should draw upon scientific evidence. Evidence of people's preferences, care outcomes and clinical best practices should guide the provision of end-of-life care services. In addition, more efforts must be taken for research to translate scientific results into clinical practice, as evidence is not always incorporated into routine care.

Governments could encourage more research to overcome knowledge gaps which are particularly salient and prioritise funding for research with respect to timeliness of access, models of care, and cost-effectiveness. In addition to reducing barriers around the stigma related to the topic, public efforts should also target addressing broader systemic barriers, especially the limited number of funding sources for palliative care and lack of well-trained investigators (Chen et al., 2014[115]). Belgium, Canada and Norway have provided public funding to specific research centres focusing on end-of-life care, while Ireland, France and the Netherlands have organisations supporting palliative care research (OECD interviews, 2021) (Plateforme nationale pour la recherche sur la fin de vie, 2021[116]; ZonMw, 2021[117]).

Measuring quality of end-of-life care in a systematic and comparable way requires a strong data infrastructure, with comprehensive health data governance, legislation, and policies that allow health data to be linked and accessed. Across the OECD:

- 16 countries currently have mortality data with the possibility of linkages with health datasets and 10 countries regularly apply such linkages. This is mostly the case for Nordic countries (Oderkirk, 2021[118]).
- Sweden and the United States have well-established datasets for end-of-life care, while Ireland and the United Kingdom have already developed specific indicators to measure the quality of EOLC.

Other countries, such as Korea, Luxembourg, and Costa Rica, are currently working on the development of data and indicators on end-of-life care. Further efforts are required to make data available and linked and to design appropriate indicators to monitor end-of-life care services.

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Annex 1.A. Methodology for data projections

The literature identifies four trajectories of death, such as sudden death, terminal illness, organ failure, and frailty (Lunney, Lynn and Hogan, 2002[119]). Terminal illness mainly refers to cancer, organ failure mainly includes heart failure, Chronic Obstructive Pulmonary Disease, and liver failure, while frailty encompasses diseases such as dementia and Parkinson's. Sudden death includes accidents and other external causes. Such deaths are less likely to require end-of-life care and thus does not fall within the focus of this report. Chapter 2 provides further information on the trajectories of death and the diseases they include.

The projection of the future need of EOLC uses as a baseline the UN mortality probabilistic projections, (median variant), for the period 2020-50 (United Nations, 2019[11]). The latter were merged with the WHO mortality database for the period 2001-17 (WHO, 2019[120]). The number of deaths for the years 2018-19, which were not covered by either of the two databases, have been estimated as a simple mean of the deaths in the closest years (2017 and 2020), under the assumption that the growth rate of mortality could be considered constant over short periods of time.

The trajectories of death were applied to the projected mortality data. The rate of change in the distribution of deaths among the trajectories over time has been considered by applying to the projected data the average yearly change observed during the last 10 years.

Not all the individuals with organ failure, terminal illness or frailty require all the components of EOLC. According to (Etkind et al., 2017[13]), the pain prevalence related to diseases classified as organ failure corresponds to 67% (meaning that 67% of all organ failure deaths live in a situation of pain as to require physical care for the management of these symptoms). This percentage is estimated to be 84% for terminal illness and 60% for dementia. These percentages of pain prevalence have been used in the calculation of the future need of EOLC.

All patients' needs (physical, psychological, spiritual, and social) should be addressed by the end-of-life care services, which should indeed be holistic and comprehensive, rather than strictly related to symptoms management. The percentages of pain prevalence have been applied for the calculation of future end-of-life care needs to obtain a conservative estimation of EOLC needs.

Annex 1.B. Euthanasia

The term “euthanasia” (from the Greek “εὐθανασία”, literally “good death”) is often used to label different practices, such as voluntary euthanasia, involuntary euthanasia, and assisted suicide. Despite being often labelled under the same term, each of the listed practices entail different characteristics, as described in what follows.

Euthanasia is **voluntary** when a person makes the conscious decision to die and seeks support to terminate their life, while it is **non-voluntary** when the person does not have the capacity to express their preference (e.g. because of a coma or other impairment) and someone else (e.g. a relative) needs to decide on their behalf. In some cases, even when the person does not have the capacity to express themselves, their wishes are known if some form of living will is in place. Some countries only allow non-voluntary euthanasia when the person’s preferences were known before they lost the capacity to express themselves.

Assisted suicide refers to the practice of assisting a person to terminate their own life. In this case, the person at the end of life decides to end their life and kills themselves with some form of assistance from a third person. One example of assisted suicide could be when a physician or the relative of a person at the end of life provides strong medications that will be used by the dying person to commit suicide (EAPC, 2015[121]; European Parliament, 2017[122]; NHS, 2020[123]).

Countries vary in their approach to euthanasia due to different considerations. For each of the practices described above, Annex Table 1.B.1 shows which countries allow such practices across the OECD.

Annex Table 1.B.1. Where is euthanasia available across OECD countries?

Country	Voluntary euthanasia	Non-voluntary euthanasia	Assisted suicide
Australia	√ (In Victoria and Western Australia)	x	√ (In Victoria and Western Australia)
Austria	X	X	√
Belgium	√	√	X
Canada	√	√	√
Chile	X	X	X
Colombia	√	√	√
Costa Rica	X	X	X
Czech Republic	X	X	X
Denmark	X	X	X
Estonia	X	X	X
Finland	X	X	X
France	X	X	X
Germany	X	X	X
Greece	X	X	X
Hungary	X	X	X
Iceland	X	X	X
Ireland	X	X	X
Israel	X	X	X
Italy	X	X	X

Country	Voluntary euthanasia	Non-voluntary euthanasia	Assisted suicide
Japan	X	X	X
Korea	X	X	X
Latvia	X	X	X
Lithuania	X	X	X
Luxembourg	√	√	√
Mexico	X	X	X
Netherlands	√	√	√
New Zealand	√	X	√
Norway	X	X	X
Poland	X	X	X
Portugal	X	X	X
Slovak Republic	X	X	X
Slovenia	-	-	-
Spain	√	X	√
Sweden	X	X	X
Switzerland	X	X	√
Türkiye	X	X	X
United Kingdom	X	X	√ (Only in Scotland)
United States	X	X	√ (Only in some states)

Note: √ (euthanasia is legal), X (euthanasia is illegal), – (no information is available).
Source: OECD secretariat.

Some countries are currently discussing their approach to euthanasia. In Australia, Tasmania, South Australia and Queensland are currently working on legislation for assisted suicide which should enter into force between 2022 and 2023. Belgium only allows non-voluntary euthanasia if the person had expressed in advance their will to receive euthanasia. Chile is currently discussing legislation to allow euthanasia and assisted suicide. Ireland is currently discussing the legalisation of assisted suicide. In Israel, according to the law of 2005 on terminally ill patients, withholding treatment is allowed, while withdrawing treatment is not allowed. In Italy in 2021, over a million signatures have been collected to request a referendum on the decriminalisation of euthanasia. In 2022 the constitutional court has denied such request. In Norway, the Act 19 June 2009 no.74 states that “if someone out of pity kills a person who is terminally ill, or who for other reasons is close to death, the punishment may be set below the minimum sentence or to a milder type of punishment than that for murder”. In Portugal there is ongoing work on legislation to decriminalise euthanasia.

Notes

[1] There is heterogeneity across countries in the preferred place of death. Moreover, people's preferences might change as one gets closer to the time of death and preference might be more related to the family's preference than the individual. Nevertheless, home still often remains the preferred place of death.

[2] Identifying people who are approaching the end of life, assessing all needs holistically, supporting carers, providing information, reviewing needs and treatments, planning care in advance, communicating across services and co-ordinating care, providing care in a multidisciplinary manner, transferring people across settings, providing care out-of-hours.

2

Removing barriers to access end-of-life care

This chapter describes current barriers to accessing end-of-life care (EOLC). While most dying people would benefit from EOLC, not all of them receive it, with socio-economic and geographical factors driving inequalities. When people receive EOLC, they often receive it close to death and for a very limited time, due to delays in referral and access. The place where people die often differs from their wishes. Access to EOLC could improve through better workforce recruitment and retention, wider access to services in different settings and earlier identification of needs. Tailoring policies on the needs of vulnerable populations could further reduce inequalities in access to EOLC.

Introduction

The COVID-19 pandemic has brought attention to the lack of proper support for people at the end of life, the fact that access to such care was not always possible and the importance of reducing suffering for those dying. Similarly, the Lancet Commission on Palliative Care and Pain Relief highlighted the important gap in access to palliative care and the large numbers of people still experiencing serious health-related suffering that could be ameliorated by palliative care (Knaul et al., 2018[1]). While a large proportion of the gap in access happens in low- and middle-income countries, the lack of timely access to palliative care for terminally ill patients has also been pointed out in many OECD countries (Palm et al., 2021[2]).

This chapter emphasises socio-economic and geographical inequalities in access to health care and unmet needs in OECD countries in end-of-life care. Inequalities may arise because of differences in mortality risks by socio-economic status, as there are gaps in life expectancy by income and education and higher premature deaths for those more disadvantaged because of higher cardiovascular risk and differences in health behaviour and in health literacy (Bosworth, 2018[3]; Murtin et al., 2017[4]). There are also inequalities in the use of health care at the end of life because geographical imbalances in service provision can lead to more acute and hospital-based end-of-life care and less palliative care in some areas, including those that are less sparsely populated or more economically disadvantaged (French, 2021[5]). Such inequalities in the end-of-life experience can also result in unmet needs whereby some groups in society are less likely to receive services or have special needs that are not well met.

In addition, the chapter highlights the importance of end-of-life care[1] to be offered more broadly. First, it is important to expand training to have a better availability of specialist palliative care services and to overcome delays in referral to such services. Second, expanding generalist training and integrating care of different professionals seems more relevant than ever. To overcome access constraints, the Lancet Commission on the Value of Death emphasises the importance of expanding relevant trainings for health and social care professionals on what are deemed to be core skills (Sallnow et al., 2022[6]). With more professionals competent in caring for dying patients and their families at home, in care homes and in the community, together with access to essential medicines and supplies for relieving symptoms, access constraints could be progressively overcome. Third, timely diagnosis and referral to adequate services should also be improved to ensure adequate access.

The remainder of the chapter is organised as follows. Section 2.1 highlights the sub-principles of an accessible end-of-life care. Section 2.2 illustrates the consequences of current health systems lacking such focus, while 2.3 explores policies and best practices to ensure the well-staffed, equitable, and timely end-of-life care.

Key findings

- While most people at the end of life would benefit from access to services, substantial gaps remain, with fewer than 40% of those in need of palliative care actually receiving it.
- Socio-economic and geographical inequalities in access to care are marked. People with lower schooling are 50% less likely to receive end-of-life care services and more likely to have intensive life sustaining treatment. People in rural areas experience long travel times to reach facilities and lower availability of home care and are less likely to receive palliative care: 40% of people in urban areas receive palliative care versus 33% in rural areas.
- Despite up to 84% of people preferring to die at home in OECD countries, half of deaths still happen at the hospital on average in OECD countries (in 2019). Even if countries are prioritising community services, the availability of end-of-life services at home is not always sufficient in many countries, leading to people being transferred to hospitals.
- End-of-life care is often subject to late identification of needs and referrals, resulting in delays in care access. The mechanisms to ensure timely access to end-of-life care are scarce, with only 29% of countries having national programmes/policies to monitor the time span between referral to EOLC and access to such services and only 15% having indications on the timing for referral. Such delays can result in people receiving EOLC services for a short period: most people receive palliative care one month prior to death, compared with the advice of three to four months.

Policy options

- Countries need to incentivise training opportunities to have sufficient palliative care specialists and design policies to increase retention. Increasing the opportunities for residency positions for doctors in palliative care would be important. Additionally, optimising the scope of practice for different health professionals will be helpful to address current and future shortages. Australia has shown that nurse-led models could be effective, especially in sparsely populated areas. Addressing the retention of professionals will also be important, such as with the use of techniques to reduce burnout, as in the United States.
- It is paramount to improve the availability of trained staff in non-hospital settings, especially in primary and long-term care. Germany has developed the capacity to provide 24h care at home, by creating home teams composed of professionals available in health care settings. Widening the range of professionals who have sufficient general palliative care knowledge can promote a wider access. It also needs to be coupled with support and co-ordination with specialists in case of more complex needs. New Zealand decided to create regional managed clinical networks (MCNs) to combine primary-care teams with support from specialists.
- Countries should also implement nation-wide policies on improving the end-of-life experience of vulnerable populations. As addressing socio-economic inequalities requires a thorough understanding of the needs and challenges faced by vulnerable populations, representatives with lower socio-economic background should be involved in informing policy making on EOLC. The design of adequate co-payment schemes and programmes such as Manchester's homeless health inclusion pathway (MPath) can reduce the distance between vulnerable populations and the health care system. Policies to target remote geographical areas could also successfully reduce the inequalities in access to EOLC services.
- To ensure timely access to EOLC services, countries could improve screening mechanisms to allow for better and earlier recognition of EOLC needs, speed up the referral process and improve the integration of EOLC with other care services. Time targets and guidelines can also help ensuring timely access to care. Ontario, Canada is using automated tools to perform screening while the United States sets timelines.

2.1. Why is it important for end-of-life care to be accessible?

This section outlines why it is critical to ensure sufficient access to care provided by having care that is timely available, with well-staffed and well-distributed services and that is equitable. Each component or sub-principle of the accessible principle (well-staffed, well distributed, equitable, and timely) is discussed.

The first sub-principle is *well-staffed.* The New Zealand Palliative Care Strategy (Government of New Zealand, 2001[7]) emphasises the importance of sufficient palliative care staffing, the Chilean plan places emphasis on having a multi-professional team (Ministerio de Salud, 2009[8]) and Canada's Framework on Palliative Care includes measures to increase training and other supports for health care providers (Health Canada, 2018[9]). Multi-professional teamwork in EOLC is desirable and there is a need to improve the palliative care training of health and social workers (Pulsford et al., 2013[10]), which in turn can improve quality of EOLC.

The second is that EOLC is *well distributed* across settings, allowing people to receive care in their preferred place. Most end-of-life care is currently provided at the hospital, which is the setting where most people across OECD countries die (OECD, 2020-2021[11]). Nevertheless, the person's home is often reported to be the preferred place of death (Agenzia nazionale per i serivzi sanitari regionali, 2010[12]; CIHI, 2018[13]; Calanzani and al., 2017[14]; Gomes and al, 2012[15]). Well-distributed end-of-life care would allow people to access services in the setting of their preference.

The third sub-principle is *equitable,* an issue highlighted in the Framework of Palliative Care in Canada (Health Canada, 2018[9]). The sub-principle focuses on people having access to care irrespective of their diagnosis, social group, socio-economic background, or proximity to death. Currently, service availability and access are not uniform even within countries, with substantial inequalities in access to EOLC services. There are barriers to high quality EOLC because of socio-economic background, as people with limited economic resources often have poorer health and more complex needs. There are also geographical barriers with certain areas having less availability of services. Such inequalities compound over the life-course and are likely to be more acute at the end of life. Across North America, Europe, Australia and Asia, people living in the most deprived neighbourhoods were more likely to receive acute hospital-based care in the last three months of life, and to not receive specialist palliative care (Davies et al., 2019[16]).

The fourth sub-principle is that EOLC resources and services are *available in a timely manner*. It refers to the existence of services that individuals can utilise at the right time for them and adapted to their circumstances. Timely palliative care may be associated with improved quality of life and EOLC (Murray et al., 2005[17]). Additionally, due to limited care infrastructure, as well as some individuals having limited care needs around the time of diagnosis, focus is placed on what the right level of intervention and the right time is for the individual (Hui et al., 2018[18]; Hirvonen et al., 2020[19]).

2.2. The consequences of inadequate access to end-of-life care

2.2.1. There are substantial gaps in the supply of services with respect to needs

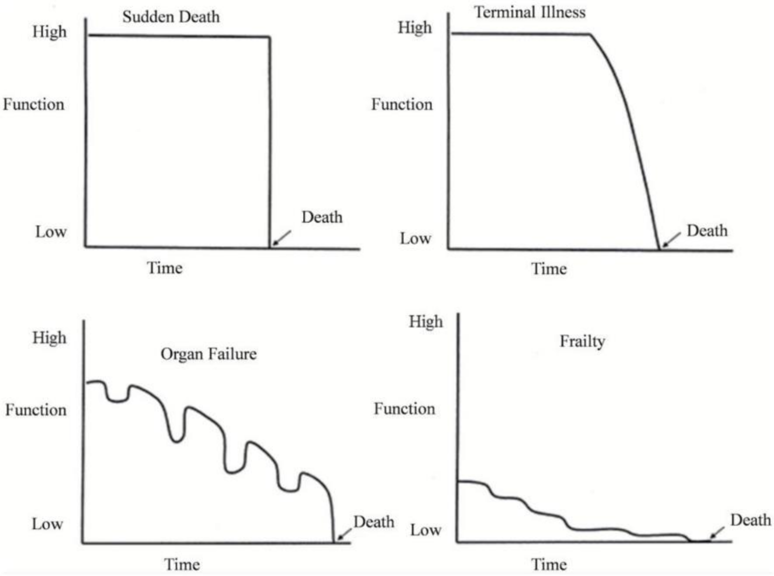
While two-thirds of people dying would need palliative care, they do not always receive it. Only half of the palliative care needs are actually satisfied in OECD countries. Estimates suggest that around 7 million people would need palliative care across OECD countries in 2019 and the number is even higher when considering the relatives of the dying people, who would also benefit from support.

The majority of those dying have palliative care needs

People who require end-of-life care have different underlying conditions which can influence the timing and duration of needs. To understand this aspect, the idea of "trajectories of dying" were first articulated in the late 1990s and map the course of decline, or the path the illness takes toward death and the speed with which it progresses. Four main trajectories of death have been identified in the literature: i) sudden death; ii) terminal illness; iii) organ failure; and iv) frailty (Lunney, Lynn and Hogan, 2002[20]) (see Figure 2.1). These are defined as follows:

- **Sudden deaths** include mainly accidents and other external causes, usually with almost no evidence of functional decline and relatively low health care expenditure growth.
- **Terminal illness** commonly refers to cancers, which have very little decline a year before death, and a drastic decline about 3 months prior to death, with costs rising particularly in the last 6 months.
- **Organ failure** includes heart failure, Chronic Obstructive Pulmonary Disease, and liver failure, often have a fluctuating pattern of decline in the years prior to death, and a drastic decline in the last 3 months of life. Costs related to organ failure are higher on average than the other trajectories in the 2 years prior to death, gradually increasing in the last 6 months.
- **Frailty** encompasses diseases such as dementia, and Parkinson's, which have involved a gradual decline in condition in time. Frailty normally involves relatively low expenditure that gradually increase through the years closest to death, except for dementia.

Figure 2.1. Theoretical trajectories of disease at the end of life



Source: Reproduced from (Lunney, Lynn and Hogan, 2002[20]).

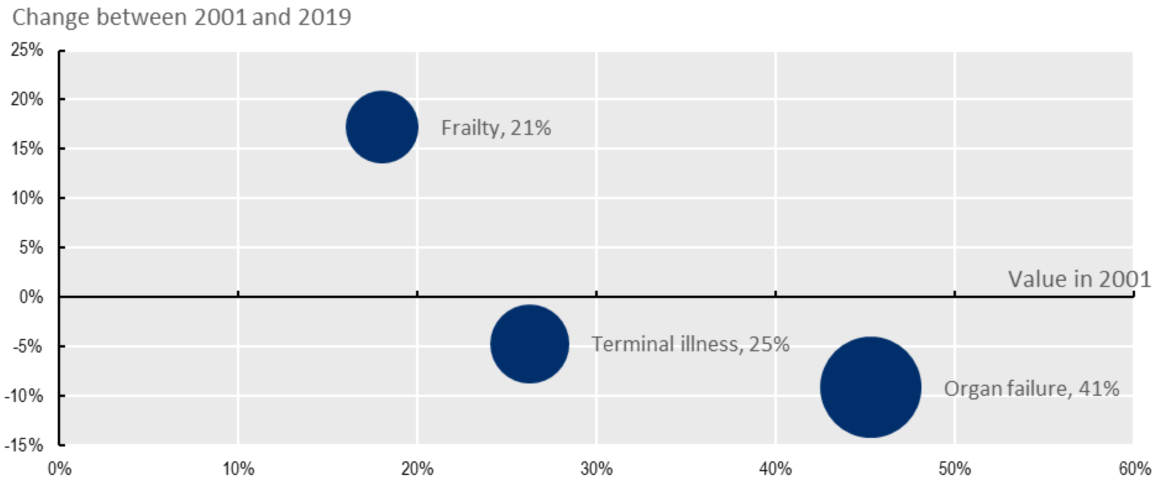
Nearly 90% of all deaths occurring in OECD countries between 2001 and 2019 are caused by organ failure, frailty or terminal illnesses, for which individuals might benefit from EOLC. Classifying mortality statistics according to the trajectories, Figure 2.2 shows that in 2019, 41% of all deaths were caused by organ failure (which mainly includes heart diseases), 25% by terminal illnesses (which mainly includes cancer), and 21% by frailty (which mainly includes Alzheimer's disease and other dementias).

The three main death trajectories have shown different trends over time. In 2019, despite its slightly decreasing trend, organ failure remains the biggest cause of death, accounting for 41% of all deaths. Frailty is becoming increasingly important due to population ageing. Nevertheless, part of the increase in the deaths reported as frailty can be attributed to a recent change in the coding practices for dementia and Alzheimer's disease, which have been increasingly recognised and coded as the main cause of death

(Roth et al., 2018[21]). This phenomenon arises from three factors: a growing propensity among physicians in north-western European countries to code dementia as the underlying cause of death, a change in the WHO guidance in 2001 on the choice of the underlying cause of death and two coding changes in 2011 and 2014, which increased the level of detail for coding dementia as the leading cause of death. For instance, the change in 2011 allowed coding vascular dementia as such, instead of the more general "cerebrovascular disease (unspecified)" (University of Oxford, 2016[22]). Terminal illness has remained comparatively stable, representing around 25% of all deaths in the period analysed (2001-19).

Figure 2.2. Trend in death's trajectories requiring EOLC in OECD countries, 2001-19

Percentage change in death trajectories (2001-19)



Note: The data include 30 OECD countries for 2001 and 28 for 2019. Greece, Ireland, Portugal and Türkiye are excluded from both years for insufficient data. The dimension of each bubble shows the percentage of deaths for each trajectory in 2019, which is also reported on the labels. The position of the bubble on the X-axis represents the percentage of deaths for each trajectory, in 2001. The 0% line represents the base value in 2001, while the distance between each bubble and the 0% line shows the percentage change in the number of deaths within each trajectory between 2001 and 2019, with this value reported on the Y-axis.
Source: WHO mortality database (WHO, 2019[23]) and (Qureshi et al., 2018[24]) for the definition of the EOLC death trajectories.

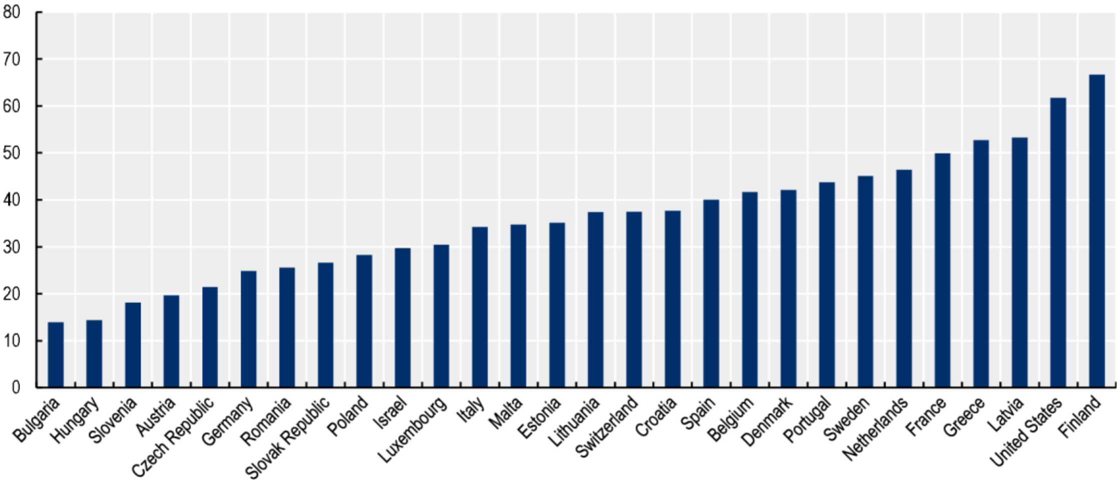
The OECD estimates that the total number of those dying and in need of palliative care amounted to almost 7 million people in 2019 (see Annex 2.A). Such estimates are based on the three trajectories discussed above (terminal illness, organ failure and frailty) and on the pain prevalence associated with those, amounting to 64% of total deaths having, on average, palliative care needs (Etkind et al., 2017[25]). More precisely, for diseases classified as organ failure the pain prevalence corresponds to 67% (meaning that 67% of all organ failure deaths live in a situation of pain as to require physical care for the management of these symptoms). This percentage is estimated to be 84% for terminal illness and 60% for dementia.

Not all those who need palliative care receive it

On average less than 40% of people in need of palliative or end-of-life care actually receive it (Figure 2.3). Survey data on the share of people aged 65 or older receiving palliative care before death shows nonetheless great differences across countries, ranging from around 15% in Bulgaria and Hungary to 65% in the United States and Finland of people receiving palliative care before death.

Figure 2.3. Mean percentage of people using palliative care or hospice for the deceased who died at age 65 or over by country

Share of people who used hospice or palliative care before dying at age 65 or older



Note: Weighted using cross-sectional weight from last core interview.
Source: Survey of Health, Ageing and Retirement in Europe (SHARE – Waves 7-8), Health and Retirement Study (HRS – Wave 14).

OECD estimates on the palliative care gap are aligned with what has been published for other countries. For instance, a study on the provision of palliative care in Colombia has estimated that current palliative care services are able to cover around 30% of the needs on average, with regional variation (Sánchez-Cárdenas et al., 2021[26]). In France it is estimated that 24% of people experiencing acute stroke are receiving palliative care, 23% among those with multiple sclerosis and 17% of people with CHF or dementia (Ministry of Health France, 2022[27]). Data from Ireland report that around two-thirds of people who die every year, who might benefit from end-of-life care in their last year of life, do not receive it (Irish Department of Health, Social Services and Public Safety, 2010[28]). In Portugal, the strategy for developing palliative care services estimates that the current community support palliative care teams are half of those needed to satisfy demand (Comissão Nacional de Cuidados Paliativos (CNCP), 2019[29]). In 2022-23 in Portugal there will be 10 more palliative care teams, which are estimated to cover about three-fifths of need. For the 12 OECD countries for which administrative data is available, gaps in care demonstrate that more than half a million individuals potentially in need of care did not receive services (see Annex Table 2.A.1 and Annex Table 2.A.2).

2.2.2. Inequalities in access persist

> *There are marked inequalities in the care that people receive at the end of life linked to socio-economic factors*

There is a large social gradient in health outcomes and this gradient is also apparent at the end of life. Lower socio-economic status is usually associated with higher rates of disability and diseases, implying more complex needs and a higher need of care at the end of life (Davies et al., 2021[30]; Davies et al., 2019[31]; Simon et al., 2016[32]; Walsh and Laudicella, 2017[33]). Previous OECD work also illustrated that those less educated are more likely to suffer from overweight and obesity and be exposed to risk factors such as smoking. These inequalities compound over the life cycle and the least well-off and the least educated have a higher risk of dying prematurely than those who face more favourable socio-economic circumstances (Michael Marmot, 2020[34]). As a result, large inequalities in life expectancy exist by socio-economic status including education level, income, or occupational group (OECD, 2019[35]).

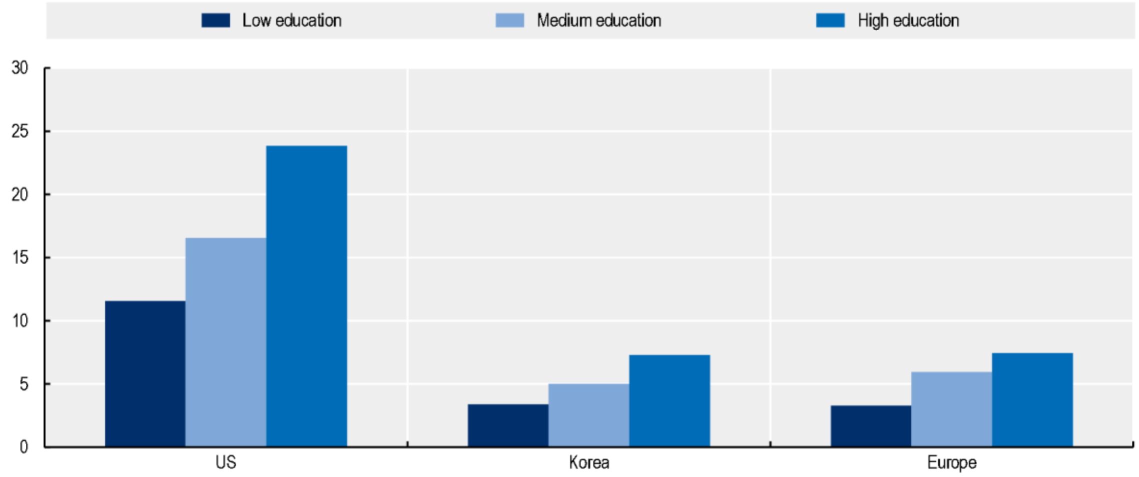
In addition to poorer initial health and risk factors which result in greater health needs, there are also socio-economic inequalities in health care services utilisation. Overall, it seems that people with a lower socio-economic position have increased symptom burden and higher difficulty navigating complex health care systems at the EOL but also limited formal and informal social support. As a result, they are less likely to participate in advance care planning, are substituting emergency care for elective care and are also more likely to receive intensive treatment at the end of life (Bowers et al., 2022[36]). Contrary to evidence that there is no socio-economic difference in the probability of hospital use throughout the life-course, there is a higher likelihood of using acute care among people with lower socio economic status at the end of life (Lewis et al., 2011[37]). Studies have found that people with lower socio-economic status were less likely to access formal health care services before death (Cárdenas-Turanzas et al., 2011[38]; Choo et al., 2007[39]; Mai et al., 2018[40]). A comprehensive systematic review on the way the socio-economic position influences the care people receive at the end of life has shown that lower socio-economic status is associated with higher likelihood of dying in the hospital and lower likelihood of receiving specialist palliative care in the last year of life (Davies et al., 2019[31]). More specifically, compared with people in the highest socio-economic position, people with the lowest socio-economic position were 3% more likely to die in hospital than at home or in a hospice (pooled odds ratio from 31 studies: 1·30, 95% CI 1·23-1·38) (Joanna M Davies, 2021[41]). Such inequalities in access and treatment also result in higher overall end-of-life care costs (Yu, Alavinia and Alter, 2020[42]).

Inequalities are particularly apparent with respect to palliative care services. There is evidence that people with lower education experience lower quality in end-of-life care and a shorter time between diagnosis of a life-limiting disease and death. Lower socio-economic status also seems to be correlated to higher levels of pain associated to an illness (Rowley et al., 2021[43]). Figure 2.4 shows that there is a gradient between education levels and access to EOLC, with higher education levels more likely to receive hospice or palliative care.

There are various explanations for such inequalities in health care service utilisation (OECD, 2019[35]). First, these inequalities can be driven by financial barriers to health care access and the ability to pay for care. For people on low income, health expenses due to illness can easily become an increasing and substantial fraction of their total income and end-of-life care expenses can be catastrophic (Bowers et al., 2022[36]). Studies also suggest that, despite the financial burden, financial support is not always reaching patients and families. Second, health literacy and information about health care, such as awareness of illness and about availability and efficacy of health care services, may vary across population. For instance, people with higher education were more likely to know their prognosis and choose comfort treatment and more likely to discard invasive sustaining treatment such as chemotherapy, intubation, use of mechanical ventilation and cardiopulmonary resuscitation (Bowers et al., 2022[36]).Third, availability and quality of care may also be influenced by area of residence and linked to socio-economic status. Finally, housing conditions suitable for supporting care at home might also be influenced by the same factors. Receiving palliative care services at home might not be a feasible option for some people whose house does not have the required conditions (e.g. space and safety) to host the needed equipment and to receive care safely (Rowley et al., 2021[43]).

Figure 2.4. People with higher education levels are more likely to receive end-of-life care

Share of people aged 65 or older receiving hospice or palliative care, by education



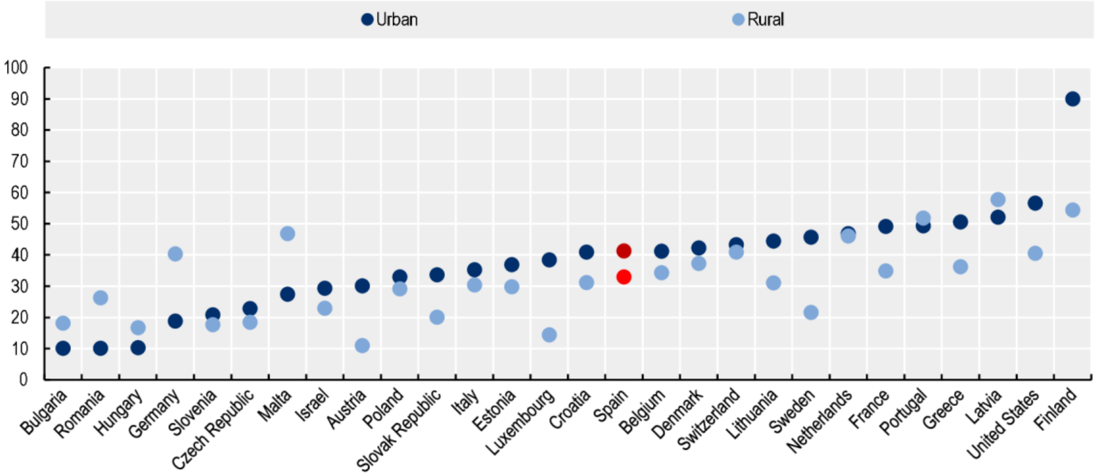
Note: Data from Europe are weighted using cross-sectional weight from last core interview. Europe includes 19 European countries. Some countries are excluded because of low observations. Low education includes people with no schooling, medium education includes people with primary and middle school degrees, high education includes people with high school or college degree.
Source: Survey of Health, Ageing and Retirement in Europe (SHARE – Waves 7-8), Health and Retirement Study (HRS – Wave 14), Korean Longitudinal Study of Aging (KLoSA – waves 2-7).

Access to care is more challenging in remote and deprived geographical areas

There are also inequalities in end-of-life care by location. Evidence from the United States and the United Kingdom suggests that there can be a 20-year gap in life expectancy between more affluent and more deprived areas (Rowley et al., 2021[43]). The VOICE survey in the United Kingdom shows that 29% of people living in most deprived areas reported end-of-life care to be fair or poor, higher than among people living in least deprived areas (22%) in 2015 (ONS, 2016[44]). A systematic review on access to hospice care in Australia, Canada, New Zealand, and the United Kingdom has found that people living in more deprived areas, together with people living in rural areas are less likely to access hospice care (Tobin J, 2022[45]). In Colombia, the majority of palliative care services concentrated in the regions of Bogotá D.C. and Antioquia while the eight Colombian regions that showed the lowest development are located in jungle areas, showing a clear imbalance between rural and urban areas across the country (Sánchez-Cárdenas et al., 2021[26]). Figure 2.5 shows that in most countries people aged 65 or older living in rural areas are less likely to access palliative care before dying, compared to those in urban areas.

Figure 2.5. People living in urban areas are more likely to access palliative care before dying

Share of people who used hospice or palliative care before dying at the age of 65 or older, urban vs rural



Note: Data from Europe are weighted using cross-sectional weight from last core interview. Use of palliative care or hospice is only available for Waves 7-8 (2017-20) of SHARE and Wave 14 (2018-19) of HRS.
Source: Survey of Health, Ageing and Retirement in Europe (SHARE – Waves 7-8), Health and Retirement Study (HRS – Wave 14).

There are several factors that explain geographical disparities in access to end-of-life care. Location and distance to services, the number of facilities providing hospice services, the driving times required for nursing and other staff to make home visits, and access to equipment and supplies are several reasons which drive inequalities (Rainsford et al., 2017[46]). People living in remote areas and experiencing serious health issues might not be able to face long travel times to reach the closest service provider. In the United States, only 17% of rural hospitals have palliative care programs compared with 90% in cities (Center to Advance Palliative Care, 2019[47]). At the same time, home care services are less available in rural areas due to long distances, while health workers are usually less widely available in smaller and rural areas, compared to urban conglomerates (Lalani and Cai, 2022[48]; Rowley et al., 2021[43]). Further evidence also shows that people who live closer to inpatient facilities providing EOLC are more likely to die in those facilities, showing that the geographic area of residence influences where people receive care and die (Chukwusa et al., 2019[49]). People living in rural areas are thus less likely to receive palliative care and more likely to receive aggressive care at the end of life (Conlon et al., 2019[50]). In Australia, people in rural and remote areas are less likely to die at home because of lack of available options and delays in care (Handley, 2019[51]). People in less affluent areas had less access to hospice care, had less home visits, were less likely to be referred to palliative care services and might suffer from transportation difficulties (Lewis et al., 2011[37]). Primary care teams in the United Kingdom provide less out of hours palliative care in areas of high deprivation than more affluent areas (Fisher, Lasserson and Hayward, 2016[52]).

Availability of palliative care services in rural areas is related to overall shortages of physicians in rural areas. A study from the United States found that the number of physicians in a county was a significant factor in whether a hospice (or palliative care services) was located there (Campbell, Merwin and Yan, 2009[53]). Across OECD countries, the number of doctors per capita tends to be much lower in rural/remote areas and in deprived urban areas. On average across 14 OECD countries in 2019 there were 4.7 physicians per 1 000 population in urban areas, against a rate of 2.9 in rural areas (OECD, 2021[54]). **Demographic change is contributing to widen territorial disparities in access to services.** Rural ageing, namely larger shares of older populations living in rural areas compared to urban conglomerates, is resulting in a growing need of care, including end-of-life care. At the same time, the rural ageing also drives the lack of health care providers in rural areas, as young health care professionals are more and more likely to move towards urban areas (McEldowney, 2020[55]) (Skoufalos et al., 2017[56]; Hospice UK, 2021[57]).

2.2.3. People rarely die where they want

Most OECD countries recognise the need to provide EOLC across various settings of care. The totality of surveyed OECD countries (26) foresees the provision of EOLC services within hospital settings and at the patients' home, 77% in hospice and 69% in nursing homes (OECD, 2020-2021[11]). Nevertheless, this does not translate in practice into the possibility for people to choose where to receive care at the end of life and where to die. The place of death does not always align with people's preferences on where they hope to die. Despite most people preferring to die at home, hospital is still the most common place of death in OECD countries.

Where people prefer to die

Analysing people's preferences for place of death can be challenging, since they can change over time, particularly when death becomes imminent (Gerber, Hayes and Bryant, 2019[58]; Vidal, 2015[59]) and they can be influenced by many factors such as certainty around the individual's health status and relationship with carers. As an example, people sometimes prefer not to die at home because of the burden it places on carers (Gerber, Hayes and Bryant, 2019[58]).

Nevertheless, home is often indicated as the patients' favourite place of death, while non-hospital health care facilities are among the least preferred settings to die (Agenzia nazionale per i serivzi sanitari regionali, 2010[12]; CIHI, 2018[13]; Calanzani and al., 2017[14]; Gomes and al, 2012[15]). While it seems that preferences for home death reduce as death nears, they do so only marginally, with most people retaining their initial intention (Vidal, 2015[59]). For example, evidence from advanced cancer patients indicates that home remains the preferred place of death in 65% of cases and that preferences barely change over time (Vidal, 2015[59]). International studies on preferences for place of death reveal that the preference for home death ranges from 51% in Portugal to 84% in the Netherlands (CIHI, 2018[13]; Calanzani and al., 2017[14]; Gomes and al, 2012[15]). Conversely, non-hospital health care facilities are the least preferred place of death in Italy, Netherlands and Spain, and the third least preferred place to die in Belgium (Flanders) (Calanzani and al., 2017[14]) and Sweden (Westerlund et al., 2018[60]).

Hospital is most often the actual place of end-of-life care and of death

Some gaps in access to EOLC relate to the place of care. Table 2.1 shows the number of patients receiving EOLC in different settings, including hospital, hospice, nursing homes and the patient's home. Data is fragmented but shows that in most countries EOLC is most often received in hospitals. Differences in the way data are collected and gaps in data availability (see the notes below the table) might hamper comparisons, but evidence in the literature is in line with such result. For instance, data from Canada show that only a minority of patients who die in LTC facilities receive end-of-life care in the last year of life: among those who were expected to live less than 6 months, only 22% received palliative care in the last year of life compared to other settings (CIHI, 2018[13]).

Table 2.1. Number of people receiving EOLC care by location

Country	Year	Hospital	Hospice	Nursing homes	Home
Australia	2017	79 932		4 793	
Belgium	2019	16 879			20 028
Canada	2019	116 666		35 218	61 531
Iceland	2020	667			57
Korea	2020	18 913		2 214	
Luxembourg	2014	1 590	118		
Norway	2020	9 997		20 267	5 330
Slovenia	2020		60		400
United States	2018		1 550 817		

Note: For Denmark, Lithuania and Israel, data refer to the number of patients receiving palliative care services, among those who died for all causes, excluding external causes of death (all ICD-10, except V00-Y99). For Australia, data report the numbers of palliative care-related hospitalisations and the number of permanent aged care residents assessed as requiring palliative care. For Belgium, data include all patients for whom the GP has asked for "forfait palliatifs". For Canada, data includes all death discharges from LTC facilities in 6 reporting provinces and a territory (YN) and does not include retirement facilities that are exclusively privately funded. Home care data are from 8 Canadian provinces and one territory, the year of data may vary. For the United States, data provided is limited to Medicare beneficiaries (65+ and some people with disabilities) who used hospice services.
Source: (OECD, 2020-2021[11]).

Across OECD countries hospitals are the predominant place of death, accounting for more than 50% of deaths on average in 2019, ranging from 20% in the Netherlands to more than 70% in some countries such as Japan and Korea (Figure 2.6). The different shares of hospital deaths are driven by different factors across countries. In the Netherlands, where the share of hospital deaths is lowest, long-term care facilities and private homes play an important role, counting 36% of deaths happening at home and 35% in long-term care facilities (2017 data). Similarly, in 2018 in Switzerland, 36% of deaths took place in long-term care facilities. In Norway, the share of deaths in non-hospital institutions increased from 40% to 46% between 2001 and 2011. Home deaths are most common in Chile (47% in 2017), and the share is growing in Korea, the United States (23% in 2001; 31% in 2018) and the United Kingdom (19% in 2006; 24% in 2018) (OECD, 2021[54]). Deaths in other facilities (e.g. hospices, nursing homes, long-term care facilities, residential care centres) have increased in Belgium, France, Ireland, Japan, and Norway. For more information about the data on place of death see Box 2.1

Box 2.1. Data on the place of death

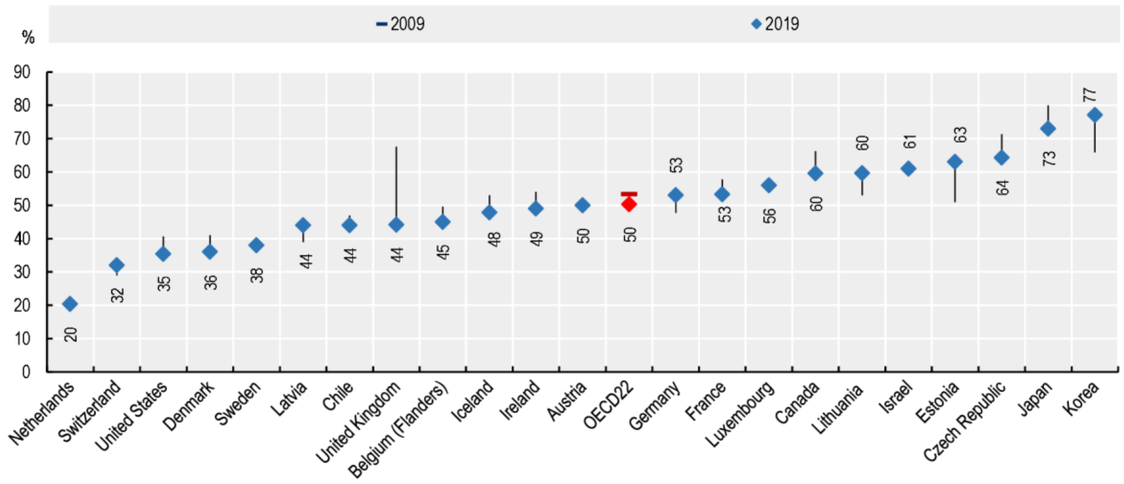
Place of death is widely considered a measure of overall end-of-life care quality and the patient's home is often considered the preferred place of death. In the literature, there is much discussion regarding the difference between place of death and place of care, as well as which one is the best measure of good end-of-life care. This work focuses on the place of death, for which data is more widely available and includes information on the patients' preferences on place of death. This will measure potential access issues to certain places of death. It will also represent a measure of how often the patients' wishes are considered in decisions on the end of their life.

Data on the places of death have been obtained through desktop review and the OECD HCQO-EOLC data collection in 2020-21.

Between 2009 and 2019 there has been a decreasing trend, with the OECD22 average share of people dying at the hospital decreasing from 53% to 50%. In 12 of the analysed countries there was a decrease in hospital deaths, with the United Kingdom experiencing a particularly drastic change. Only six countries registered a higher share of people dying at home in 2019 in comparison to 2009. A shift towards higher shares of deaths in care homes and private homes needs to be accompanied by the change in resources to ensure quality of death. More recently, the COVID-19 crisis has also led to an increase in home and nursing home deaths in some countries, especially in the United Kingdom, but it was challenging to maintain care quality with such a sudden shift toward community settings (Thomas, 2021[61]).

The reasons for the dichotomy between preferences and actual place of death are often the lack of necessary resources for home death. Getting palliative care at home in the year before death increases the chances of dying at home. In Canada, people who received palliative care at home were 2.5 times more likely to die at home compared to Canadians receiving regular home care. Many palliative care service providers experience under resourcing for both staff and equipment, especially in rural and remote areas. Several other barriers to receiving palliative care at home or in nursing home can influence the probability of hospital deaths: a lack of afterhours support, incentives for general practitioners to provide home visits, and a lack of co-ordination between hospitals and community-based services (Handley, 2019[51]). Beyond resources, studies have pointed out that place of death might be misaligned because unawareness or changing preferences. Indeed, family members might not be aware of people's preferences and that people might not want to impose a high burden on their family caregivers.

Figure 2.6. Trends in hospital death rates, 2009-19 (or nearest year)



Source: (OECD, 2021[54]).

2.2.4. Access to services is often delayed and for a short duration

End-of-life care is often subject to late identification of needs in their disease trajectory. Clinical predictions of death are not very accurate and prognostic uncertainty can be a barrier to timely assessment of palliative care needs. Studies have found that less than 10% of those who end up dying within the year have an annual mortality probability above 50% (Einav et al., 2018[62]). With a growing population dying from chronic progressive diseases following a less predictable trajectory, identifying care needs is becoming even more challenging. Most screening tools[2] use prediction of death and/or deterioration as a proxy for the identification of people who are likely to have unmet palliative care needs but usually perform poorly in prognosis and accuracy. For instance, recent evaluations of the "Surprise Question" (i.e. Would you be surprised if this patient died in the next 12 months?), have shown that it has variable accuracy as a screening tool, and as such, it should not be used in isolation as an identification tool (White et al., 2017[63]).

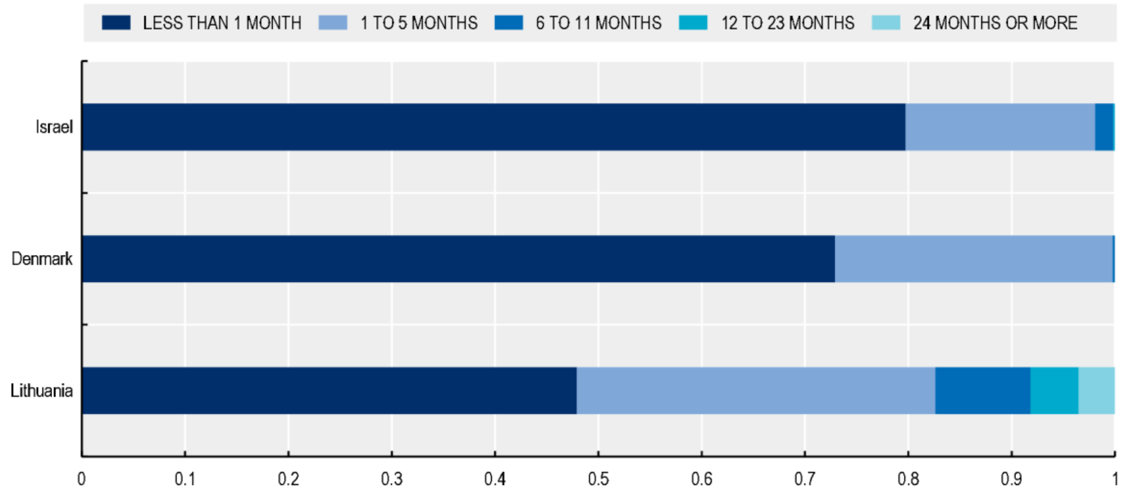
Referral to services and specialists is also happening at a late stage in the process of dying. Palliative care is often only offered late in the course of disease after curative measures have been exhausted. A nationwide study in the United Kingdom showed that the median time between referral for hospice palliative care and death was 48 days and approximately 40% of referrals were made within 30 days of death. Average times between referral and death was particularly short for people with stroke and dementia, at around nine days. This is in contradiction with international guidelines for cancer care, for instance, where the recommendations are for a referral within eight weeks of diagnosis and the guidance to have individualised plans for all patients (NIHR Dissemination Centre, 2018[64]). Part of the reasons for delays in referrals might be related to difficulties for doctors to make adequate prognosis on death and lack of adequate diagnostic for end-of-life care service, as discussed previously, but also to stigma from families and patients, and to supply constraints (insufficient specialists), (NIHR Dissemination Centre, 2018[64]).

Even when people have been referred, there are still delays in the access to the first consultation. Countries with available data report median waiting time between referral and first contact to vary between one and 12 days in 2019. In Slovenia the median waiting time is one or two days, in Canada[3] three days, in Iceland[4] it is one day for palliative care consulting team, 4.6 for palliative care unit and 12 days for palliative home care (OECD, 2020-2021[11]). In Canada, in 2016-17 to be discharged from acute care to non-acute care to receive palliative care, patients wait a median of nine days. Nearly half of them (47%) die while they are waiting, while some of them are transferred to another acute care facility (4%) or go home without support (2%) (CIHI, 2018[13]).

As a result, despite evidence that early integration of specialist palliative care can improve quality of life, the duration of palliative care before death for patients with life-limiting illness is much shorter than what is recommended and supported by evidence. Previous studies suggest that providing at least three to four months of palliative care provides maximum benefit. In contrast, across countries, the median number of days was 29 days and there is wide variation in the duration of palliative care received before death across countries, ranging from 9 days in Australia to 69 days in Canada (Jordan et al., 2020[65]). OECD analysis found that more than half of people receive palliative care services only in the last month of life. The share of people receiving palliative care services for less than a month corresponds to 48% in Lithuania, 73% in Denmark and 80% in Israel. Furthermore, no-one receives palliative care for more than one year in Israel and Denmark (Figure 2.7).

Figure 2.7. Most people only receive palliative care services for less than a month before death

Share of people receiving palliative care, by length of stay



Source: (OECD, 2021[66]).

2.3. How can countries move towards making end-of-life care more accessible?

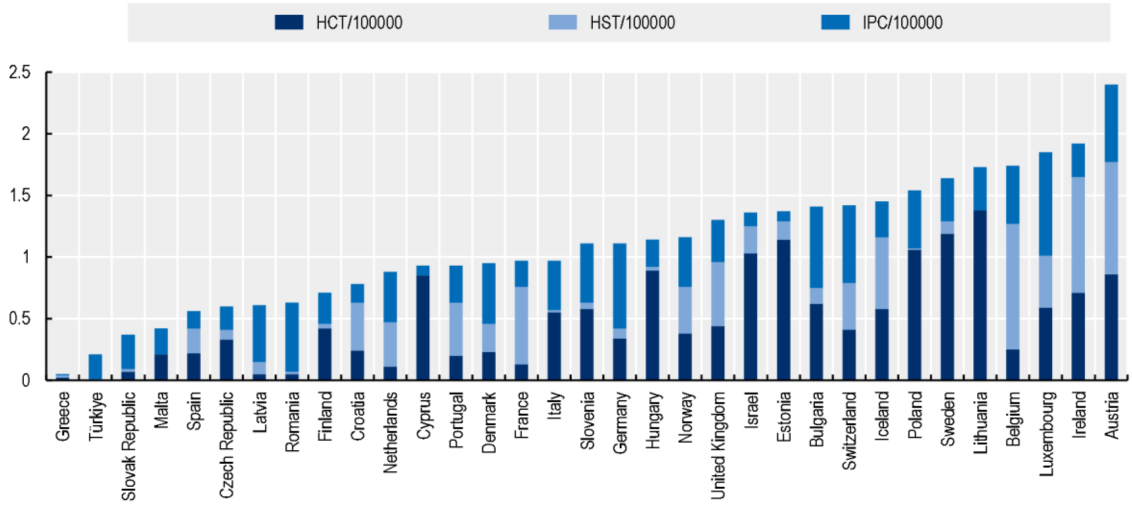
2.3.1. Expand access by improving availability of staff

This section describes examples of policies implemented across countries to increase the availability of adequate staff levels with end-of-life care knowledge. Countries have started to develop workforce planning and increasing end-of-life care training for specialists, but working conditions hamper the attractiveness of the sector. In addition, countries are working on new models of care to ensure adequate general palliative care knowledge by having sufficient staff in all settings and designing strategies to reach more vulnerable populations for whom there are more gaps in access. Best practices are also emerging in early identification of needs and early referral to adequate services, ensuring timely access to care.

Current staff levels for specialised palliative care teams are insufficient

In the past 15 years, specialised service provision increased throughout OECD countries, yet it still seems to fall short in several OECD countries. Central and Eastern European countries showed significant improvement in home care teams and inpatient services, while Western European countries showed significant improvement in hospital support and home care teams (Arias-Casais et al., 2020[67]). The European Association for Palliative Care recommends 0.5 hospital support teams (HST) and 0.5 inpatient palliative care services (IPC) per 100 000 inhabitants and 1 home care team (HCT) per 100 000 inhabitants, but no European country meets all these three goals (Figure 2.8). Austria, Ireland, Luxembourg, and Belgium are among the countries with the most teams available, while Greece, Republic of Türkiye and the Slovak Republic stand on the lower end. In 2022, the Portuguese national health care system included more hospital palliative care teams than home palliative care teams (45 vs 33), and there are also 27 palliative care units in hospital (237 beds) and 14 palliative community units (OECD, 2020-2021[11]).

Figure 2.8. Home care teams, hospital support teams and inpatient palliative care teams in European countries, 2019



Source: (Arias-Casais et al., 2020[67]).

The skill-mix in palliative care differs also widely across countries, signalling different ways of organising the delivery of palliative care and the distribution of tasks among professionals. Countries record wide differences in the number of specialised palliative care doctors and nurses. The number of specialised palliative care doctors per 1 000 deaths ranges between 0.20 in Japan to 4.11 in Luxembourg, while the number of specialised nurses per 1 000 deaths varies from 0.89 in Iceland to 22.67 in Australia (Table 2.2).

Table 2.2. There is wide variation in the availability of specialised palliative care staff across OECD

Number of specialised palliative care doctors and nurses per 1 000 deaths for all causes excluding external causes of mortality (all ICD-10 codes, except V00-Y99)

Country	Specialised palliative care doctors	Specialised palliative care nurses
Australia	1.72	22.67
Belgium	-	11.58
Canada	4.05	-
Iceland	-	0.89
Japan	0.20	1.90
Luxembourg	4.11	21.96
Norway	1.73	-
United States	2.67	-

Note: Data for refers to 2014 for Canada and Luxembourg, 2018 for Australia and 2020 for all other countries.
Source: (OECD, 2020-2021[11]).

Workforce planning and increased training can help improving recruitment

Workforce development and future workforce planning are important avenues to address shortages and avoid future gaps. Three-quarters of OECD countries (18 of 24 countries providing data) have developed specialisations in palliative care medicine that are available and officially recognised for physicians but the numbers being trained and choosing that speciality might still be insufficient in many countries. Research from the United States shows that maintaining the status quo in terms of training is unlikely to provide enough workers to keep up with population ageing and concerns over future oversupply are unlikely (Kamal et al., 2019[68]). Canadian data highlights that given population projections on the number of dying persons and the type of diseases, in Nova Scotia, a 64% increase of specialist palliative care teams including nurses, physicians and social workers would be needed to address current gaps and 13% more would be needed in the next 20 years (Taghavi and al., 2021[69]). As for other medical professions, countries need to train enough to meet future needs and it is a fine balance to expand training places to address shortages while preventing a risk of oversupply in the future.

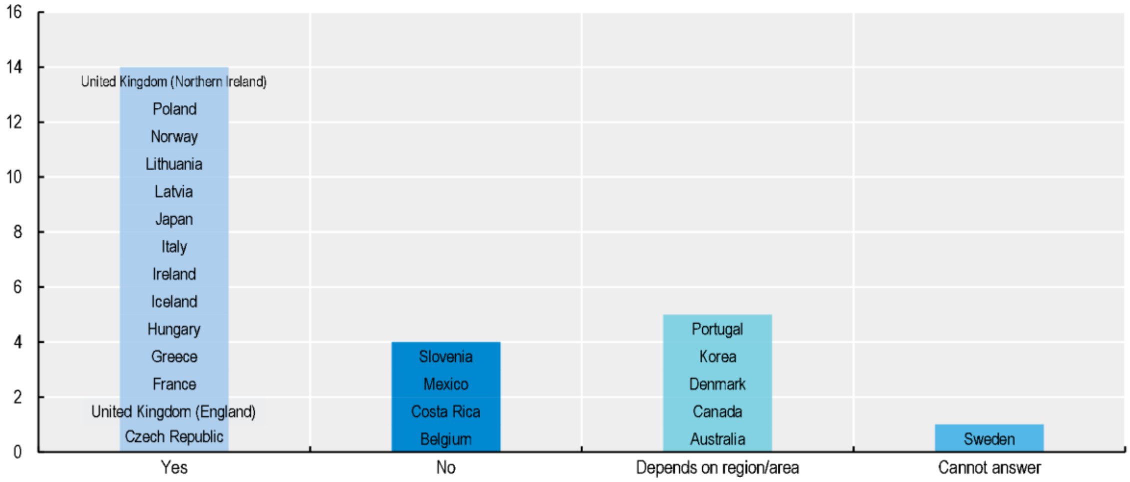
Some countries are thus increasing the availability of training to become palliative care specialists. In 2021 Italy has established the first school of medical specialisation in palliative care (Decree of 28 September 2021). Beyond increasing graduates, one possible avenue to encourage staying in the sector is to fund the development of physician-leaders through palliative care academic career development awards (Kamal et al., 2019[68]; Lupu et al., 2018[70]). The Palliative Care and Hospice Education and Training Act, which was reintroduced in the US House of Representatives in 2022 would fund the development of physician-leaders through palliative care academic career development awards and would provide salary support for early-career physicians to develop clinical, educational, and research expertise and grow into leadership roles (Kamal et al., 2019[68]).

To increase access more widely, it would also be important to optimise the scope of practice of different health care providers, with a view to make the best use of their qualifications and skills. Palliative care training is more embedded within nursing school education, with nearly three-fifths (58%) of responding

OECD countries (14 of 24) reporting that undergraduate nursing school curricula includes mandatory palliative care training, and a further 5 (21%) reporting that palliative care training in undergraduate nursing programs is mandatory in at least some regions of the country (Figure 2.9). Nurses constitute thus a potential resource to expand access to palliative care.

Figure 2.9. OECD countries reporting mandatory palliative care training in undergraduate nursing school curricula

Countries answers to the question "Do nursing schools include mandatory palliative care education in undergraduate curricula?"

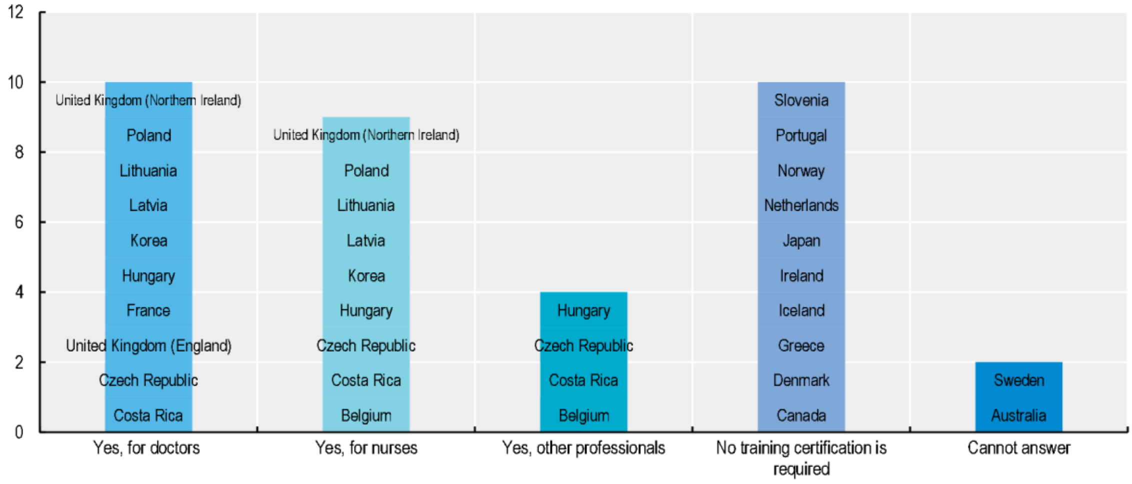


Source: (OECD, 2020-2021[11]).

Countries can reduce barriers in the scope of practice and ensure that innovations in advanced practice and nurse-led models of palliative care can effectively bridge gaps in health care service delivery. Further training of nurses through additional funding might be necessary to improve their knowledge base (Rosa et al., 2022[71]). The European Association of Palliative Care (EAPC), for instance, recommends three educational levels for nurses: basic education in palliative care for all nursing professionals, intermediary education for nursing professionals who frequently care for patients at the end of life (adults and children), and specialised education for nursing professionals. Korea has general hospice palliative care nurses and hospice advance practice nurses trained as master's-level advanced nursing professionals. In Australia, there is positive evidence of nurse-practitioner-led models in palliative care: an evaluation of a pilot project whereby palliative care trained nurse practitioner working together with GPs in rural setting resulted in early intervention of palliative care and hospital avoidance (Mitchell et al., 2016[72]). The Australian College of Nursing has designed an implementation toolkit for establishing such nurse-led models (ACN, 2020[73]). Since 2013 Belgium is incentivising the use of hospital nurses with a palliative care qualification who are working in palliative care by providing them with a bonus (Service Public Federal Belgum, 2017[74]).

Adequate knowledge and staffing of different health professionals might also be important to provide multidisciplinary specialised care. Currently, basic training in palliative and end-of-life care is far from universal. Across 23 responding OECD countries, training certificates were most likely to be required for doctors (10 of 23 countries) or nurses (9 of 23 countries) working in the field of palliative or end-of-life care, with far fewer countries – just four – reporting that training requirements existed for other health and social care workers providing palliative and end-of-life services, including social workers and personal care workers (Figure 2.10).

Figure 2.10. OECD countries where a training certificate is required to work in palliative care and/or end of life care services



Note: ‘Other professionals’ include psychologists, psychotherapists, radiotherapists, physiotherapists, paramedics, social workers, personal care workers, and others.
Source: (OECD, 2020-2021[11])areas (Hansford, Thomas and Wyatt, 2022[75]).

Supporting specialist palliative care doctors and nurses with other staff is increasingly recognised in strategies and plans. For instance, Ireland in its National strategy has recommended a review of staffing needs for health care assistants to meet certain ratios. It is also emphasised that as palliative care is provided early in the disease trajectory, giving additional importance to rehabilitative palliative care and adequate staffing of professionals will be needed. The Irish Report of the National Advisory Committee on Palliative Care has thus specific recommendations on disciplines to ensure adequate mix of physiotherapists, social workers, speech therapists and dietitians, as well as pastoral care and not forgetting administrative support (HSE, 2019[76]). In France, palliative care specialisations will be developed for higher levels of education and funding will be provided for the roles of specialised “palliative medicine assistants”. Palliative care courses included at all levels of education will also foresee practical training through internships (Ministry of Health France, 2022[27]). In Australia, New South Wales has committed to invest AUD 746 million over 5 years, on top of the yearly AUD 300 million budget for palliative care, starting from 2022. The investment will employ 600 new nurses, allied health professionals, doctors, and support staff for palliative care, increase hospital capacity, improve access to pain management, strengthen community care, among other measures (NSW government, 2022[77]).

Better working conditions are also needed to promote retention

Working conditions in end-of-life care might be challenging for professionals. Mental distress is common among health care professionals working in end-of-life care (Coleman, Sanderson-Thomas and Walshe, 2021[78]). Surveys from several countries show that stress and burnout are high among palliative care staff. For instance, in the United States, burnout was reported by approximately one-third of physicians, nurses, and social workers (Kamal et al., 2019[68]; Wang et al., 2020[79]). In Canada, 38.2% of respondents reported a high degree of burnout due to high emotional exhaustion and high depersonalisation (Wang et al., 2020[79]). Furthermore, health care professionals report not feeling competent to provide spiritual support (O’Brien et al., 2018[80]). Mental issues among palliative care workers become even more relevant during emergencies, such as a pandemic. During such events, health care workers have reported posttraumatic disorders, sleep disturbances, anxiety, and depression, among other symptoms. Mental ill-health during pandemics arises from the mix of difficult situations faced daily on the job, together with the societal fear of contracting the infection form health care workers (Porter et al., 2021[81]).

Certain interventions to support staff in stress-relief can be helpful and include training in mind-body skills and cognitive strategies to help reduce negative self-talk (Perez et al., 2015[82]). A Stress Management and Resiliency Training (SMART) programme has been shown to increase resiliency and reduce stress among palliative care physicians in the United States (University of Vermont - medical center, 2018[83]). Australia, Canada, Ireland, New Zealand, the United Kingdom, and the United States offer health care professionals the Schwartz Rounds. The latter consist of sessions where health care professionals can meet to exchange experiences and feelings related to their job. Participants have reported a decrease in the stress and isolation, more feelings of compassion towards patients and better teamwork (The Schwartz Center, 2022[84]).

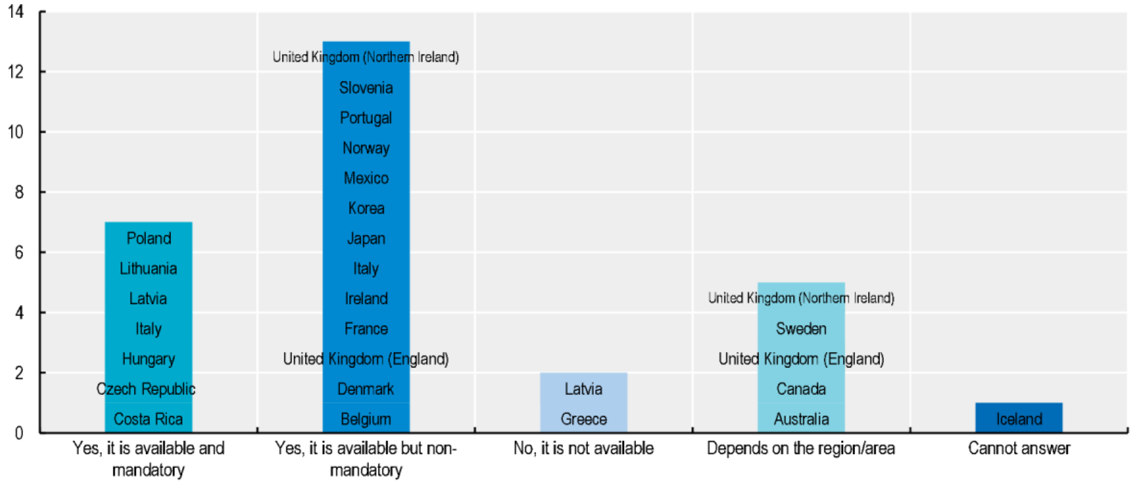
Beyond the stress of dealing with patients, time constraints and workload are also cited among the deterrents and possible stressors for palliative care staff. Countries can take a range of other workforce measures for retaining workers in palliative care (Mills and Ven, 2019[85]). In this sense, quality of the management of everyday organisational life and the organisation's approach can have a strong impact on stress and the feeling of support for professionals. Hospice UK recommends effective leadership, a participatory culture and good line management and supervision of staff (Hospice UK, 2015[86]). More flexibility and autonomy in managing the schedule appear to be important to ensure work-life balance: studies report that workers in hospice suffer from frequent changes in scheduling (Lehto et al., 2020[87]). Telehealth is opening avenues for improving such work-life balance while staff found them effective and patients report similar quality of care outcomes (Dolan et al., 2021[88]). Finally, given overall level of health care shortages, ensuring sufficient compensation in relation to other specialities might also help to attract and retain workers.

Improving on-the-job training is essential, especially for mature workers

Despite the importance of training in palliative and end-of-life care, both the availability of on-the-job training programs and their quality still stand to be improved in many cases. While most countries (20 of 24, 83%) report that on-the-job training in end-of-life and palliative care is available (Figure 2.11), less than one-third of countries (7 of 24, 29%) reported that such training is mandatory for staff working in the end-of-life or palliative care fields. A national survey of oncology fellows in the United States found that even where training in palliative care was available, the quality of training in palliative care was poorer than the broader training in cancer care, particularly related to improving communication skills, providing psychosocial care, and pain management in palliative care (Thomas et al., 2015[89]).

Figure 2.11. Availability of on-the-job training in end-of-life and/or palliative care

Countries answers to the question “Is EOLC/PC on-the-job training available and/or mandatory for palliative care?”



Source: (OECD, 2020-2021[11]).

Some countries have included the development and improvement of on-the-job training in their national plans. For instance, the French Ministry of Health included in the 2021-24 national plan the development of on-the-job continuous learning for all health care professionals who wish to improve their skills and knowledge on end-of-life care. The national plan foresees actions aiming at evaluating the quality of training on end-of-life care, including indicators on the quality of training among the indicators of care quality evaluation, develop continuous learning for all professionals working in end-of-life care, and foresee surveys to evaluate the satisfaction of trainees (Ministry of Health France, 2022[27]).

In some countries there are specialised training centres providing training and support on end-of-life care. In England (United Kingdom), to improve the quality of on-the-job end of life care training, Skills for Care provides technical and financial support to employers in the care and social sectors. The Government of England (United Kingdom) has established the Skills for Care in 2001, as a strategic workforce development and planning body, for the social and care sector. Skills for Care provides employers with materials to train their workforce, including written and video support. Furthermore, Skills for Care has a free e-learning programme offering 150 modules on end-of-life care (e-ELCA, End-Of-Life-Care for All). It also provides pathways to support workers caring for people at the end of their life (Skills for care, 2022[90]). Similarly, the Center to Advance Palliative Care (CAPC) was established in the United States in 1999 to improve the care and support provided to people suffering from serious illnesses and their families. The centre provides a plethora of material, spanning from toolkits to courses, webinars, virtual office hours where people can exchange thoughts and information. All health care providers can become member organisations and access to a variety of available tools.

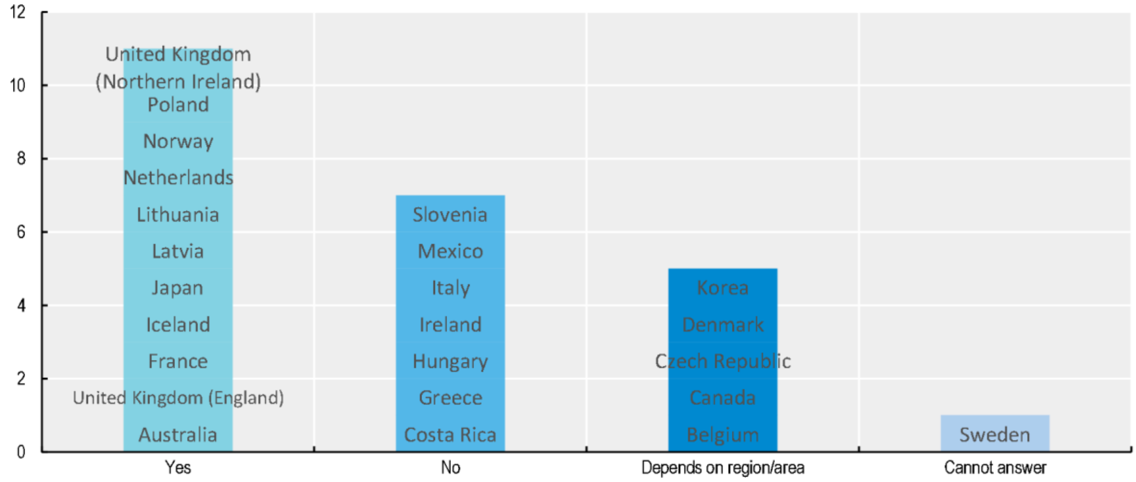
Certain strategies are also put in place to increase the accessibility of training. The Lincolnshire, England (United Kingdom) Implemented a new training and education programme that mixes existing courses and new initiatives on end-of-life care. The programme uses community-based digital tools (e.g. video conferencing facilities) to facilitate the access to the training and education, reducing travel time and increasing the frequency of training and education (NHS UK, 2021[91]). Making information regarding training easily available also helps students, workers and volunteers navigate the training opportunities available. Australia has several national and local initiatives to provide training on end-of-life care. The initiatives span from online training to short workshops, to vocational training with certifications. Furthermore, the trainings target a large audience, covering all health care professionals, students, informal carers, and volunteers. The Australian Government Department of Health funds the Program of Experience in the Palliative Approach (PEPA). PEPA aims at providing free workshops on palliative care for clinical workforce, as well as supporting health care providers to integrate palliative care training within the workplace (PEPA, 2022[92]). Furthermore, the Australian End of Life Directions for Aged Care (ELDAC) provides resources (e.g. toolkits, guidelines, support for service development) to support Long-Term Care workers providing end of life care to older Australians (ELDAC, 2022[93]). Victoria's department of health published a palliative care education audit, listing all trainings available at the national level (Department of Health Victoria, 2018[94]). Sweden has also improved access to training by providing online training on palliative care at the end of life. The training is free of charge and available to all health care workers and interested stakeholders. The Bethania Foundation provides such inter-professional education and skills development in palliative care and existential support. The training is based on national guidelines, particularly the National knowledge support for good palliative care at the end of life published in 2013 by the Swedish National Board of Health and Welfare. The latter published guidance, recommendations, terms, definitions, and indicators on palliative care. In Portugal, the National Commission for Palliative Care (CNCP) is developing basic palliative care training for health care professionals, which will be made available online nation-wide.

2.3.2. Widening access to different settings and times

To expand access at home and in community-care settings, more efforts need to target primary care professionals. Inclusion of palliative care at the primary care level in undergraduate institutions varies greatly from country-to-country. Nearly one-third (7 of 25) of OECD countries reported that undergraduate medical training does not include a palliative care component, with fewer than half responding OECD countries (11 of 25, 44%) reporting that palliative care training is mandatory nationwide, and a further 24% reporting that palliative care training requirements vary based on region (Figure 2.12). Generally, residency programs for family physicians incorporates some palliative care training in 22 countries (65%), and 17 countries (50%) report having these components included in the training for general physicians (GPs). In Ireland only 1% of GPs/primary care doctors had received palliative care training in 2020, while in Belgium only 7% in 2019, an increase compared to the 2% in 2000. Luxembourg reported a higher share, with 28% in 2009 (OECD, 2020-2021[11]). Such insufficient training prevents the early identification of needs and the provision of care. In Europe, only 12 countries reported primary care teams identifying more than 20% of their patients for palliative care before they died (across all diseases).

Figure 2.12. OECD countries reporting mandatory palliative care training in undergraduate medical school curricula

Countries answers to the question “Do medical schools include mandatory palliative care education in undergraduate curricula?”



Note: In Portugal, palliative care training is only compulsory in the Faculdade de medicina da universidade do Porto.
Source: (OECD, 2020-2021[11]).

Certain countries are making efforts to ensure core competencies in palliative care are achieved by every medical school graduate. In France, the end-of-life care plan 2021-24 aims at improving the number of health care professionals with palliative care training. To do so, the plan foresees the development of palliative care courses in university curricula and the inclusion of palliative care training in all health care professionals’ education paths (Ministry of Health France, 2022[27]). The French national plan 2021-24 sets the objectives of including palliative care in all health sectors’ degrees, to ensure an inter-professional and holistic approach to the care of people at the end of life. Portugal has developed a palliative care network (CNCP) that involves primary health care, hospital health care and integrated continuous care. The CNCP 2017-18 implementation report of the strategic plan for the development of palliative care reported that it is imperative that all health professionals have basic training in palliative care. Moreover, professionals working in services with a high prevalence of elderly people or with life threatening diseases must have intermediate level palliative care training. This requirement aims at providing all people with serious and/or life-threatening illnesses with access to effective end-of-life care, regardless of their diagnosis, age, or place of care (CNCP, 2017[95]).

Building general expertise in palliative care at primary level should not undermine the importance of having a well-co-ordinated mechanism with specialists, in case of needs for additional expertise. In the Netherlands, the national policy states that palliative care should principally be provided in the primary care setting with general practitioners and district nurses playing a leading role in providing palliative care at home. At the same time, they can refer to specialist palliative care in case of complex problems. According to a study, most general practitioners reported that they sometimes or often involved palliative home care teams (99%), hospices (94%), and palliative care consultation services (93%) while most district nurses reported sometimes or often involving volunteers (90%), hospices (88%), and spiritual caregivers (80%) (Koper, Pasman and Onwuteaka-Philipsen, 2018[96]). In Australia, the Australian Greater Choice for at Home Palliative Care Measure (GCfAHPC) also aims to improve access to safe quality palliative care at home to reduce unnecessary hospitalisations and ensure continuous improvement of services. The measure was piloted in 2017-18 in 11 primary health care networks and expanded to 31 networks from 2021-22.

Several countries have developed networks to ensure different expertise on palliative care and the co-ordination across the levels. New Zealand decided to create regional managed clinical networks (MCNs) to plan and deliver services based on their region's needs. The idea is that such networks are linked groups of health professionals and organisations from primary, secondary, and tertiary care working in a co-ordinated manner, and the goal was to make better use of scarce specialist expertise and prevent duplication of effort and resources. Such networks build on the evidence that well-trained primary care teams supported by specialist palliative care can successfully care for most of the palliative care need in their region. Ireland is working on a model of palliative care where hospital, community, primary care, and specialist palliative care providers are supported to work together to provide an integrated care. Care can be provided for those without complex needs by usual services with indirect support from specialists. In this sense, one important recommendation to promote wide access is that consultants for specialised services are expanded and that they divide their time between hospitals and community services (HSE, 2019[76]).

One important challenge for the expansion of access to home care services is ensuring out-of-hours care such as at night and weekends. Developing the use of telehealth and telephone services appears to be essential for this. In Germany, since 2007, palliative care should be available 24 hours a day. To ensure this, a home team is prescribed to a patient, is integrated into already existing health care structures, and provided by GPs, nurses and others if needed. In addition to care, specialist palliative home care physicians keep stock of and may dispense opioids for patients under their care during out-of-office hours in emergency situations. The Australian After-hours Palliative Care Framework, which is based in Victoria, identifies key elements for out-of-hours models and include the importance of advance care planning, good information systems and a focus on increasing symptom management and education of clients and families/informal carers (Victoria State Government, 2012[97]). The model relies on telephone advice to carers and families primarily about symptom management and uses telephone triage to decide if a nursing visit is necessary based on a risk assessment and specific triggers (Health Research Board, 2019[98]). In Canada, the provinces of Nova Scotia and Alberta have launched programs to improve the availability of palliative care services at home. The programs foresee the training of paramedics to deliver care at home for the management of physical symptoms as well as social support for the patients and their families. In Nova Scotia, the programme reduced avoidable hospital visits by 55%, while in Alberta 89% of patients were treated at home rather than being admitted to emergency rooms and 94% of relatives reported that the patients received care in their preferred location (CIHI, 2018[13]). The programme has subsequently been expanded across Canada (Healthcare Excellence Canada, 2022[99]). Some countries also provide emergency medication kits at home to allow for symptom management 24 hours a day. In Luxembourg, during the pandemic people dying at home or in nursing homes had emergency access to a medication kit containing morphine and other end of life medication. They could also have emergency access to oxygen therapy at home and in nursing homes, even at night and during the weekends.

Palliative care knowledge among staff in long-term care should also be improved. Three-quarters of countries (21 out of the 28 reporting European countries) do not reach the 40% threshold in terms of staff´s palliative care training (Arias-Casais et al., 2019[100]) (see Table 2.3). Given the high share of people dying in nursing homes in some countries, it is important to improve expertise of the staff in this topic or ensure appropriate support to avoid referrals to hospitals. Some countries have started this change, for instance the Australian state and territory governments have funded the Comprehensive Palliative Care in Aged Care (CPCiAC) measure. CPCiAC aims at facilitating the development of innovative models to improve palliative and end-of-life service provision and care co-ordination, for older people living in residential aged care, by increasing the availability of palliative care. In Austria, the project "Hospice Culture and Palliative Care in Old People's and Nursing Homes (HPCPH)" aims at improving access to palliative care for older people through the increase in training provision to all employees in older people's homes and nursing homes. Furthermore, since early 2022 Austria passed the Hospice and Palliative Fund Act, which includes grants to the regions for modular hospice and palliative care offers. The fund intends to guarantee the needs-based and affordable hospice and palliative care services. The federal government, the states and the social insurance will also provide special-purpose grants. Starting from 2025, the fund is also planned to increase annually. At the same time, initiatives to implement such knowledge in nursing homes have been scarce and not always evaluated. Results from evaluations have sometimes been disappointing and the staff shortages and high staff turnover make it challenging to provide good care (Lamppu and Pitkala, 2021[101]). Evaluations of interventions show limited impact on quality of life for residents and on unnecessary hospitalisations (Van den Block et al., 2020[102]).

Table 2.3. Staff in long-term care facilities trained in palliative care, Europe 2015

Percentage of staff trained in Palliative Care	Countries
>=90%	Lithuania
60-90%	Netherlands, Poland
40-60%	Belgium, Switzerland, France, United Kingdom
20-40%	Spain, Germany, Austria
<20%	Czech Republic, Italy, Greece, Israel
No trained staff	Denmark, Estonia, Finland, Hungary, Iceland, Ireland, Latvia, Luxembourg, Norway, Portugal, Slovak Republic, Slovenia, Sweden, Türkiye

Source: Reproduced from (Arias-Casais et al., 2019[100]).

Some recent initiatives to improve training among long-term care staff appear promising, even if not yet widely implemented. In Australia, the ELDAC has a toolkit for staff in nursing homes to help them in end-of-life care (ELDAC, 2022[103]). Recently, in England, an innovative model of training was piloted and rolled out across care homes using a team from hospital including a palliative care consultant, a palliative care nurse consultant, a palliative care matron and three clinical nurse specialists to train and support nursing home staff. Training included recognising dying, advance care planning (ACP), co-ordination of care, symptom control, and bereavement care. In addition to education and training, the programme included clinical rounds to identify people who could be approaching a terminal phase, advice and guidance, communication, and care co-ordination. Nursing home residents are offered an electronic end-of-life care plan and results showed that this resulted in a high number of people (85%) dying in their recorded preferred place (EJPC, 2020[104]). In Spain, as part of the NUHELP programme, a selected group of nurses, occupational therapists, psychologists, social workers, physical therapists, and physicians working in nursing homes received basic palliative training. The analysis of the effectiveness of training showed improved staff knowledge, improved use of early assessment of needs and advance care planning and early interventions for relatives with respect to grieving (Mota-Romero et al., 2021[105]). A review of interventions points to the importance of having a multi-faceted approach to improve palliative care in nursing homes, including 1) the addition of an external mentor to facilitate training, 2) the possibility of having an external expert nurse or hospice consultation, 3) the development of an internal champion or champion team, and 4) regular debriefing and case conferencing (Kaasalainen et al., 2019[106]).

2.3.3. Addressing gaps in access for vulnerable populations

Due to inequalities in access, end-of-life care experiences differ across socio-economic levels and geographical areas. Countries are putting in place some measures to tackle access inequalities, but further efforts would be beneficial.

Access policies should be more tailored to people's diverse needs

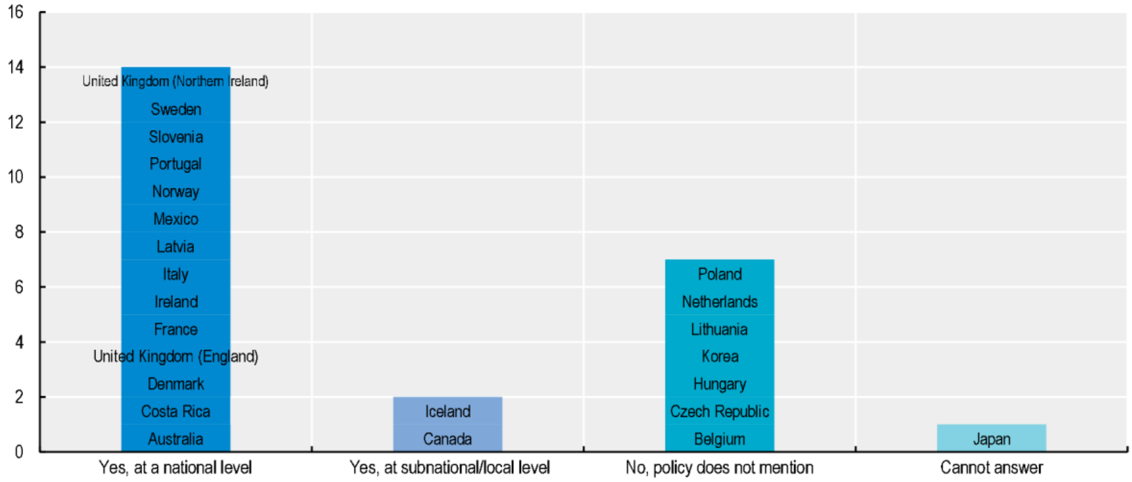
Some of the existing policies designed to improve the population's knowledge around EOLC might not fit well with the needs and opportunities of people with lower socio-economic status. For instance, people with long working hours and care responsibilities might find it particularly difficult to balance personal and professional duties and might not be able to attend "death café" and workshops or webinars on the end-of-life care opportunities. Furthermore, people who hardly make ends meet might perceive short-term issues as more urgent to address than looking forward to future care preferences. The concepts of advance care planning and living wills are likely might not be the priority for some people. Finally, the development of compassionate communities, which represent a valuable way of providing psychosocial support at the end of life, assumes the existence, in the community, of volunteers who have the time and means to dedicate to care and support. Such an assumption might not necessarily hold in more deprived areas.

To address the issues related to the socio-economic inequalities in accessing end of life care service, policy makers must understand needs and barriers to access among groups. Involving representatives with lower socio-economic background in conversations to guide policy making and, in research on EOLC could be a way to tailor policy making on people's needs (Rowley et al., 2021[43]). Community-based participatory action research is a research method that serves this scope, with existing evidence showing that it improves health and well-being in the communities and reduces disparities (Salimi Y, 2012[107]). In community-based participatory action research, communities are involved in a co-production process, in some or all steps of the research project. Engagement and outreach are also important components of providing information to some groups. Establishing compassionate communities can in some cases act as contact points between vulnerable people and the health care sector. For instance, in 2018 Plymouth (United Kingdom) established the End-of-life Compassionate City Network. About 90 individuals and organisations participate to the network to review end-of-life care policies and guidelines in collaboration with schools, colleges, workspaces, trade unions, worship places, care providers, museums, and art galleries. Among its activities, the network gets in touch with hostels and shelters for homeless people to reach vulnerable people and provide them with information on end-of-life care possibilities and guidance on how to receive the most adequate end-of-life care in line with their wishes (Transform Integrated Community Care, 2021[108]).

One-third of the OECD countries that participated to the survey does not have policies to ensure equity in the access to EOLC. Around half of the countries have such policies at the national level and only 8% at the subnational level (Figure 2.13).

Figure 2.13. Around half of the countries have policies to ensure equity in the access to EOLC

Countries answers to the question "Is there a policy to ensure equity in EOLC?"



Source: (OECD, 2020-2021[11]).

In some of the countries where such policies exist, policies are broad and do not define concrete actions but are rather focusing on the principle of non-discrimination. In Latvia, policies to ensure equity only consist of a law on the right of patients, which prohibits any differential treatment based on a person's race, ethnic origin, skin colour, gender, age, disability, state of health, religious, political or other persuasion, national or social origin, property or marital status or other circumstances (OECD, 2020-2021[11]). While people must not be treated differently based on their characteristics, it is also crucial that policies consider all the characteristics that differentiate people living in the community.

A number of countries (Austria, Denmark, Germany, Luxembourg, Norway and Sweden) set ceiling for co-payments (OECD, 2019[35]), while in other countries, detailed and effective policies to improve access to end-of-life care exist at the sub-national level, but they are not widespread within the country. The Care Quality Commission in England (United Kingdom) collected examples of good practices to provide equitable end-of-life care for everyone among English care providers. One care provider created a charity to support homeless people. The charity covered the cost of funerals and memorials for homeless people, as well as the cost of the last wishes of patients at the end of life (e.g. covering the cost of one day trip to the sea for a dying homeless person). Furthermore, the Manchester's homeless health inclusion pathway (MPath) was established in 2013 to ensure good care for homeless people at the end of life and reduce emergency admissions at the end of life. It entails the "acute hospital rounds", primary care follow-up and community follow-up and support. During the acute hospital rounds, GPs regularly visit the homeless patients in hospital to identify those who are reaching the end of life and to facilitate their discharge. The primary care follow-up provides the full range of specialist care services, while the community follow up and support aims at supporting homeless people in the community with issues such as housing, benefits, health care access, with the aim of avoiding repeated emergency admissions. After six months of pilot MPath implementation, the MPath reduced the admissions to emergency care and improved the engagement with primary care services among homeless people (MPath, 2013[109]).The NHS Fast-track Funding has the scope of ensuring that people whose health is deteriorating quickly can receive the appropriate care they need in a short time and free of charge. The Fast-track Funding consist of the possibility to undergo a health assessment and to obtain access to the appropriate care package within 48 hours (NHS, 2021[110]).

Countries are tackling developing care models for improving care provision in rural areas

Several countries are testing models to improve the provision of end-of-life care in rural areas. In England (United Kingdom), the Northwest End of Life Care Model provides guidance for the assessment and planning of care for patients living in the Northwest of the country and reaching the end of life. The model identifies five phases of the illness and designs key practices to provide adequate care in each of the identified phases (NHS, 2015[111]). Australia adapted the NHS Northwest End of Life Care Model to the Far West New South Wales, an Australian rural area where 12% of the population is Aboriginal or Torres Strait Islander. The model's assessment showed that the model improved care outcomes and communication for people at the end of life, their families, and carers, as well as integration and collaboration among care providers. To further develop the model, Australia is currently working on the development of shared-care patient records and an electronic resource centre (Wenham, Cumming and Saurman, 2020[112]). Furthermore, Australia also implemented a nurse-practitioner-led models in palliative care in rural settings. An evaluation of this model has shown early intervention of palliative care and hospital avoidance (Mitchell et al., 2016[72]). Similarly, in Canada an intervention with a nurse co-ordinator, who is supported by a community-based clinical team that includes a general practitioner and nurse practitioner who have additional palliative training, showed that it improved quality of care. The major focus of the nurse co-ordinator was on supporting and teaching about chronic life-limiting disease management and the attending physical symptoms (Rowley et al., 2021[43]). Certain countries are also testing the use of telehealth options to reach people in rural areas. Palliative care services delivered via telehealth are generally showing promise as models of care. In the United States, in California, some providers are using a blend of home-based and virtual care with an initial in-person visit followed by virtual ones using videoconferencing (Center to Advance Palliative Care, 2019[47]).

2.3.4. Early identification and integration of palliative care

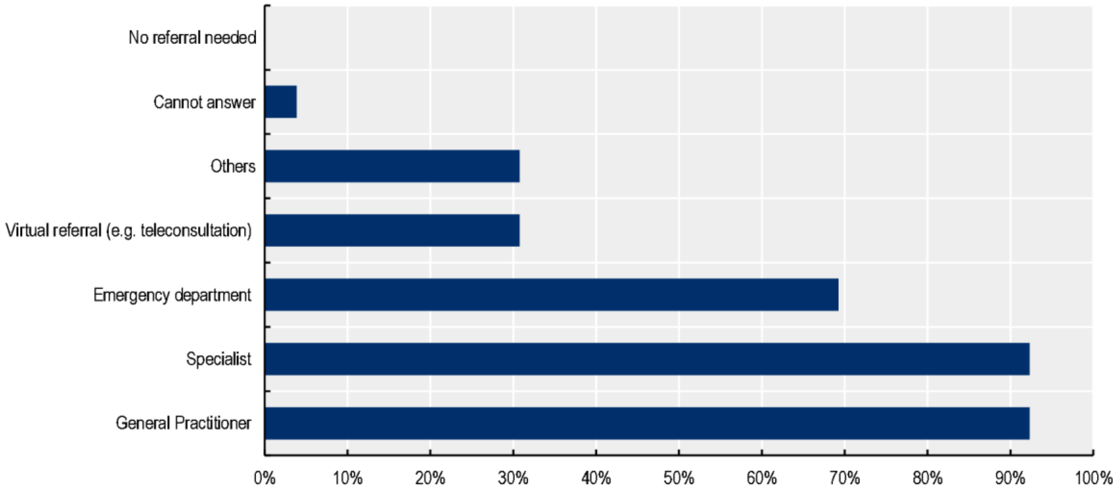
Systematic symptom screening and registration appears to be an avenue for improving timely identification and assessment. Studies point to the importance of moving away from prognostication and focus on assessment needs to identify the palliative care phase. The European Association for Palliative Care (EAPC) recommended that clinical predictions of survival should not be used alone but in conjunction with other prognostic factors (Maltoni et al., 2005[113]). The screening tool should be based not solely on predicting mortality and deterioration, but rather on symptoms and on anticipating the evolving needs of patients. Evaluation studies of screening tools to systematically record symptoms, such as the Edmonton Symptom Assessment System (ESAS) self-assessment tool, shows that it increases the likelihood of discovering symptoms that might otherwise be overlooked (Vigstad, Clancy and Broderstad, 2018[114]). Initial trials of the use of such screening mechanisms show positive results. The STEP method (Symptom screening with Targeted Early Palliative care) systematically identifies patients with the greatest need, using symptom screening at every outpatient visit, with triage and targeted referral to palliative care. It shows that such method distinguishes between patients who remain stable without early palliative care and those who benefit from targeted early palliative care (Zimmermann et al., 2021[115]). Automated tools such as the “Risk Evaluation for Support: Prediction for Elder-life in the Community Tool” (RESPECT) and the “Hospital-Patient One-Year Mortality Risk (HOMR) which incorporate electronic prognostic algorithms appear to be effective at providing information about survival and anticipating future care needs and could be more widely used (RESPECT - project big life, 2022[116]; van Walraven et al., 2015[117]).

Some OECD countries have set up successful programmes to allow early identification of needs. In Canada, a partnership between the Central West Palliative Care Network and the local health integration network (LHIN) in the province of Ontario developed a programme to allow earlier identification of patients with palliative care needs. The programme consisted in the design of the Early Identification and Prognostic Indicator Guide, which helps care providers to identify palliative care needs among patients. The project successfully reduced hospital admissions and readmissions (-40%), increased the number of patients with palliative care needs dying at home, and improved the overall end of life experience for patients and families (CIHI, 2018[13]). In Italy, Fondazione G. Berlucchi and Fondazione Floriani developed the “ARIANNA” project, an observational study on a model of early identification of patients with palliative care needs through the integration between primary care and Italian home palliative care units. The study lasted 18 months, between 2014 and 2015, and showed successful results, with 70% of patients receiving adequate palliative care and dying at home (Arianna Working Group, 2018[118]). In the United Kingdom (Northern Ireland), there are local arrangements to ensure timely access to EOLC services, which are linked to regional KPI monitoring (OECD, 2020-2021[11]). In the United States, the Sharp Healthcare system teaches professionals timely identification of end-of-life care needs using “evidence-based prognostication” (Commonwealth Fund, 2022[119]).

Improving the referral process might also contribute to more timely access*.* In 24 out of 26 countries that responded to the survey (92%), access to EOLC services is available through referral of a GP or a specialist. Emergency department referral and referral through digital health services are available in respectively in 69% and 31% of countries, while no OECD country allows access to EOLC without referral (Figure 2.14).

Figure 2.14. GPs and Specialist referrals are the most common way to access EOLC

Available options to obtain referral to EOLC services



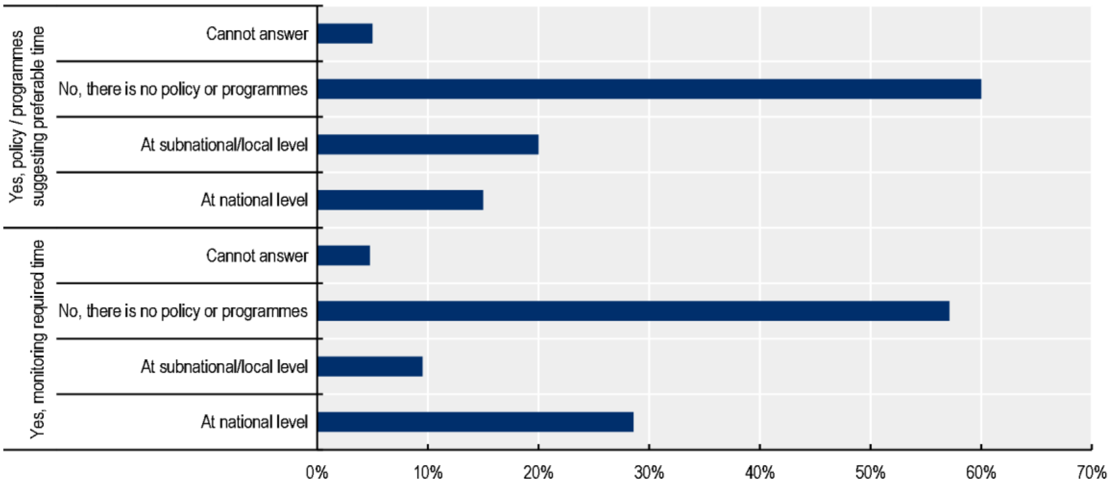
Source: (OECD, 2020-2021[11]).

Several countries have good examples of successful changes in the referral stage. In Ireland all referrals need to be triaged within 24 hours to determine the urgency of need. Patients then receive the services in an appropriate time span according to the level of urgency. The regulation does not include a defined timeline between referral and the receipt of actual care (OECD, 2020-2021[11]). Results of systematic symptom screening can be used to identify patients who meet standardised referral criteria to initiate timely access to palliative care. For instance, in the case of cancer, international experts reached a consensus in the list of criteria for referral of patients with advanced cancer at secondary or tertiary care hospitals to outpatient palliative care and there are standardised criteria to trigger automatic referral (Hui et al., 2017[120]).

Mechanisms to ensure that access to end-of-life care is timely are scarce. Countries very rarely monitor the time that is required to access EOLC after receiving referral. Only 7 of the responding countries[5] (29%) have national programmes/policies to monitor how long it takes for people with a prescription for EOLC to access such services. The lack of policies and programs suggesting what is the preferable time for patients to access the services also hampers monitoring timely access. Only Ireland, Italy, and Norway (15%) provide national indication of such timing (Figure 2.15).

Figure 2.15. Policies and programmes for timely access to EOLC are rare

Answers to the question "Do you have a policy for timely access (i.e. EOLC is accessible when prescribed by a qualified health professional, without a too long waiting time) to EOLC across the country?"



Note: For programmes/policies on monitoring required time N=21; For programmes/policies suggesting preferable time N=20.
Source: (OECD, 2020-2021[11]).

To improve timely access, it might be interesting to apply measures from other areas of health care. For instance, OECD countries have implemented a range of policy measures to tackle waiting times for cancer care, including: 1) the introduction of maximum waiting time targets; 2) the regular evaluation and assessment of waiting times; 3) the introduction of fast-track pathway (OECD, 2020[121]). In addition to improved early identification, time targets have proved helpful. The United States set specific timelines for the assessment of needs to ensure that access to EOLC is not delayed. Under Medicare, hospices must perform patient-specific comprehensive assessment of the patient's needs. It consists of an initial assessment within 48 hours from referral and the physician, patient or patient's representative can request to complete it in less than 48 hours. Following the initial assessment, a comprehensive assessment must be completed within five days from referral (OECD, 2020-2021[11]). In the United Kingdom, the NHS has put in place a fast-track assessment of needs for people whose health status is deteriorating quickly. The fast-track funding allows patients to receive free and appropriate care and support in the shortest available time, within 48 hours. The assessment is performed by a clinician and then by a clinical commissioning group. The outcome of the assessment is regularly reviewed and updated (NHS, 2021[110]).

Early integration of end-of-life care in the care of people with life threatening and life limiting conditions has proven to be beneficial to improve their quality of life (Vanbutsele et al., 2018[122]). In some cases, weak links between hospitals and community-based providers can exacerbate limited access to palliative care. To overcome this, there are positive examples of models of care promoting the early identification of palliative care needs, early introduction of palliative care, the creation of linkages and communication channels between care settings. This has been undertaken for patients with cancer, suggesting that palliative care can be integrated into the routine practice of oncology providers, with appropriate education, integration into existing clinical workflows, and administrative support (Adams and al., 2019[123]). In some instances, to ensure early referral, automated referral based on triggering criteria is being actively explored, using routine technology-assisted symptom screening, combined with targeted needs-based automatic referral to outpatient palliative care (Mathews, Hannon and Zimmermann, 2021[124]). Studies show that such early integration through monthly consultation by a palliative care nurse and more frequent consultations by a psychologist show improvements in patients' quality of life (Kaasa and Lodge, 2018[125]). Germany is currently testing the Palliative Care Indicator Tool (SPICT) to help GPs identify palliative care needs among the population. The tool is currently tested and evaluated in Lower Saxony, a predominantly rural region. The project will run for 42 months with a budget of 690 000 euros (Gemeinsamer Bundesausschuss, 2022[126]).

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Annex 2.A. Estimates on number and share of people needing and receiving end-of-life care

Annex Table 2.A.1. Estimated deaths that require EOLC

Estimates of the total number of deaths that would have required EOLC in 2019 in OECD countries, by cause of death

Country	Deaths from organ failure requiring EOLC	Deaths from terminal illness requiring EOLC	Deaths from frailty requiring EOLC	Total deaths requiring EOLC	Total deaths
Australia	47 895	39 973	20 616	106 296	166 475
Austria	24 811	20 542	10 680	55 065	86 241
Belgium	31 760	25 905	13 671	70 486	110 393
Canada	83 575	69 498	35 975	185 483	290 495
Chile	33 328	28 739	14 346	73 967	115 844
Czech Republic	32 602	26 492	14 033	72 355	113 319
Denmark	15 797	13 338	6 800	35 059	54 907
Estonia	4 489	3 636	1 932	9 964	15 604
Finland	15 763	12 697	6 785	34 983	54 789
France	172 881	141 834	74 417	383 686	600 912
Germany	271 943	223 124	117 058	603 540	945 238
Hungary	36 597	28 203	15 753	81 223	127 207
Iceland	651	541	280	1 444	2 261
Israel	13 128	10 831	5 651	29 136	45 632
Italy	187 256	149 416	80 605	415 589	650 877
Japan	395 336	327 756	170 173	877 394	1 374 136
Latvia	7 907	6 258	3 404	17 549	27 485
Lithuania	11 161	8 708	4 804	24 771	38 795
Luxembourg	1 169	1 035	503	2 595	4 064
Mexico	217 791	188 961	93 749	483 358	757 014
Netherlands	44 050	35 992	18 961	97 763	153 112
New Zealand	9 546	8 071	4 109	21 186	33 180
Norway	12 009	9 940	5 169	26 653	41 742
Poland	113 315	91 154	48 777	251 487	393 867
Portugal	31 983	25 642	13 767	70 983	111 170
Korea	90 931	80 230	39 141	201 809	316 064
Slovak Republic	15 341	12 842	6 604	34 048	53 325
Slovenia	5 951	4 933	2 562	13 208	20 686
Spain	124 584	100 777	53 627	276 498	433 038
Sweden	26 308	21 136	11 324	58 388	91 444
Switzerland	19 537	16 403	8 410	43 359	67 908
United Kingdom	178 966	147 366	77 036	397 191	622 063
United States	837 301	699 374	360 418	1 858 275	2 910 348

Note: The data include 33 OECD countries. Greece, Ireland and Türkiye are excluded for insufficient data.
Source: WHO mortality database (WHO, 2019[23]), UN database for mortality projections (United Nations, 2019[127]), (Lunney, Lynn and Hogan, 2002[20])for the definition of the EOLC death trajectories and (Etkind et al., 2017[25]) for the percentages of pain prevalence.

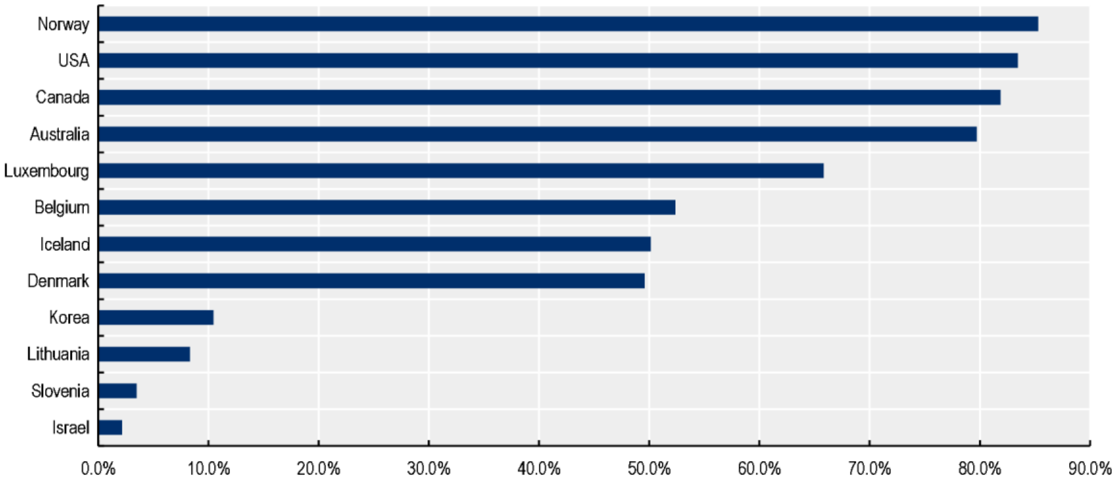
Annex Table 2.A.2. Estimated share of people in need of EOLC that receive EOLC/PC services

	Year	Number of people receiving EOLC/PC	Estimated total deaths in need of EOLC (in 2019)	Share of people receiving EOLC/PC among total deaths in need of EOLC
Australia	2017	84 725	106 296	79.7%
Belgium	2019	36 907	70 486	52.4%
Canada	2019	151 884	185 483	81.9%
Denmark	2019	17 385[1]	35 059	49.6%
Iceland	2020	724	1 444	50.1%
Israel	2018	629[1]	29 136	2.2%
Korea	2020	21 127	201 809	10.5%
Lithuania	2020	2 061[1]	24 771	8.3%
Luxembourg	2014	1 708	2 595	65.8%
Norway	2020	35 594	41 742	85.3%
Slovenia	2020	460	13 208	3.5%
United States	2018	1 550 817	1 858 275	83.5%

Note: [1] Number of patients receiving palliative care services, among those who died for all causes, excluding external causes of death (all ICD-10, except V00-Y99). For Norway, data refers to the share of people receiving end-of-life care among all deaths.
Source: (OECD, 2020-2021[11]) and (OECD, 2021[66]) for the number of people receiving EOLC/PC services. WHO mortality database (WHO, 2019[23]), UN database for mortality projections (United Nations, 2019[127]), (Lunney, Lynn and Hogan, 2002[20])for the definition of the EOLC death trajectories and (Etkind et al., 2017[25]) for the percentages of pain prevalence.

Annex Figure 2.A.1. Not everyone who needs EOLC/PC receives it

Share of people receiving EOLC/PC among total deaths estimated to need EOLC, 2019 or latest year available



Note: For Denmark, Lithuania and Israel, data refer to the number of patients receiving palliative care services, among those who died for all causes, excluding external causes of death (all ICD-10, except V00-Y99). For Australia, data report the numbers of palliative care-related hospitalisations and the number of permanent aged care residents assessed as requiring palliative care. For Belgium, data include all patients for whom the GP has asked for “forfait palliatifs”. For Canada, data includes all death discharges from LTC facilities in 6 reporting provinces and a territory (YN) and does not include retirement facilities that are exclusively privately funded. For Norway, data refers to the share of people receiving end-of-life care among all deaths. For the United States, data provided is limited to Medicare beneficiaries (65+ and some people with disabilities) who used hospice services.
Source: (OECD, 2020-2021[11]) and (OECD, 2021[66]) for the number of people receiving EOLC/PC services. WHO mortality database (WHO, 2019[23]), UN database for mortality projections (United Nations, 2019[127]), (Lunney, Lynn and Hogan, 2002[20])for the definition of the EOLC death trajectories and (Etkind et al., 2017[25]) for the percentages of pain prevalence.

Notes

[1] This report conceptualises end-of-life care as the care provided to people who are in the last 12 months of life. It refers to the terminal stage of palliative care, as well as including some elements of curative care and help with mobility limitations. Chapter 1 of this report provides a more detailed definition of EOLC.

[2] Several prognostic tools have developed over time but there is still considerable variation about accuracy. The most commonly available tools are the following: Gold Standard Framework – Proactive Identification Guidance (GSF PIG), Supportive, and Palliative Care Indicators Tool (SPICT), RADboud indicators for PAlliative Care Needs(RADPAC), and Necesidades Paliativas [Palliative Needs]: NECPAL tool). In addition, there are Surprise Question (SQ), and the double Surprise Question which have been suggested as a trigger for referral to specialist palliative care and are considered easier diagnostic tools.

[3] Data refers to median waiting time for end-of-life home care.

[4] Data from Landspitali and Akureyri Hospital.

[5] Countries with national policies to check the length of timing to access services include Estonia, Ireland, Italy, Korea, Portugal, Slovenia, United States.

3

Making end-of-life care more people-centred

This chapter discusses people-centredness of end-of-life care (EOLC). It illustrates that information gaps among the general population and health care professionals lead to stigma and hamper conversation and shared decision making. Efforts to involve patients in decision-making are rising but fall short. Evidence shows that gender, age, diagnoses, ethnic and cultural background influence people's experience at the end of life. The chapter suggests pathways towards more people-centred EOLC which include raising awareness around death and fostering the voice of patients and communities. Training and guidelines can support health care workers to undertake difficult EOLC conversations to align care to people's wishes, while patient reported measures can help monitoring people's satisfaction with EOLC. Finally, multidisciplinary EOLC conversations involving all relevant stakeholders can facilitate co-ordination and improve the end-of-life care experience.

Introduction

As in other parts of health systems, there is a need to make sure that people at the end of life receive appropriate care according to their needs and wishes. People-centredness in end-of-life care[1] (EOLC) has been found to improve user satisfaction, outcomes and may also help to lower health care expenditures (Thomas K, 2018[1]). Given the wide range of benefits, a focus on a more people-centred end-of-life care can help policy makers, health care professionals and providers understand better how to improve quality of care and how well care is organised around people's needs. It can also help those in need of care to have their say in terms of the care process and choices. People-centredness is integral to more holistic and humane care for people dying and their relatives.

Yet, this chapter shows that disinformation and stigma around death and dying hamper the provision of people-centred EOLC. Knowledge around end-of-life care is poor in the general population as well as among professionals. Only a minority of patients make use of advance care planning (ACP). Communication with, and involvement of, patients in decisions regarding their end of life remains rare among professionals without palliative care training, with lack of information by both the clinicians and the patients' side is often cited among the main causes of poor communication. Moreover, stigma towards the end of an individual's life, language barriers and other cultural traits hamper the spread of information among some patients' groups, creating disparities. When people reach the end of their life, they often experience physical, psychosocial, and spiritual needs that are not always adequately addressed.

The chapter discusses how EOLC can become more people-centred through greater information regarding the process of dying and the care opportunities for people reaching the end of their life. Public discussion, better training for clinicians, planning care in advance (i.e. making decisions regarding their care preferences, in a shared decision-making process) and creating or increasing the number of multidisciplinary EOLC teams (i.e. creating groups of health care professionals qualified in different fields to holistically address all the needs of the person at the end of life) are some of the steps countries can take to make EOLC more people-centred. This chapter provides examples from best practices in countries to illustrate this range of policies.

The remainder of the chapter is organised as follows. Section 3.1 highlights the sub-principles of people-centred end-of-life care. Section 3.2 illustrates the consequences of current health systems lacking such focus while 3.3 explores policies and best practices to ensure an informed, collaborative, inclusive and holistic end-of-life care.

Key findings

- Knowledge of the type of end-of-life care services available is rare among the general population. Fewer than one in two adults in OECD countries report having some knowledge around EOLC, despite more than 80% of OECD countries having programs to promote palliative care[2] literacy. Only 8 countries measure stigma around EOLC, despite its role in hampering the use of EOLC services.
- Communication on health status and care possibilities at the end of life are less frequent than they should be: fewer than half of persons have such conversations with their doctor. Professionals often feel unprepared to start such discussions with patients and relatives and are not fully knowledgeable about the concepts of advance care planning and advance directives (AD). Planning, recording of wishes and shared decision-making fall short: Only one-quarter of patients and professionals write advance directives, and data on the use of advance care planning is not regularly collected.
- Disparities at the end of life by type of disease, gender and ethnicity prevail. Cancer patients – representing between 29% and 95% of palliative care recipients – are far more likely to receive palliative care at the end of life compared to other patient groups and women are more likely to receive it than men. While ethnic and cultural disparities at the end of life are well-known, only 10 of 24 OECD countries have developed some form of regulation to take cultural aspects into account in the decision-making process around the end of life.

Policy options

EOLC services need to be more oriented towards the patients' and their families' wishes, with services provided in compliance with their preferences. This involves several components:

- Greater public discussion on death and dying is needed to improve people's knowledge regarding end-of-life care and to reduce stigma around the topic. Public campaigns are an effective way to spread information and facilitate discussion. The French campaign on palliative care, for instance, resulted in 86% of long-term care facilities' managers showing good knowledge on the topic. Furthermore, countries are already developing associations, lobbying groups, and professional associations to give people a voice in policy making around end-of-life care. Most European countries have at least one national association on palliative care and OECD countries have between 1 and 7 national professional associations on palliative and end-of-life-care. Belgium, Canada, Costa Rica, New Zealand, Spain, United Kingdom, and the United States have started to develop compassionate communities, which provide support to people at the end of life and their families, as well as spreading knowledge around end-of-life care within the general population.
- Multidisciplinary and recurrent conversations seem to be beneficial enablers of good, shared decision-making. As decision making at the end of life goes beyond medical decisions, support by trained non-physicians can be desirable particularly in the earlier stages of disease, while physicians are required to step in for specific health care decisions. Improved training for health care workers can help to foster communication and involvement of patients and their families in decision-making regarding their loved ones' health. Data collection on the use of advance care planning would be instrumental to monitor progress on the uptake of care planning. Canada and the United States have developed training and guidance for health care professionals to support open communication with people at the end of their lives.
- Translating relevant information into different languages and training professionals on ethnic and cultural differences would facilitate access to EOLC services for ethnic and cultural minorities. Fighting the stigma around death and dying and improving general knowledge of end-of-life care could contribute to reducing disparities at the end of life. The United States provides training and guidance on cultural specificities to professionals who care for people with culturally diverse backgrounds. Australia includes tailored communication for cultural minorities within campaigns and programmes to spread information on EOLC within the population.

3.1. Why are people-centred end-of-life care systems important?

For end-of-life care, as for other parts of health care, there are rising expectations over what professionals should deliver and a push for systems to become more responsive to the people who use them. The OECD has developed a framework for people-centred health systems which highlights that such a system entails placing people, their families, and communities at the heart of health systems, empowering them, building care around the needs and expectations of the individual, and delivering health in a way that makes the best use of the resources available (OECD, 2021[2]). Building on such framework and the literature and strategies on end-of-life care and palliative care, this section develops the different components of what people-centred end-of-life care would need to provide quality of life to people at the end of life, while also being tailored on the patients' and their families' needs. The section reflects the components (sub-principles) of the people-centred principle: *informed*, *collaborative and inclusive* EOLC.

To make EOLC people-centred would require that people are *informed* regarding death and care possibilities at the end of life. This includes developing knowledge and awareness of end-of-life care in the general population and reducing the stigma associated with death and dying. The lack of good information around the end of life is correlated to low use of end-of-life-care, hampers good communication between patients and professionals and can cause disparities at the end of life (Kleiner et al., 2019[3]). With societies becoming increasingly diverse, with a variety of cultures and beliefs coexisting within communities, it is critical that these differences are respected. People from ethnic and cultural minorities face bigger challenges related to language and cultural barriers, resulting in lower access to end-of-life care (Ejem et al., 2019[4]). Patients and their families must receive information to empower them to make decisions about their and their loved ones' care, feel able to communicate openly with health care workers, their ethnicity and cultural traits respected by health care workers, are listened to and their wishes followed.

Professionals report that *collaborative* EOLC can be challenging due to a lack of training on how to start adequate and open communication around death and dying (Swerissen, 2014[5]). Patients and families may also lack the required information to understand the importance of planning care in advance and they may not be able to recognise the right moment to start conversations around death (Bamford et al., 2018[6]; Brighton and Bristowe, 2016[7]; Henderson et al., 2018[8]; Travers and Taylor, 2016[9]). Poor communication around the end of life reduces the access to information and hampers the use of care planning. Improving communication requires ensuring that professionals have the right skills and knowledge around EOLC to face such discussions and that people and their families are entitled to their choice in care, that they are consulted and receive care that is respectful.

Decision making regarding the end of life should be *inclusive*, with people at the end of their life and their relatives able to plan care in advance to ensure that their preferences are clearly stated and taken in account. This would require improving awareness around care planning among the general population as well as professionals. Not planning care in advance might lead to undesired care and misalignment between preferences and experiences around the end of life (e.g. their preferred place of death). The lack of advance directives also puts the burden of choices on the patients' relatives, who might not be aware of the patients' preferences.

3.2. The consequences of a lack of people-centred end-of-life care

End-of-life care provision is not truly people-centred yet. Information and knowledge about services is often lacking among the population and even among health care professionals and communication about services and treatment is often poor. People at the end of life and their relatives experience disparities of care (e.g. disparities across ethnic groups, ages, genders, and disease groups), mental ill-health and poor focus on psycho-social, spiritual and bereavement help.

3.2.1. Knowledge around end-of-life care services is limited

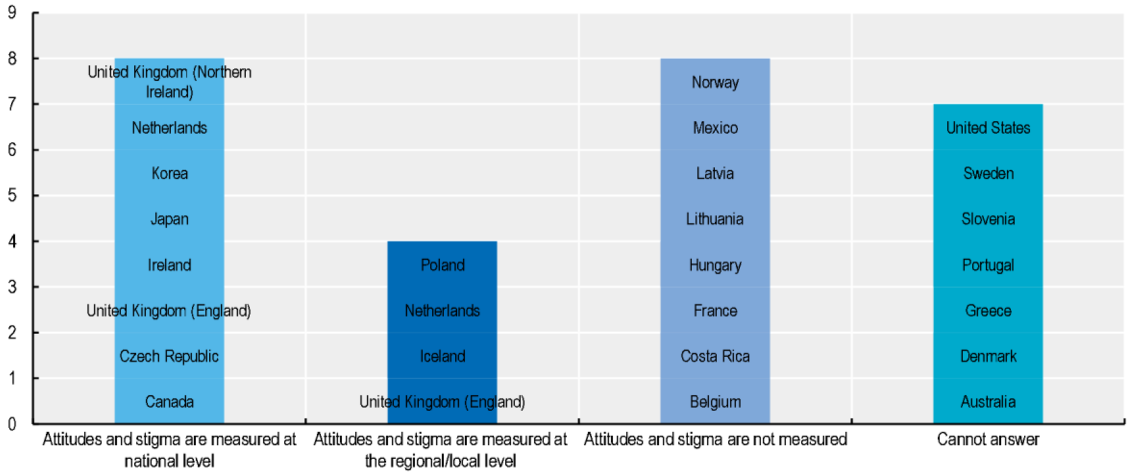
Lack of awareness around palliative care services among the public is widespread. Evidence from Australia, Canada, Japan, Italy, Sweden, and the United States report that most adults lack good knowledge regarding palliative care, while more encouraging results emerge only from New Zealand and Scotland. A minority of people interviewed in Australia (38%) and in Canada (48%) were able to provide a good definition of palliative care. Similarly, a high share of people interviewed in Japan (63%), Italy (40%) (Sonja McIlfatrick, 2013[10]) and Sweden (84%) reported having some or no awareness of palliative care (Westerlund et al., 2018[11]). In France, 81% of people aged 50 or older did not know what advance directives were (Centre National Fin de Vie Soins Palliatifs, 2018[12]). In the United States, studies highlight that the share of adults with no knowledge around palliative care has been steady and equal to 70% between 2011 and 2016 (Lane, Ramadurai and Simonetti, 2019[13]). Although New Zealand and the United Kingdom (Scotland) seem to perform better, with a good part of respondents being able to provide a definition of this type of care (respectively 85% and 49% of surveyed samples) (Sonja McIlfatrick, 2013[10]), they represent only a minority of OECD countries. Studies in Germany showed that between 20% and 30% of patients did not know what advance directives were (Evans et al., 2012[14]).

Barriers recognised as hindering the spread of knowledge regarding these services include: i) taboos associated with death – which cause shame – and absence of public debate, ii) lack of discussion at the time of diagnoses of a life-limiting disease, leading to inadequate information and iii) lack of funding for EOLC services (Sonja McIlfatrick, 2013[10]; Westerlund et al., 2018[11]). In Australia, where 90% of surveyed adults agreed on the importance of thinking about end-of-life care wishes in advance, only 50% did so. Respondents to the survey considered the topic of death and dying too difficult to approach with their family members (Mirage, 2021[15]). Taboos around death and dying are common around the general population as well as among health professionals. Clinicians often find it challenging to start conversations regarding the end of life and prefer to propose life prolonging care to provide hope.

Because taboos, shame, and stigma around EOLC can slow down the spread of information, it is important to be able to recognise and address such barriers. Yet such attitudes are seldom measured and monitored. Out of 27 surveyed countries, only 8 reported measuring the attitude and stigma around EOLC and death at the national level, and 4 at the local level (Figure 3.1).

Figure 3.1. Attitudes and stigma around EOLC and death are rarely measured

Countries' answer to the question "Does your country have any way of measuring attitudes or levels of stigma around EOLC or discussion on death?"



Note: N=27.
Source: (OECD, 2020-2021[16]).

Two key international measures of awareness about EOLC information among the population already exist. The European Association of Palliative Care (EAPC) collected information from 51 countries in 2019, including 28 OECD countries. It explored the existence of a national palliative care directory of services, which provides information about existing services and raises awareness at a population level around the availability of EOLC services (Arias-Casais et al., 2019[17]). The 2015 Quality of Death Index Ranking includes analysis as to whether countries have discussion and public awareness about end-of-life choices, as well as the availability of volunteer workers for EOLC. It ranked 80 countries, including 32 OECD countries, and found that Belgium, New Zealand, France and the United Kingdom performed best, while Türkiye, Colombia, Mexico, Lithuania and the Czech Republic were among the OECD countries with the worst performance on this indicator (Murray, 2015[18]).

3.2.2. People are still frequently left out of care decision making and policy design

People-centred end-of-life-care includes giving people an active role in planning the end of their life. People's involvement starts from clear and timely conversations on their health status and care opportunities and includes shared decision making based on their wishes (e.g. through advance care planning, see Box 3.1). Evidence exists that advance care planning conversations not only reduces patients' and relatives' anxiety and depression and clinicians' distress, but that patients further benefit by receiving less intensive treatments, receiving care in line with their wishes, and dying in their preferred place of death (Khairuddin et al., 2020[19]; Silveira, 2022[20]). Furthermore, listening to people's experiences and preferences of care through surveys and vital communities can give people voice, giving policy makers and providers a better idea of their preferences and care satisfaction, which can be fed into policy design. Nevertheless, evidence suggests that open conversations between clinicians and patients regarding death and dying and the possibilities of care rarely take place, or to a lower extent than what people wish (Bélanger, Rodríguez and Groleau, 2011[21]).

Box 3.1. Terminology: Advance Care Planning and Advance Directives

Conversations between people reaching the end of their life, their relatives and clinicians serve to provide information regarding the patient's health status and the possibilities of care and to involve them in decision making regarding the end of life.

When talking about such conversations, Advance Care Planning (ACP) refers to the process through which the people at the end of life make decisions regarding their care preferences, in a shared decision-making process. People can make their wishes clear and may designate a proxy person (or attorney) to make decisions for them when they will no longer be able to. They can also decide to include Do-Not Attempt Resuscitation (DNAR) orders within their preferences.

The terminology Advance Directives (AD) refers to the final output of the planning process, a document where all decisions made during the ACP conversation are described. The extent to which AD are legally binding varies by country and based on its content (e.g. the description of a preferred type of treatment vs a DNAR order).

3.2.3. Several barriers hamper good communication on health status and care preferences

Communication plays a key role in accepting and addressing issues related to the end-of-life phase of an individual's life, both for the individual and their family. Communication enables patients and families to be informed and involved into the decision-making process regarding the end of life. Evidence suggests the importance of communication between the person near their end of life and health care workers to reduce distress both on the patient's and clinician's side, as well as to align the care received with the person's preferences (Khairuddin et al., 2020[19]; Silveira, 2022[20]).

People and their relatives do not always perceive the communication with health care professionals to be satisfactory. In Ireland, nearly half (45%) of surveyed bereaved relatives reported that the person at the end of life was probably or definitely not aware of being likely to die, while only 40% of them reported that the news that the person was likely to die was communicated in a sensitive way (Ó Coimín et al., 2019[22]). In Sweden, 34% of surveyed family members believed that professionals provided information regarding the imminence of death in a caring and respectful way, but 33% also thought that the dying person was not aware that their death was imminent (O'Sullivan, 2021[23]). In the United Kingdom, according to the VOICES survey for bereaved families, most people (between 74% and 86%) agreed that they had received and understood information on the health status of the dying person and that they had enough time to ask questions to the staff. Nevertheless, such results were much lower in hospital settings than at home (ONS, 2016[24]).

Barriers to EOLC conversations exist on both clinicians and patients' sides. Finding the right moment to start a conversation and provide understandable and clear information can be difficult for clinicians. Clinicians often find it difficult to talk about death and prefer to provide life-prolonging treatments to give patients and their families some hope (GAO, 2019[25]; Luna-Meza et al., 2021[26]; Swerissen, 2014[5]). Data from Dutch studies report that only 38% of nursing home staff and 40% of care home staff answered four to five out of five when tested around end-of-life conversations, showing a lack of knowledge around the topic (Evenblij et al., 2019[27]). Moreover, lack of adequate space and low staff ratios in long-term care seem to hamper the opportunity for people in long-term care (LTC) facilities to engage in end-of-life care conversations. Such barriers add up to stigma and lack of adequate training which are widely shared across health care settings (Harasym et al., 2020[28]).

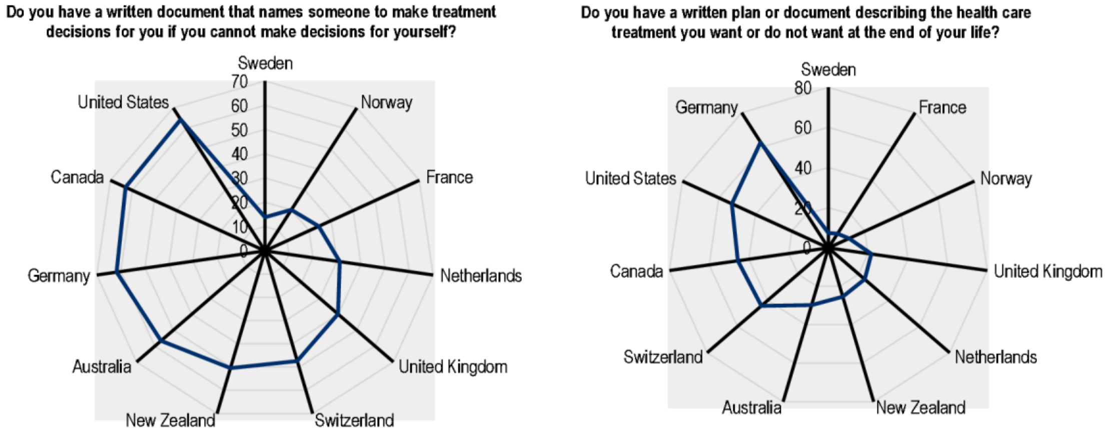
Poor understanding of the end-of-life process by patients and family members make it difficult to initiate such conversations and flag decisions not in line with patients' choices. For instance, people affected by dementia and their families may not recognise dementia as a life-threatening disease and might refuse to talk about death and dying until it becomes too late (Bamford et al., 2018[6]). Furthermore, patients may also miss the opportunity to ask questions or may even receive contradictory information from different clinicians (Brighton and Bristowe, 2016[7]; Henderson et al., 2018[8]; Khairuddin et al., 2020[19]; Travers and Taylor, 2016[9]). Clinical and technical issues may also limit the flexibility in undertaking conversations on the end of life. For instance, when the disease is too advanced, or the bureaucracy involved in expressing and ensuring a patient's wishes are carried out can feel overwhelming for a person or their families (Kononovas and McGee, 2017[29]).

3.2.4. Shared decision making does not take place to the extent people wish

Involvement in decision making and recording people's preferences is lower than what people wish. A systematic review of studies on shared decision making found that between 40% and 87% of people want to participate in decision making on their health care (Bélanger, Rodríguez and Groleau, 2011[21]). The 2021 Commonwealth Fund International Health Policy Survey of Older Adults reports that in most countries analysed, less than half of older people (aged 65 or older) have a document reporting their preferences of care or has defined a proxy person (Figure 3.2). Another survey of Australian residential aged care facilities in New South Wales showed that only a small minority (5%) of residents had completed ACP (Swerissen, 2014[5]). In France, a survey reported that 34% of adults aged over 50 would like to write advance directives, but only 13% has written one (data from 2019) (Fin de vie soins palliatifs - centre national, 2019[30]). In New Zealand the VOICES survey to bereaved family reports that only 26% of decedents had completed ACP and 51% of relatives reported that ACP was beneficial (Reid et al., 2020[31]). In Belgium and the Netherlands, ACP was applied to around 30% of terminally ill patients in 2011 and most often discussed only verbally and with the patients' families (Meeussen et al., 2011[32]). Switzerland has recorded an increase in AD completion between 2014 and 2017, moving from 25% to 36%, with much variation among its regions (Kleiner et al., 2019[3]). None of the surveyed OECD countries were able to report the total number of people completing ACP or DNAR, except for Iceland which recorded in 2020 around 247 patients with DNAR at the moment of their death and 389 with end-of-life orders recorded, compared with 1 037 people who died in Iceland from diseases that most often require EOLC.

Figure 3.2. In most countries, less than half of older adults has an advance directive

Share of older adults who replied “yes” to the following questions, in 2021



Note: Share of older adults who replied “yes” to the questions “Do you have a written plan or document describing the health care treatment you want or do not want at the end of your life?” (left-hand side) and “Do you have a written document that names someone to make treatment decisions for you if you cannot make decisions for yourself?” (right-hand side). Older adults refer to people aged 65 or older.
Source: (Commonwealth Fund, 2021[33]).

Studies analysing the practitioners’ side reveal a similar picture. In Germany, studies have reported that only 39% of physicians indicate having conversations on advance directives with patients. Most surveyed physicians also indicated a preference for patients and families to initiate a conversation about AD (Evans et al., 2012[14]). In Japan, only 29% of doctors and 28% of nurses interviewed answered that they were practicing ACP, while 48% of doctors and 57% of nurses declared that they were not planning to use ACP (Tamiya, 2018[34]).

Studies also indicate that there is a lack of knowledge around advanced directives among health professionals (Swerissen, 2014[5]). Only 16.7% of health professionals in Lithuania were familiar with the concept of advance directives, with physicians being more familiar than nurses and pharmacists (Peicius, 2017[35]). Similar results have been found in New Zealand, with nurses having scarce knowledge of the legislation regarding AD and low AD completion rate, despite viewing AD’s as being valuable to patients (Duke and Thompson, 2013[36]).

People at the end of life often experience a set of comorbidities that require several specialists. This causes fragmentation in the care received, which translates in poorer outcomes of care. Studies have found that people in the last year of life, particularly those with comorbidities and chronic illnesses are more likely to receive fragmented care, resulting in higher costs of care and more aggressive care at the end of life (Hafid et al., 2022[37]; Sharma et al., 2009[38]). When starting conversations on preferences of care at the end of life, these might involve a multidisciplinary team to minimise care fragmentation.

3.2.5. Efforts to give people voice are rising, but further development is still needed

Users' survey on experiences at the end of life are uncommon and surveys' results are rarely published (Rumbold and Aoun, 2021[39]). Collecting information on people's experiences of care and engagement in care decisions produces useful information to steer policy making. Where surveys assessing people's and families' experiences with end-of-life care exist, they are often used for internal purposes, rather than for benchmarking and policy making. The Views of Informal Caregivers Evaluation of Services (VOICES) survey in the United Kingdom collects and publishes data on the way people experience end-of-life-care services. It is a survey for bereaved family members, around the care provision in the last 3 months of life. The survey includes questions regarding the quality of conversation between people at the end of life and health care workers, the clarity of information, the kindness and respectfulness experienced, the involvement in decision making. Other countries, such as Ireland, New Zealand and Sweden translated and adapted the VOICES survey to collect similar information. The Survey of Health Ageing and Retirement in Europe (SHARE) collects information on the experiences of end-of-life care through a survey to families after the person dies. The survey asks whether the pain medication, the help with anxiety and with breathing issues was adequate, how often the personal care needs were met and how often the staff was caring and respectful with the patient. Results from years 2017-20 show that the staff was perceived as being caring and respectful most of the time. Over 70% and over 20% of people reported that the staff was respectively 'always' or 'usually' respectful and caring (SHARE, waves 7-8). Results from questions on care needs are reported in more detail in Figure 3.9 below.

The activity of palliative care professionals and associations varies greatly across countries. Such associations can help to set EOLC high in the public discussion and policy making and to ensure that the needs of the patients and their families are adequately addressed. Public involvement can help advance research by developing people-centred research questions, aid recruitment to studies, and support dissemination of findings to a wider community. Associations and lobbying groups representing people's preferences can also influence policy making and contribute to designing a more people-centred end-of-life-care. Active end-of-life care communities are starting to emerge, with certain countries showing a greater degree of community engagement and vitality. The EAPC reported that around 1 180 participants attended the 10th World Research Congress of the EAPC in Bern, Switzerland. The United Kingdom had the highest number of attending delegates (133), even more than the hosting country, Switzerland (130). The Netherlands (112), Germany (96), Belgium (55), Sweden (34), Denmark (32) and Spain (30) also had a good number of participants. These 8 countries represented more than half of all participants, showing that representation from other countries was substantially lower (Arias-Casais et al., 2019[17]). Furthermore, the 2015 Quality of Death Index measured the community engagement by looking at public awareness of palliative care and the availability of volunteer workers. New Zealand and Belgium ranked at the top, followed by France and the United Kingdom (The Economist Intelligence Unit, 2015[40]).

Compassionate communities, which can contribute to awareness around EOLC and support families going through the process, have developed in the past decade, but are still incipient in many countries. Compassionate communities consist of groups of people who are engaged in their communities to provide support to people with life threatening and life limiting diseases who are near the end of their life and to everyone who is experiencing death and dying of loved ones. Such communities represent a way to ensure that all people's needs are considered, holistically, providing psychosocial and spiritual support to the people at the end of life and their families. Furthermore, compassionate communities can also facilitate discussion about the end of life and advance care planning. Some evidence of the impact of compassionate community exists and has found that they improve patients' and carers' quality of life, influence the place of death, and reduce unplanned visits and hospitalisations. For instance, results from Spain show lower unplanned hospitalisations while evidence from the United Kingdom reports both lower unplanned hospitalisations and lower patient isolation (Aoun et al., 2020[41]). A systematic integrative review on the existence of compassionate communities worldwide found articles with respect to 22 communities, of which 11 were in Europe, 6 in South America, 2 in Australia and 1 in Canada and such communities were mostly limited to an individual town. One common trait across communities is that they involve schools, local organisations, media, and politicians. Despite their bottom-up implementation, compassionate communities often require political support, to allow for better development and funding, especially since ensuring the sustainability of initiatives can be a challenge (Quintiens et al., 2022[42]).

3.2.6. Disparities in treatment and care are apparent

Factors such as ethnicity and cultural background, gender, age, as well as the type of disease can influence the type and quantity of care people receive at the end of their lives. Despite a growing diversity, ethnic and cultural disparities at the end of life persist in OECD countries. Women seem to receive more EOLC, compared to men, and younger people have easier access to this type of care compared to older patients. Moreover, cancer patients receive EOLC more often than patients affected by other diseases do. A review of reviews regarding conversations at the end of life and advance care planning found that discussions happen most often with patients who are older, white, female, well-educated and with cancer or comorbidities (Hall, Rowland and Grande, 2019[43]). The health care sector must ensure equal access to a comfortable end of life, attaining the highest possible quality of life until the very end. Providing a truly people-centred EOLC entails offering care that is appropriate and tailored to the individual. Differences in age, disease type, gender, ethnicity, and cultural background should be considered to provide tailored care but should not represent causes of discriminations or disparities.

Ethnic and cultural disparities persist despite growing diversity

Ethnic minorities constitute a growing part of OECD societies. Ethnic diversity has increased and is forecasted to increase even more in a number of countries, such as Australia (from 31% in 1996 to 38% in 2016 (Wilson et al., 2020[44])), New Zealand (from 27% in 2018, to 25% in 2013 (Stats NZ, 2019[45])), United Kingdom (non-white groups expected to represent around 20% of the population in 2051 (Natalia Calanzani, 2013[46])) and the United States (ethnic minorities are estimated to constitute 40% of the population over 65 by 2050 (Martina Orlovic, 2019[47])).

Despite growing ethnic and cultural diversity in OECD countries, disparities in access to end-of-life care among minorities persist. Several studies have shown that ethnic and cultural minorities tend to receive less end-of-life care, compared to the general population. Furthermore, minorities are more likely to receive more aggressive care at the end of life and less likely to plan care in advance, resulting in care that is inconsistent with the patients' preferences (Ejem et al., 2019[4]). While most of the studies on the topic have been carried out in the United States, similar results have also been found in Australia, Canada, New Zealand, and the United Kingdom. In the United States, the National Hospice Palliative Care Organisation has found that a large majority of palliative care users are White/Caucasian (81% in 2013), a high percentage compared to their size within the general population (estimated to be 60% in 2019 (United States Census Bureau, 2019[48])) (NHPCO, 2022[49]). Low use of end-of-life care services among minority groups has also been encountered in Australia (Clark and Phillips, 2010[50]), Canada (Yarnell et al., 2020[51]), New Zealand (Nelson-Becker and Moeke-Maxwell, 2020[52]) and in the United Kingdom (United Kingdom) (Marie Curie Cancer Care, 2014[53]). These results are even more concerning when considering that often minorities have higher rates of chronic illness and higher death rates from chronic illnesses that require end-of-life care (Isaacson and Lynch, 2017[54]). Moreover, ethnic minorities are less likely to plan their end of life in advance compared to White/Caucasian Americans, a finding that holds even after controlling for cultural and religious belief (Orlovic, Smith and Mossialos, 2019[55]).

Poor information and understanding of end-of-life care, together with the language barrier hinder access to good end-of-life-care for ethnic and cultural minorities. Studies from the United States on Mexican American end-of-life care recipients aged 50 or older report difficulties in accessing information in their native language. Policies aimed at improving end-of-life care knowledge and discussion mainly produced adverts in English, while Spanish translations were rarely available. Moreover, even Mexican American patients who are generally proficient in English encountered serious difficulties carrying out health care discussions in English, when they were distressed (Crist et al., 2018[56]).

Beyond the language barrier, broader cultural barriers often appear to cause disparities in access to end-of-life care, as misunderstanding can arise from cultural differences between patients and clinicians. Misalignment in perceptions between health care providers and patients are an issue, with clinicians feeling empathetic and open to communication and patients perceiving a very detached approach from the health care side (Isaacson and Lynch, 2017[54]). Furthermore, an analysis involving Colombian physicians reported that professionals face greater challenges when starting end-of-life-care conversations with indigenous population, which can, in some cases, be particularly reluctant to talk about death due to cultural taboos (Luna-Meza et al., 2021[26]). Personal beliefs and cultural factors can shape care preferences, with some cultures valuing patient autonomy while others placing greater value on family support and involvement in decision making. Informed consent and end-of-life care discussion can be a cause of anxiety and depression for some cultures, while others want to be protagonist of their health care choices for as long as possible (Clark and Phillips, 2010[50]).

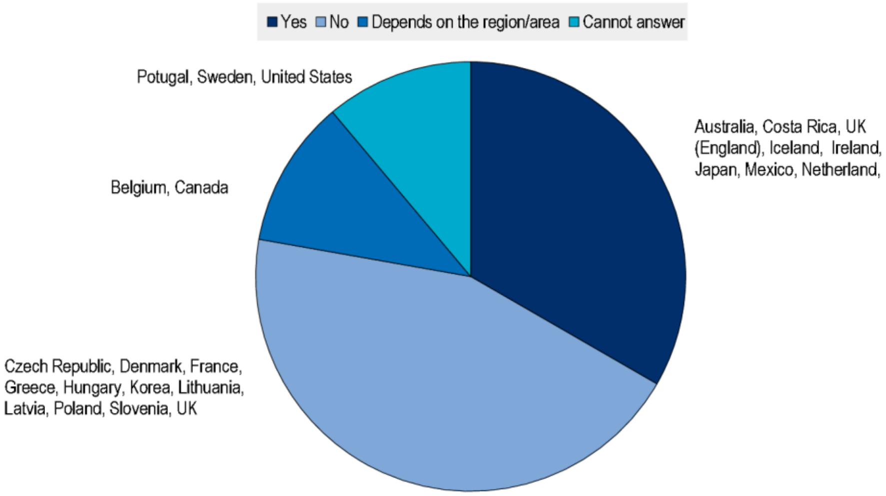
Mistrust and lack of familiarity with the health care sector might also explain the lower access to end-of-life care and early planning of end-of-life care. Patients from ethnic minorities sometimes express a strong preference for intensive treatment and they refuse to have treatments withheld at the end of life due to a perceived unequal access to the health system throughout their life (Orlovic, Smith and Mossialos, 2019[55]) and thus fear of under treatment (Connolly, Sampson and Purandare, 2012[57]). In the United States, African American and Hispanic people tend to receive more intensive care at the end of life and are more often hospitalised for symptom relief at the end of life than White/Caucasian Americans. Misunderstandings between the patient's and clinicians' side further boost the sentiment of distrust (Laguna et al., 2012[58]).

The COVID-19 crisis has exacerbated ethnic and cultural disparities at the end of life. The measures in place to stop the spread of the virus have been challenging for all patients at the end of their life and their families, regardless their background and beliefs. Nevertheless, minorities appeared particularly affected by these measures. Wearing masks made communication particularly complicated for non-native speakers. Visiting restrictions reduced the possibility to rely on external translators and hindered the possibility to fulfil religious and cultural rituals and responsibilities. Face-to-face access to faith leaders from ethnic minorities was limited, restraining the opportunities to receive adequate spiritual support at the end of life (Bajwah et al., 2021[59]). In Italy and Spain, migrants were more likely to be hospitalised, while France, the Netherlands, Sweden and the United Kingdom recorded higher all causes mortality among migrants in 2020, compared to previous years (Kumar et al., 2021[60]). Results from a survey conducted in the United Kingdom have also highlighted disparities in accessing adequate care. Among service providers, hospitals were more likely to care for patients coming from minority groups, compared to hospice and home care teams. Finally, care was rarely tailored on the specificities of the patients. Most respondents (66%) reported supporting all patients in the same way, regardless their ethnic and cultural background (Bajwah et al., 2021[59]).

Despite this, measures to address the abovementioned barriers to people-centred end-of-life care are not widespread. Currently only 10 out of 24 OECD countries have developed some form of regulation to take cultural aspects into account in the decision-making process around the end of life (Figure 3.3).

Figure 3.3. Only a minority of OECD countries consider cultural differences in decision-making at the end of life

Share of countries that replied "yes" to the question "Do you have regulation or policies to take into account cultural differences in the decision-making for care and support at the end of life?"



Source: (OECD, 2020-2021[16]).

Cancer patients are more likely to receive EOLC

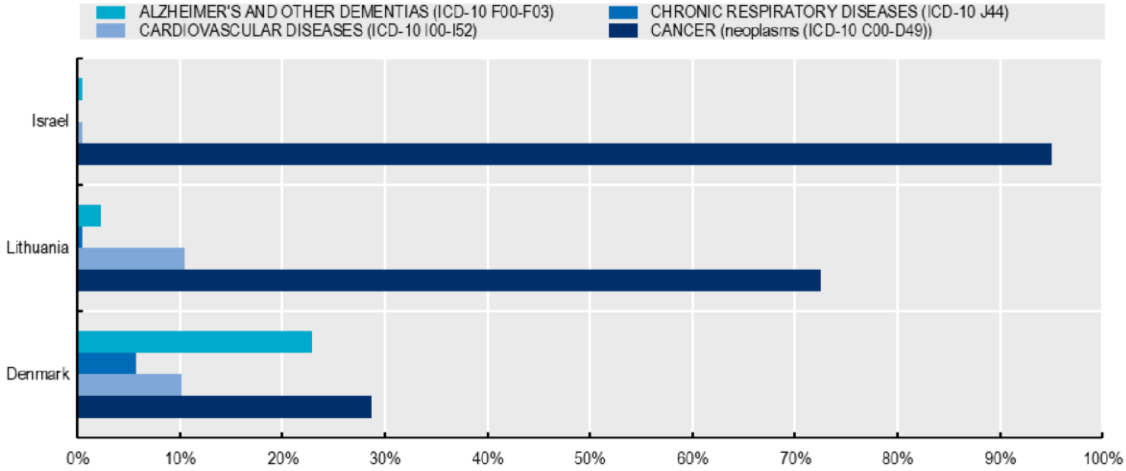
Another element of disparity at the end of life is the diagnosis. Cancer patients are more likely to receive hospice care and to plan care in advance than non-cancer patients are. Cancer and dementia patients also report better quality of care at the end of life. A study performed in Australia showed that, in 2010, 69% of people who died from cancer had access to palliative care during the last year of life, compared to only 14% of non-cancer patients (Sleeman et al., 2015[61]). Similar results also come from Canada, Ireland, and the United Kingdom. In Canada, people with cancer diagnoses are up to three times more likely to receive palliative care in the last year of life (CIHI, 2018[62]). In the United Kingdom, a study reported that between 2012 and 2013, most patients (75%) who received hospice care at home were cancer patients (Buck et al., 2020[63]). This mirrors findings from Germany that the overall percentage of non-cancer diseases receiving palliative care is disproportionately low, with barriers to palliative and hospice care for these patients persisting (Stiel et al., 2015[64]). Already in 2003, the Irish House of Commons recognised the inequity in access to palliative care services for non-cancer patients (Irish Department of Health, Social Services and Public Services, 2010[65]). The share of non-cancer patients receiving end-of-life-care in Ireland has increased in recent years but remains a minority. For specialist palliative care in the community, the share of non-cancer patients was 17% in 2010 and 30% in 2016, while for inpatient care it moved from 7% to 14% over the same period (HSE, 2017[66]). family members of palliative care recipients who died from cancer reported significantly better quality of EOLC with higher rates of palliative care consultations and do-not-resuscitate orders and fewer deaths in the intensive care units as the causes of higher quality palliative care (Wachterman et al., 2016[67]). These findings may be partially explained by palliative care having historically focused on those with cancer and the bulk of literature informing palliative care practices stemming from the care of cancer patients (Bostwick et al., 2017[68]). On the other hand, cancer patients are also more likely to be hospitalised during the last year of life in OECD countries, despite cancer having a more predictable trajectory at the end of life compared to other diseases and therefore being easier to plan for (De Korte-Verhoef et al., 2014[69]; OECD, 2020-2021[16]; Vestergaard et al., 2020[70]).

The OECD analysis of data from Denmark, Israel and Lithuania shows a large difference in access to palliative care across disease groups is striking in all the countries has produced similar results

(Figure 3.4). The difference analysed and particularly so in Israel, where the overwhelming majority (95% in 2018) or patients receiving palliative care services are cancer patients. The differences in access to palliative care are less striking in Denmark, where patients with highest access to palliative care are cancer (29% in 2019) and dementia (23% in 2019) patients, while patients affected by chronic respiratory diseases and cardiovascular diseases are less likely to receive palliative care (respectively 6% and 10% in 2019).

Figure 3.4. Cancer patients are far more likely to receive palliative care services compared to patients affected by other diseases

Share of patients receiving palliative care services, by disease group, 2020 (or closest year available)



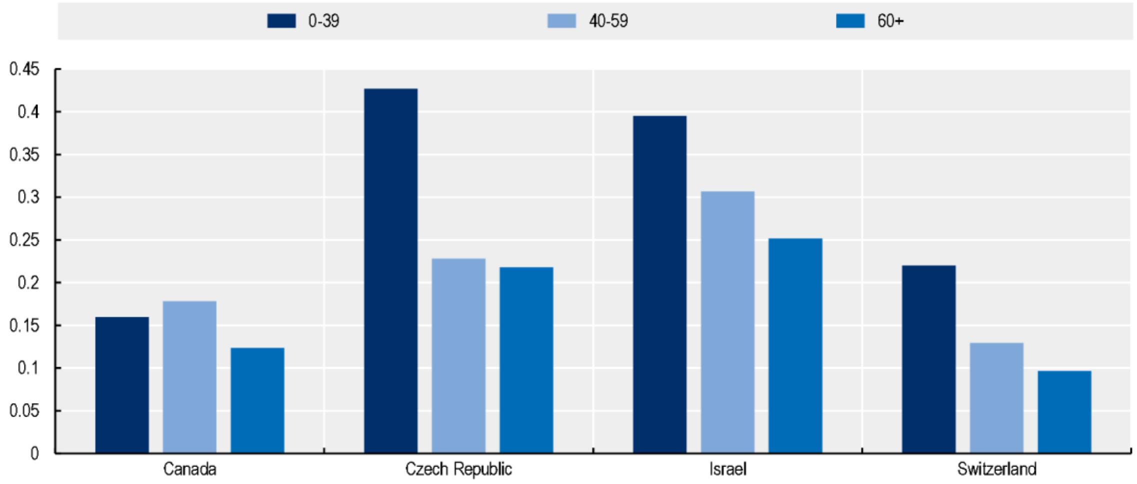
Note: Data refer to 2018 (Israel), 2019 (Denmark), 2020 (Lithuania).
Source: (OECD HCQO-EOLC pilot, 2021[71]).

Patients' age influences care preferences and treatment at the end of life

Both care preferences and the care received at the end of life seems to vary depending on the patients' age. Younger patients usually tend to prefer more life-prolonging treatments compared to older patients, who tend to value less aggressive care more. At the same time, older patients appear to be less likely to receive desired life-prolonging treatments than younger patients are, while younger patients are less likely to avoid unwanted life-prolonging treatments. These results have been found by a study on deceased cancer patients in the United States (Parr et al., 2010[72]). Similar findings come from France, where an analysis of French hospital databases showed that a high proportion of young cancer patients (61%) received chemotherapy in the last 14 days of life, and/or were admitted to hospital, intensive care units, emergency departments during the last 30 days of life (Das, 2019[73]). Several studies have also found that ICU and intensive treatment decrease with age (Bylicki et al., 2019[74]; Levinsky et al., 2001[75]; Menec et al., 2007[76]). An analysis of the OECD data on ICU admissions in Canada, Czech Republic, Israel, and Switzerland indicates a decreasing rate of admissions in the last 30 days of life as the age of the patient increases (Figure 3.5)

Figure 3.5. During the last 30 days before death, younger people are more often admitted to ICU

Share of people admitted to ICU during the last 30 days before death among people who died in the reference year

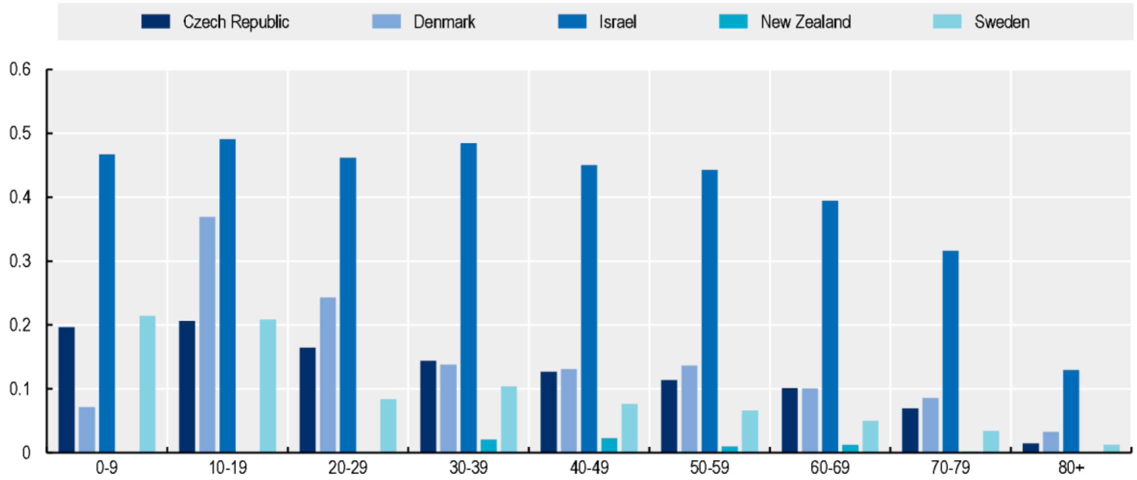


Note: Data refer to 2018 for Canada, Israel, and Switzerland and to 2019 for the Czech Republic.
Source: (OECD HCQO-EOLC pilot, 2021[71]).

Data on chemotherapy received highlights that younger patients are associated with higher use of chemotherapy in the last 30 days prior to death (Figure 3.6). Other studies also found similar results (Abdel-Razeq et al., 2019[77]; Hui et al., 2013[78]; Mathew et al., 2017[79]; Randén et al., 2013[80]; Zhu et al., 2018[81]). This mismatch between patients' preferences and care received might be driven by a societal bias. The death of younger people is less acceptable than that of older people. Thus, older people asking for and younger people avoiding life-prolonging treatments both challenge this societal norm (Parr et al., 2010[72]).

Figure 3.6. Younger people are more likely to receive chemotherapy in the last 30 days before death

Share of people who died in the reference year, who received chemotherapy in the last 30 days before death

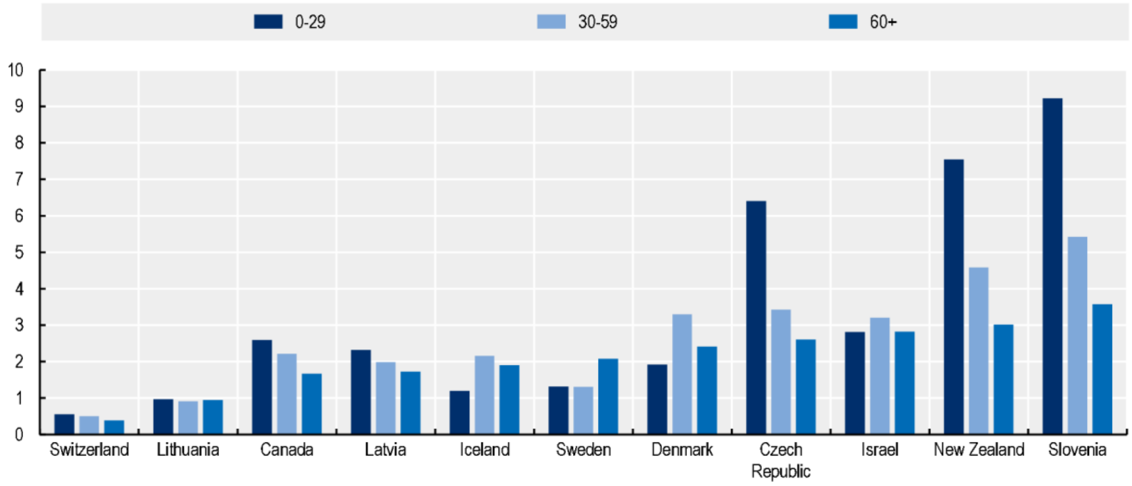


Note: Data refer to 2017 for New Zealand, 2018 for Israel, 2019 for the Czech Republic and Denmark, 2020 for Sweden.
Source: (OECD HCQO-EOLC pilot, 2021[71]).

Finally, an analysis of hospital admissions during the last year of life in 11 OECD countries shows that people aged 60+ are less likely to be admitted to hospital during the last year of life than those aged 30-59 in all countries except Lithuania and Sweden. However no clear trend exists between age groups (Figure 3.7).

Figure 3.7. People aged 60+ are less likely to be hospitalised during the last year of life

Ratio of hospital admissions during the last year of life per death (for patients who died in the reference year)



Note: Data refers to 2017 for Slovenia, 2018 for Canada, Israel, and Switzerland, 2020 for Sweden, 2019 for other countries.
Source: (OECD HCQO-EOLC pilot, 2021[71]).

Males tend to receive more aggressive care at the end of life

Gender can also be listed among the factors determining disparities at the end of life. Evidence has shown that, when death nears, females are more likely to receive palliative care while males tend to receive more aggressive care until the end of life (Gott, Morgan and Williams, 2020[82]; Saeed et al., 2018[83]; Singh et al., 2017[84]). An analysis performed by the OECD also supports these findings, with only 27% of males receiving palliative care services in Denmark in 2019, a lower share compared to females (41%). Moreover, it appears that when males receive palliative care services, they are more likely to receive it only during the last days or weeks of life (Table 3.1).

Table 3.1. Males are more likely than females to receive palliative care for less than one month before dying

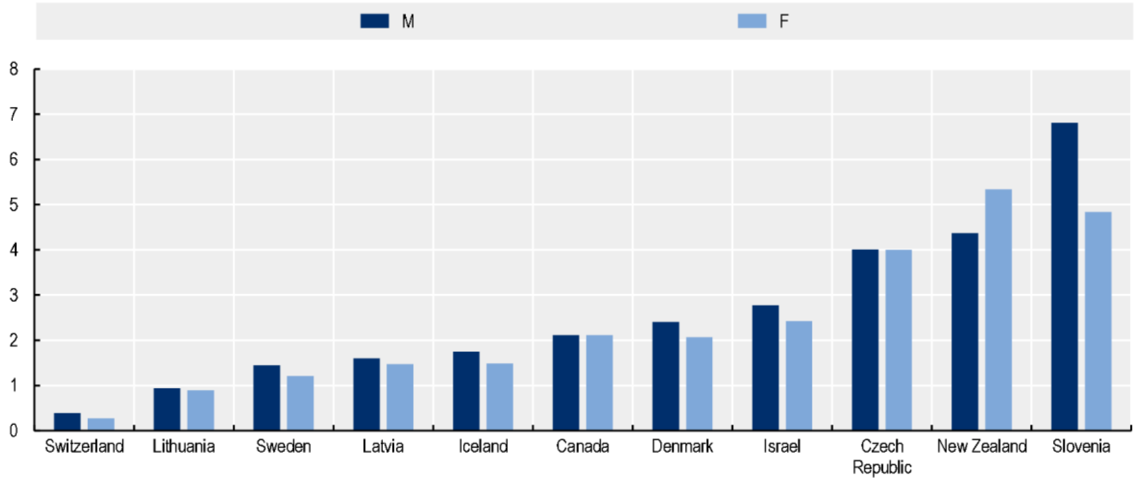
Country	Year	Share of males receiving palliative care for less than one month before death	Share of females receiving palliative care for less than one month before death
Denmark	2019	77%	69%
Israel	2018	82%	77%
Lithuania	2020	54%	42%

Source: (OECD HCQO-EOLC pilot, 2021[71]).

Figure 3.8 shows that a higher share of patients hospitalised during the last year of life are males. Furthermore, an analysis performed by the OECD has found that males are more often admitted to ICU during the last 30 days before death than females, in Israel (26% of males vs 19% females in 2018) and Switzerland (10% of males vs 6% females in 2018). Similar results have been found for ED admissions in the last 30 days before death. Finally, the share of males receiving chemotherapy during the last 30 days of life is higher than that of females in Denmark and Israel (8% vs 7% in Denmark in 2019 and 30% vs 26% in 2018 in Israel).

Figure 3.8. A higher rate of patients hospitalised during the last year of life are males

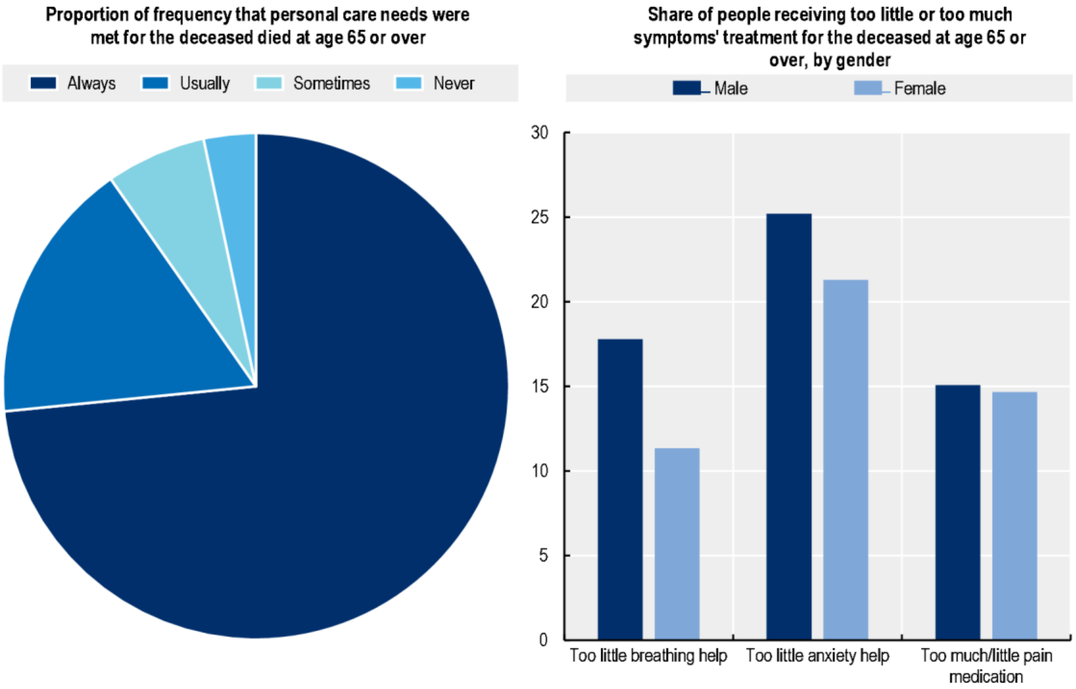
Ratio of hospital admissions during the last year of life per death, by sex



Note: Data refers to 2017 for Slovenia, 2018 for Canada, Israel, and Switzerland, 2020 for Sweden, 2019 for other countries.
M = male, F = female.
Source: (OECD HCQO-EOLC pilot, 2021[71]).

Men seem to be more likely to receive too little or too much treatment compared with women (Figure 3.9), according to the Survey of Health, Ageing and Retirement in Europe (SHARE) which asks family members of deceased older people (aged 65 or older) whether symptoms' treatment was sufficient at the end of life. This occurs despite most people reporting that care needs were always (73%) or usually (17%) met.[3]

Figure 3.9. Men experience worse symptoms treatment than women



Note: Data weighted using cross-sectional weight from last core interview.
Source: SHARE Waves 7 and 8.

The provision of more aggressive types of care to male patients seems to be in line with their preferences. Females tend to prefer palliative care over other types of care at the end of life, while the opposite holds for males (Gott, Morgan and Williams, 2020[82]; Saeed et al., 2018[83]). The reasons underneath this gender difference in preferences of care and care received seem to be partly related to a persistent cultural bias. Societal norms still tend to see men as less vulnerable than women, a bias which might influence male patients' preferences of care. Male patients might be reluctant to seek palliative care as they might perceive it as a sign of weakness to give up the fight against the diseases (Gott, Morgan and Williams, 2020[82]). Better information around the importance of palliative care has proven to improve the acceptance of palliative care services (Saeed et al., 2018[83]; Hoerger et al., 2017[85]). Thus, improving general population's knowledge around EOLC might be beneficial in closing this gender gap.

3.3. How can countries make end-of-life care more people-centred?

Countries have adopted in recent years a range of measures to provide more people-centred EOLC. Several best practices adopted by countries are discussed in this section. Policies contributing to people-centredness of EOLC include the following: i) initiatives to improve discussion on death and dying and to address disinformation and stigma related to the end of life; ii) policies to increase the involvement of communities and professional associations in helping families and promoting public awareness; and iii) strategies to provide clinicians with the training needed to engage in the right communication with EOLC patients and their relatives and boost the use of instruments to plan care in advance.

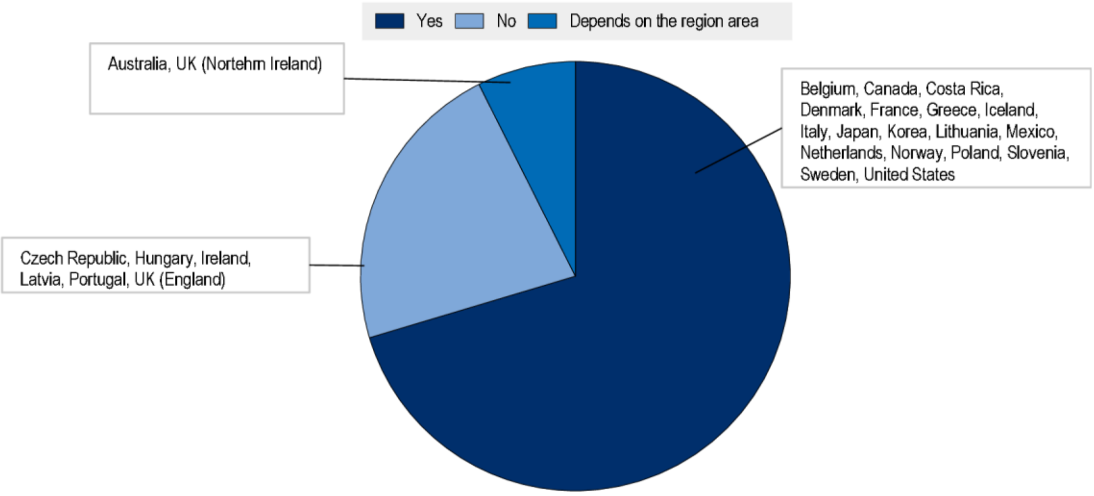
3.3.1. Expanding information available and knowledge on end-of-life care across professionals, patients, and families

Improving the knowledge around end-of-life care in the general population, as well as health care professionals may reduce misconceptions. Being informed about EOLC is often correlated with higher recognition of its importance or willingness to use such services, showing the crucial role of information to develop a more people-centred EOLC. In Switzerland, people who knew about advance care planning or used it in the past had more positive perceptions of it than people with low knowledge of such concepts (Kleiner et al., 2019[3]). In the United States, nine out of ten adults interviewed recognised the importance of these services after receiving a brief description of what palliative care entails (Lane, Ramadurai and Simonetti, 2019[13]).

Considering the lack of awareness and information around EOLC services, countries are making efforts to improve the provision of information to patients in need of EOLC. Data collected by the OECD Secretariat indicates that 67% of responding OECD countries have some form of regulation requiring patients and families be informed of decisions regarding their EOLC, while 8% report having regulations at least in some regions or areas (Figure 3.10).

Figure 3.10. Most OECD countries have regulations around the provision of EOLC information to patients and their families

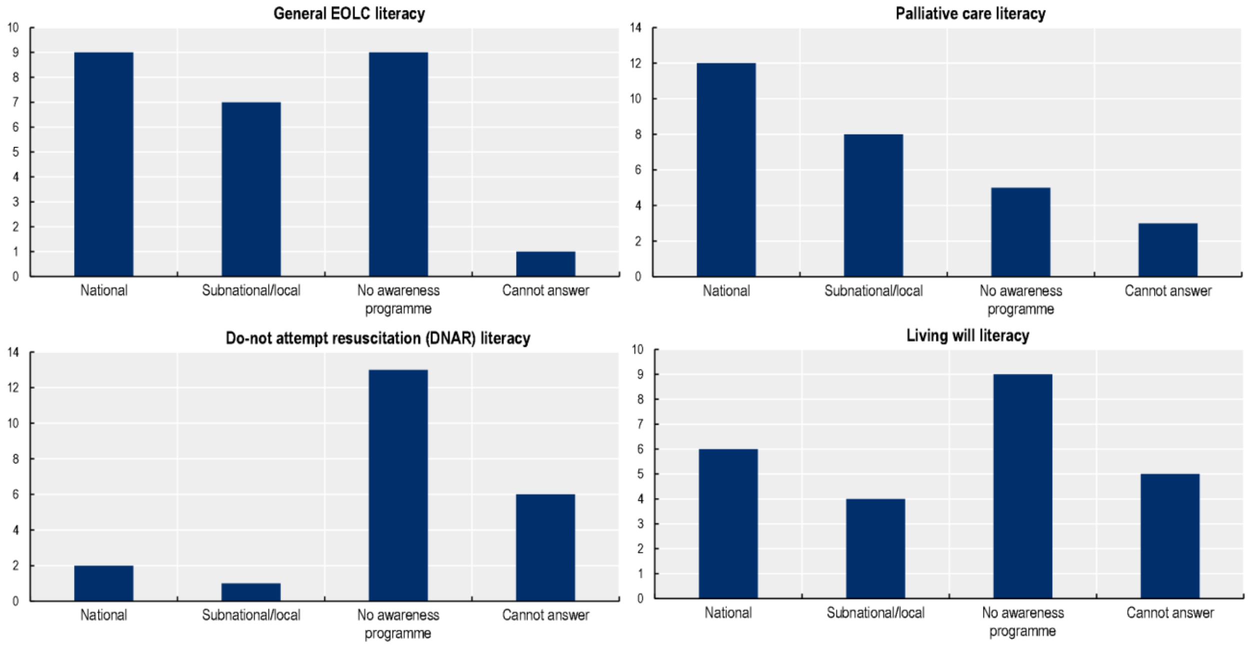
Share of countries that replied "yes" to the question "Do you have regulation requiring that patients and families be informed of the decisions regarding EOLC?"



Note: N=27.
Source: (OECD, 2020-2021[16]).

OECD countries are also developing programs to improve information and awareness regarding the end of life in the general population, although more still needs to be done. Among the surveyed OECD countries, 83% declare having programs at the national and/or subnational level on palliative care literacy, 72% on general EOLC literacy, 45% on living will literacy and only 14% on Do-not Resuscitate (DNAR) literacy (Figure 3.11). The data shows that programs providing general information on end-of-life care or palliative care are more common than programs on more specific topics such as living wills and DNAR. While it is important to build awareness on care opportunities, it is also crucial that people are informed regarding their advance care planning opportunities (e.g. living wills and DNAR), to let people become real decision makers of their own care choices.

Figure 3.11. Existence of national or subnational programs that focus on improving general population's understanding or knowledge of EOLC



Note: General EOLC literacy: N=22; Palliative care literacy: N=24; DNAR literacy: N=22; Living will literacy: N=22.
Source: (OECD, 2020-2021[16]).

Some countries already developed programs to improve the provision of care at the end of life and raise awareness around the topics of death and dying among the general population, as well as among care providers. Talking about end-of-life care, including it among the topics of discussion on television (TV) and social media can help normalising the topic and reducing the stigma around it. Such programmes and campaigns have been organised in countries such as Japan, Korea, Luxembourg, Norway, Slovenia, and the United States (see Annex for more detail). In the United Kingdom, the organisation "Hospice UK" makes grants available for specific projects aiming at sharing information regarding the end of life in an innovative way (e.g. through art). Grants can go from GBP 999 to GBP 5 000. The latest programme opened in 2021 (Hospice UK, 2021[86]).

Programmes and campaigns have been used to spread information around EOLC among the general population through a variety of media platforms have been successful at dissemination. For instance, Australia has put in place eight different programs between 2015 and 2020, developed at the governmental (national) level and by non-governmental organisations, with a duration of at least one year. Four of the programs focussed on raising awareness and sharing information in the general public regarding death, dying and opportunities of care at the end of life. In the effort to involve a wide audience, such programs have been shared on TV, radio, and social media, as well as advertising billboards and flyers. The programs also included tailored communication to make the programme easily understandable for cultural minorities. For instance, the initiative "Palliative care: it's more than you think" shared videos with animated characters showing the benefits of palliative care with a light and entertaining style. The initiative's webpage also shares the stories of people who have gone through the end of life of a loved one, providing an opportunity to gather information around EOLC. In Ireland, in the last decade, such programs were organised by non-governmental organisations and endorsed by the Ministry of Health, targeting the general population and diffusing information through broad media involvement. Dissemination channels included TV, radio, social media, advertising billboards and flyers. In France, in 2016 the government established the "Centre national des soins palliatifs et de la fin de vie" to disseminate information around the end of life among the population and the health care workers, participate into decision-making to improve the support to people at the end of life and to collect data regarding end-of-life care. The centre also has a platform that people can contact to receive specific information on the end of life (Centre national des soins palliatifs et de la fin de vie, 2021[87]). Furthermore, the centre launched TV campaigns in 2017 and 2018 sharing information regarding the end of life and the possibilities to plan care in advance. France also used a website and social media to diffuse information to the general population and to professionals (Centre national des soins palliatifs et de la fin de vie, 2021[87]). Although awareness around end-of-life care conversations among the population and use of advance directives still show room for improvement, data from 2019 show that information around advance directives was widespread within LTC facilities, with 86% of LTC facilities' managers showing good knowledge. Furthermore, 84% of the respondents who were informed around end-of-life care, reported having acquired the information through the media. Such results show that the programs and campaigns can be an effective way to improve the general population's awareness around end-of-life care (Fin de vie soins palliatifs - centre national, 2019[30]).

In the United Kingdom, discussion around end of life has recently gained momentum, partly thanks to the death awareness movement. The movement aims at increasing awareness and reducing the stigma around death and dying and proposes alternative activities to discuss such topics. Examples are the death cafes and the coffins clubs. The death cafes represent an occasion for people to meet, have a drink and discuss death, while the coffins clubs are an international initiative (with eight groups in the United Kingdom) organising events where people can meet to make their own coffins and discuss death (Hansford, Thomas and Wyatt, 2022[88]).

Some countries developed programs that consisted of conferences and webinars for the general population, but also training for professionals on the topic of the end of life. For instance, Iceland organised programs to address attitudes towards death and dying and to monitor the quality of EOLC services. Five programs (four governmental and one non-governmental) took place between 2015 and 2016, with most of them lasting for a few hours or less than one month. Three of the programs consisted of a conference open to the general population, involving communities and services providers. Four Australian programs targeted health care providers, to train health care workers and improve the quality-of-care services for people at the end of life. The programs involved health providers and local communities. In the last decade, an international third sector partnership has started the 'Last Aid' project, which aims at providing training on end-of-life care to everyone interested in the topic. The project is carried out through a collaboration of partners of the third sector (i.e. the Paula Kubitscheck-Vogel-Stiftung foundation, the Würdezentrum think tank, Startsocial and the University of Southern Denmark) and currently provides training in several countries worldwide (around 20), including Norway, Denmark, Switzerland, Lithuania, Austria, Australia, Brazil, Slovenia, and Scotland, among others. Around 40 000 people have already received the training and around 3 500 instructors have received training. The courses are brief – they can typically be compacted into one afternoon – and cover four areas: i) dying as a part of life; ii) provision and decision; iii) relieve suffering; iv) farewell (Last Aid, 2022[89]).

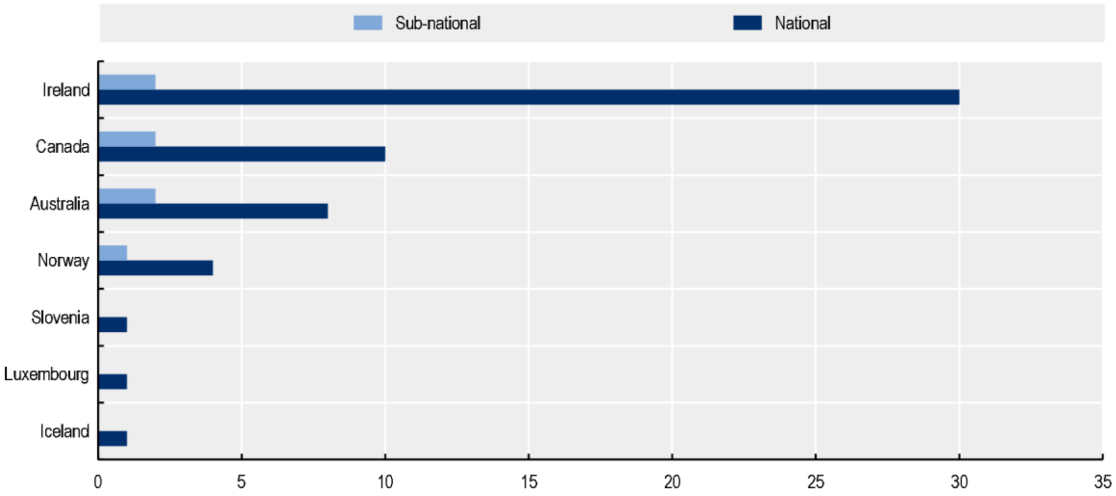
Furthermore, there are several possible measures to address ethnic disparities at the end of life, such as translating relevant material on end of life, simplifying sentences, and using culturally relevant metaphors. Adapting campaigns and programs for minority languages can help improve end-of-life care knowledge among all communities within OECD countries. Improving information around the end of life entails sharing the message that end-of-life care is available for every person affected by a life-threatening and life-limiting disease, who might reach their end of life soon, regardless their diseases, age, gender, ethnic and cultural background.

3.3.2. Fostering the voice and engagement of families and communities in public discussions

A vibrant EOLC community, with active associations and lobbying groups can play a role in diffusing knowledge around the end of life, reduce the stigma attached to end-of-life care and influence decision making, placing EOLC higher in the agenda. Figure 3.12 shows the number of associations and lobbying groups devoted to end-of-life care and/or palliative care in 7 OECD countries, whose data are available. Ireland reports the highest numbers with 30 national and 2 subnational associations, followed by Canada, Australia, and Norway, with 5 or more associations/lobbying groups. Iceland, Luxembourg, and Slovenia reported at least one at the national level. Associations and lobbying groups on EOLC/palliative care also exist in Japan and in the United States. Although a comprehensive list is currently missing, Japan counts at least 3 national associations/lobbying groups and the United States at least 10. Colombia has been developing end-of-life-care since 2014. As of 2021, there are two national associations with associates coming from 17 out of the 33 regions. Colombia also organises biannual national palliative care congress (Sánchez-Cárdenas et al., 2021[90]).

Figure 3.12. Number of associations/lobbying groups devoted to EOLC/PC

Number of associations/lobbying groups devoted to EOLC and/or palliative care



Source: (OECD, 2020-2021[16]).

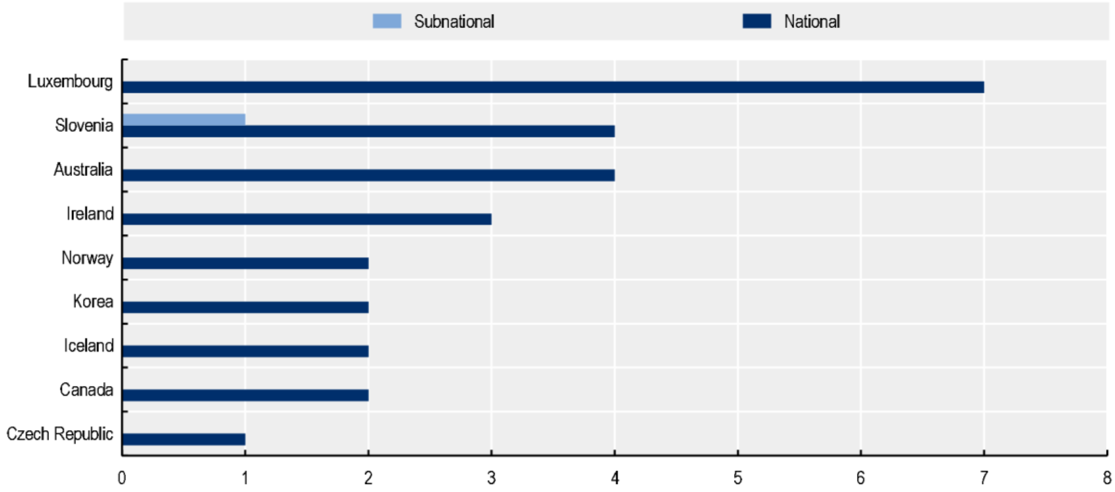
As of 2019, most European countries had established at least one national association on palliative care, but only around 24 European countries had established more than one. Among the latter, Germany, Norway, the Netherlands, Switzerland, and Latvia established a specific association on palliative care for children. Poland, Portugal, and the United Kingdom have established palliative care nursing national associations (Arias-Casais et al., 2019[17]). Among Latin American countries, Chile, Colombia, and Costa Rica had more than one association but Mexico had none reported.

There are also examples of international associations focusing on EOLC and palliative care. The EAPC, for instance, has specific task forces for prisoners, migrants, refugees in need of palliative care, as well as the EAPC primary care group. Such groups carry out research on possible innovative palliative care services. Such associations focusing on specific groups of people might improve the awareness around the needs and wishes that these groups of people might have at the end of life and share tailored information around the end of life among these groups. Improving the understanding of minorities' needs at the end of life can contribute to the reduction of disparities and the provision of people-centred EOLC.

Belgium, Germany, Italy, and the Netherlands also have associations devoted to end-of-life care and/or palliative care. Belgium has both associations and networks engaged in the diffusion of information on these topics and in raising awareness among the general public. In Germany, the German Association for Palliative Medicine (DGFP) is active on several fronts. It carries out lobbying activities, while it also spreads knowledge around EOLC and palliative care through the organisation of congresses, meetings of working groups as well as publications. Germany also has specific associations for the provision of palliative care at home and for children. In Italy, there is the Italian Society for Palliative Care (SICP) – a professional association – as well as the Palliative Care Federation, which is composed by NGOs and works in close contact with the SICP. The Netherlands also has several specialised associations and foundations on EOLC and or palliative care (Arias-Casais et al., 2019[17]). The work of such associations contributes to a more people-centred EOLC on several fronts. Developing and sharing informative material helps improving the awareness around the end of life among the general population and sparks public discussion. Furthermore, participating to the policy making and collaborating with governmental bodies allows such associations to make the needs and wishes of people heard and represented in policies (IAHPC, 2022[91]).

Figure 3.13 shows the number of national and subnational professional associations on EOLC/palliative care.[4] All responding countries but Slovenia only report associations at the national level. The number of associations ranges from one in the Czech Republic, to seven in Luxembourg. Luxembourg reported the highest number of professional associations despite its modest country size, showing that the professional environment on the topics of EOLC and palliative care is likely to be lively.

Figure 3.13. Number of EOLC/palliative care professional associations



Source: (OECD, 2020-2021[16]).

Compassionate communities aim at fostering the voice of people at the end of life and support people with life-limiting diseases, those facing dying, death, caregiving, and grief to live well in communities that are aware and well informed around death, dying and end-of-life care. Over the past decade, compassionate communities have started to develop across OECD countries. Some countries have included the development of compassionate communities among their goals and have incentivised people to volunteer. For instance, the government of the United Kingdom has included the creation of compassionate communities among the objectives of the “Ambitions for Palliative and End-of-life care 2015-20”, which has then been reviewed in 2019 and relaunched in 2021, covering the period 2021-26 (NHS UK, 2021[92]). In New Zealand, Hospice New Zealand included community engagement among the goals of its strategic plan, and in Spain there is a strong community of volunteers providing end-of-life care who are involved in fundraising and in some cases receive training (The Economist Intelligence Unit, 2015[40]).

Examples of compassionate communities across OECD countries are in Belgium, Canada, Costa Rica, Germany, New Zealand, Spain, United Kingdom, and the United States. In the United Kingdom, the cities of Inverclyde (Scotland) and Plymouth (England) are examples of compassionate cities. In Inverclyde and Plymouth, community engagement and development to support people dealing with an end-of-life experience has involved a plethora of communities (schools, churches, workplaces, community centres, hospital, local hospice, youth groups and voluntary organisations). In Plymouth, there has been a focus on people who are homeless or in prison, and on improving death literacy through an education programme for children and their families. In Spain, the city of Vic developed a plethora of different activities (e.g. cultural initiatives, training, informative events) and has shown high participation and satisfaction of participants. In Germany, the city of Cologne started working on the development of compassionate community project in 2018, with a participatory round table open to all interested stakeholders (PHPCI, 2022[93]). Furthermore, in the United States the Conversation Project distributes free material online to learn about end-of-life care and end of life conversations and Costa Rica has developed a network of day centres and volunteer teams (The Economist Intelligence Unit, 2015[40]). More recently – in 2020 – Bruges became the first compassionate city in Belgium and organised a festival of compassionate communities in September 2022, hosting a selection of cultural activities to raise awareness around death and dying (End of life care research group, 2022[94]).

In some countries, national non-governmental organisations are playing an important role in the development of compassionate communities across the country. This is the case of Compassionate Communities UK, a charity that aims at supporting communities to build compassion by providing guidance through a consultancy service, offering education programmes, providing support and expertise to plan and manage projects. Since the onset of the COVID-19 pandemic, Compassionate Communities UK also provided specific guidelines to develop compassionate neighbourhoods during a pandemic (Compassionate Communities UK, 2022[95]). In Canada, the non-profit organisation Pallium Canada engaged in accelerating the creation of compassionate communities across Canada. Pallium Canada provides information and guidelines regarding compassionate communities, provides a toolkit to start new compassionate communities and an evaluation toolkit to measure the impact of such communities. They also set up the compassionate communities' exchange, an online space where members of compassionate communities can meet and exchange to learn from each other (Pallium Canada, 2022[96]).

3.3.3. Incentivising recurrent conversations between patients and clinicians and recording care wishes in advance

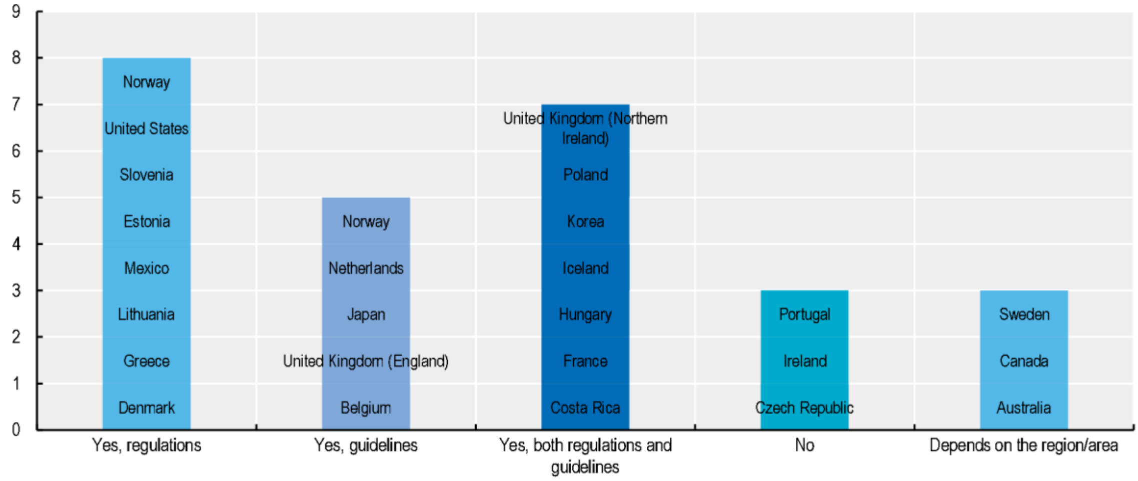
Evidence suggests the importance of communication between the person near their end of life and health care workers. People associate more and more a personalised EOLC with high quality of the end of life. Involving the dying person, listening to their needs, and considering them in care choices are associated with good end-of-life care (The Choice in End of Life Care Programme Board, 2015[97]). Engaging in ACP conversations helps patients and their family and friends to better face the end of life, experiencing less anxiety and depression and being better prepared for the event of death (Kononovas and McGee, 2017[29]). It also reduces clinicians' distress. A survey in France explored the willingness of general practitioners to talk to patients about ACP as well as helping them in writing their advance directives. 90% of respondents declared to be willing to help patients writing advance directives and 74% recognise this practice as helpful for patients (Hubert et al., 2019[98]). Despite the willingness to talk about the end of life, this rarely happens in practice, as mentioned previously in this chapter. The lack of EOLC conversation spans across all settings of care and the barriers are similar and often related to the lack of preparedness of health care professionals around EOLC. Preparing individuals, relatives and informal carers for the changes that will accompany illness progression into the end-of-life phase, undertaking advance care planning and shared decision-making facilitates care (Waldrop and Meeker, 2012[99]). Patients also benefit by receiving fewer intensive treatments, receiving care in line with their wishes, and dying in their preferred place of death (Silveira, 2022[20]). For patients with dementia or neuro-degenerative diseases, being able to plan care before losing decisional power due to their condition, is essential to choose for themselves and to choose a proxy person who will make decisions on their behalf when they are no longer able to.

Regulation and guidelines on end-of-life care conversation and shared decision making are important, but not sufficient

Among OECD countries, the majority (81%) report having regulations, guidelines or both requiring people and their families have ongoing conversations with health professionals regarding their health status and health care options, as well as being involved in the decision-making process regarding their end of life (Figure 3.14). More precisely, eight countries (Denmark, Estonia, Greece, Lithuania, Norway, Mexico, Slovenia, and the United States) have regulations, five countries (Belgium, Japan, Norway, the Netherlands, and the United Kingdom (England)) have guidelines and eight countries (Costa Rica, France, Hungary, Iceland, Italy, Latvia, Poland, and the United Kingdom (England)) have both regulations and guidelines on these topics. In Australia, Canada and Sweden, the existence of such regulations and guidelines may vary by region/area. New Zealand has guidelines on end-of-life care decision making, which include guidance for health care staff to navigate decision making on children and young people, hydration, and nutrition choices, drafting of advance directives, withholding, and withdrawing treatments, as well as resolution of disputes with patients and families (NSW government, 2021[100]).

Figure 3.14. Most OECD countries have regulations/guidelines requiring recurrent conversations and involvement of people in decision-making about their end of life

Countries' answers to the question "Do you have regulation or guidelines requiring that people and families have recurrent conversations with the health professionals about their health status as well as be involved in decisions regarding the heath care and support to receive at the end of life?"



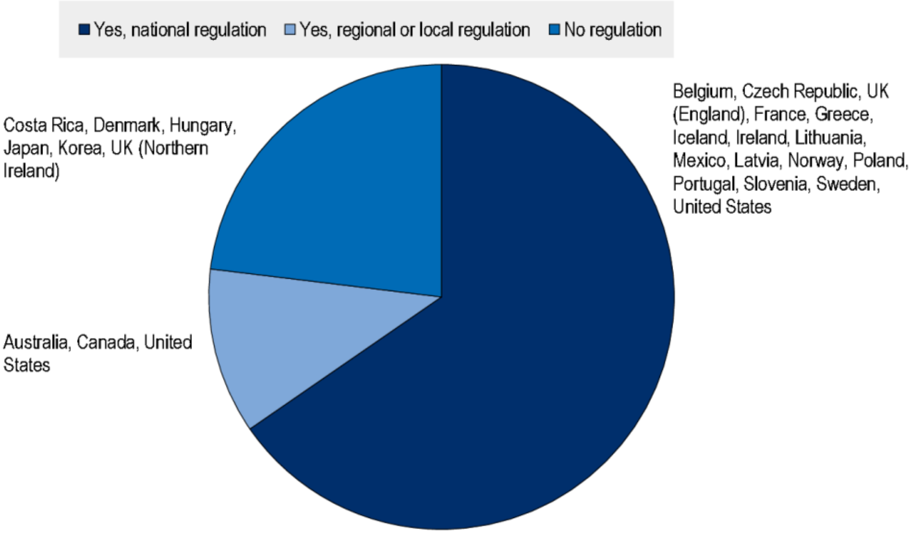
Note: N=27.
Source: (OECD, 2020-2021[16]).

Figure 3.15 shows that most OECD countries (77% of surveyed countries) also have regulation regarding the designation of an attorney for decision making, who would step into decisions regarding the patient's care when the latter loses the ability to understand and decide for themselves. Although studies have shown sometimes weak alignment between the preferences of the person at the end of life and their attorney, the designation of the proxy person is still the best option available when the person loses the ability to make decisions for themselves. The designation of an attorney/proxy person becomes particularly important in case of a health care dilemma that was not foreseen during the advance care planning phase

(Silveira, 2022[20]). All countries with available data have legislation and 17 out of 27 have some guidance on ACP. A much lower share of countries reports some form of training or workshops on ACP for professionals (6 out of 27) or governmental initiatives (Central or local government) on ACP (4 out of 27). More information on which countries have legislation, governmental initiatives, guidelines and/or training on ACP is reported in the annex.

Figure 3.15. Most OECD countries have regulations to designate attorneys for decision making for advance directives or advance care planning

Share of countries that replied "yes" to the question "Do you have any regulation in designating attorney (i.e. a person representing the patient) for decision-making on advanced directive or advance care planning?"



Note: N=26.
Source: (OECD, 2020-2021[16]).

Some countries have programmes supporting individuals in the communication and decision making regarding their end of life. Evidence has shown that such programmes improve the quality of the decision making. One example of a successful programme is "Respecting Choices", adopted by health systems in Australia and the United States, which has improved the alignment between the person at the end of life and the designated proxy person. Another successful example is the "Prepare for Your Care" programme, which has proven to increase the use of ACP (Silveira, 2022[20]). The United States have implemented a system of financial incentives for physicians whose patients complete advance directives. Studies have shown a modest increase in the completion of directives following the introduction of such an incentive (Barnato et al., 2017[101]). Nevertheless, public opinion does not seem to be particularly in favour of physicians' financial incentives for advance care planning. Financial incentives for patients who complete advance care planning seems to attract more favourable opinions (Auriemma et al., 2016[102]).

Nevertheless, conversations at the end of life are still an underused practice because of several barriers. Qualitative research over end-of-life conversation in long-term care facilities has shown that the attitude of family members towards talking about death and the lack of awareness from the health care side regarding patients' wishes and needs are among the barriers to EOL conversations (Harasym et al., 2020[28]). Furthermore, a review of studies performed in Australia, Canada, the Netherlands, New Zealand, Norway, Sweden, and the United States has defined a set of prerequisites of shared decision-making. Such set includes interdisciplinary teamwork, with health care professionals providing a reasonable number of alternatives among which the patient can choose without feeling overwhelmed. Health care professionals also need to establish open communication and try to understand people's willingness to talk and get a good understanding of their preferences. Overall, a good and trustworthy patient-health care professional relationship is important to ensure that health care professionals truly understand people's preferences and that the patients feel well supported and understood. A favourable environment, with adequate space and time and ensuring the privacy of the person also appears to facilitate end-of-life care discussions (Kuosmanen et al., 2021[103]). These findings confirm that to improve communication on EOLC, the availability of good training is key. Guidelines are necessary for health care workers on how to assist the decision-making process for individuals and their families on an individual's health and care in the final stages of their life. This should stress the importance of appropriate information and explanations provided by medical professionals, with the individual having sufficient and ongoing discussions to take a decision before proceeding with medical care in the final stage of life. Findings have shown that people with dementia tend to prefer starting conversation earlier on in the disease progression, while cancer patients prefer to postpone conversation until when there is no other care possibility. Such differences exacerbate the challenge of understanding the right moment to start conversation for clinicians.

Health care professionals would benefit from better training on end-of-life care conversations

Training would help clinicians understand how and when it is appropriate to start conversation with different patients, based on their preferences and the trajectory of disease (Hall, Rowland and Grande, 2019[43]). Surveys of Japanese doctors further demonstrate the importance of improving end-of-life care training. Among the doctors interviewed in a survey undertaken in Japan, those who received and completed end-of-life care training were more likely to use ACP (Tamiya, 2018[34]). Nurses and ancillary staff can play a big role in improving the communication with patients, building upon the trustful relationships they can install with patients, often in a closer and more informal way than doctors can do (Kononovas and McGee, 2017[29]).

Improvements in the quality of training would also be beneficial. Some studies have highlighted that when training is available, not much effort is made to ensure its quality, with patients and families rarely involved in the development of training. These trainings often lack outcome measurements, with the impact of training on patients and families rarely assessed, a lack of control groups utilised, or follow up (Lisa Jane Brighton, 2017[104]).

Simulation-based learning experiences are increasingly used to teach communication on end-of-life care to nursing students, nursing practitioners and other health care professionals, although assessments of their effectiveness are still limited. This type of training aims at reproducing real-life scenarios to allow trainees to practice communication skills as much as possible before facing patients. The aim is to improve their communication skills and reduce the anxiety that health care workers face during end-of-life conversations. The simulation can take place within several scenarios (e.g. workshops, lectures, gaming sessions, group sessions) and in several forms, such as the use of manikins, actors and role playing. A systematic review of studies on simulation-based learning experiences found that while some studies proved this training effective and preferrable to standard training, more evidence is needed to validate these positive results and promote the further spread of simulation based training (Smith et al., 2018[105]).

Examples of training regarding end-of-life conversations already exist for medical and nursing students. In the United States, several medical schools are developing specific training programmes on end-of-life care and with specific focus on undertaking end-of-life care conversations. The Universities of Washington, Pittsburgh and Duke developed the Oncotalk training programme, which has trained between 15% and 20% of the nation's oncologists over 5 years. The training focuses on conversations regarding care status and palliative care choices. In addition to in person training, researchers are currently developing an online tool that allows people to describe real life experiences and receive feedback on how to best approach them (Commonwealth Fund, 2022[106]). In Canada training on advance care planning is available for public education at the national level (Government of Canada, 2019[107]).

Several training programmes on end-of-life care conversations for health care workers also exist in several countries, including Australia, Canada, New Zealand, United Kingdom, and the United States. The Vital Talk community is an example of available online and in-person training for clinicians approaching EOLC conversations (VitalTalks, 2022[108]). Australia funds the Indigenous Program of Experience in the Palliative Approach, which provides training to the workforce to support them in the delivery of culturally responsive palliative care. IPEPA also provides palliative care training to Aboriginal and Torres Strait Islander workforce and spreads knowledge around palliative care among the Aboriginal and Torres Strait Islander communities (IPEPA, 2022[109]). Furthermore, the End-of-Life Directions for Aged Care (ELDAC) developed guidelines to support long-term care providers in the provision of culturally appropriate end-of-life care among older Australians (i.e. for Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people and LGBTQI+ people) (ELDAC, 2022[110]). Canada also has several training options, some of which may differ across provinces. For instance, general end-of-life care guidelines are available for nurses at the national level. Canada also issued a reference guide for clinicians to support them in conversation regarding serious illness. The Canadian Hospice Palliative Care association also provides training opportunities for volunteers, including webinars and online training programs. Alberta, Nova Scotia, and Ontario provide additional opportunities of training for health care workers (Government of Canada, 2019[107]). In New Zealand, NSW health provides online training modules for health care workforce to improve knowledge around end-of-life conversations (NSW government, 2021[100]). In the United Kingdom, the Helix Centre has developed a form that guides the conversation on end-of-life care between professionals and patients, the ReSPECT process. The guide is easy to understand and makes use of graphics to clarify concepts and make them understandable for all patients. The centre also developed a web-based app that provides training for all professionals using the ReSPECT process. The process has been implemented in more than 130 centres across the United Kingdom and Ireland (ReSPECTprocess, 2022[111]). Furthermore, a collaboration between NHS England and NHS Improvement developed the Universal Principles for Advance Care Planning in 2022, to facilitate a consistent national approach to advance care planning in England (NHS, 2022[112]).

> *Specific training on culturally and ethnically appropriate conversation should be encouraged and might contribute to reducing inequalities at the end of life*

Clinicians are required an effort to understand and adapt to the patients' preferences, understanding their ethnic and cultural diversity. Providing the same EOLC services to all patients, regardless their cultural and ethnic background is often perceived as equal, but it might not ensure equity, as it does not consider the specificities of the person and their specific needs. Communication training and guidelines on how to approach end of life discussion with ethnically and culturally diverse communities could be useful to help shaping the right approach to discussion, based on the patients' needs. It would make end-of-life-care more people-centred, improving the end-of-life care experience of ethnic and cultural minorities. Including bilingual team members or interpreters within end-of-life care teams has also proven successful in this regard (Isaacson and Lynch, 2017[54]). Some studies from Australia and the United States on training on cultural appropriateness in health care have found that trained professionals showed higher awareness of cultural differences at the end of life and improvement in the management of culturally sensitive discussions – including end-of-life-care conversations (Cruz-Oliver et al., 2017[113]; Northam et al., 2015[114]). Further studies on the effectiveness of such training and on the best approaches to culturally teaching appropriateness in health care would be beneficial to form a solid evidence base to lead the development of further training in a larger set of countries.

In the United States, the National Hospice and Palliative Care Organisation (NHPCO) provides guides and toolkits for EOLC providers to improve the way they deal with minorities. The guides that include outreach guides for Black people, Chinese Americans, and Hispanic/Latino people, provide insights on cultural values that are shared within minority communities. They point out to particularly sensitive issues and provide recommendations around how to engage with the communities, for instance by organising events, participating to the community's events, and using their media to dive into the culture. Furthermore, NHPCO provides consumers' brochures in English, Spanish and Mandarin to provide support to the people at the end of their life and their loved ones (NHPCO, 2021[115]). The NHPCO also published a position paper in 2020, to support American Black Communities at the end of life in the framework of the COVID-19 pandemic (NHCPO, 2020[116]). The paper describes the mental health repercussions of restrictive measures aiming at reducing the spread of the virus on American Black Communities, for instance through the prohibition of religious ceremonies to honour the dead body of loved ones. The paper is at the same time an occasion to share information around cultural and spiritual needs of such communities and to raise awareness around the disparities in access to EOLC. It also provides guidance on how to address such disparities.

Multidisciplinary conversations would reduce discontinuity of care and disagreements on end-of-life decisions

Besides good training, clinicians approaching discussion around end-of-life with patients and their relatives must be well aware of the patient's health status and history. It is in fact paramount that patients and their clinicians establish a trustful relationship to get involved into a shared decision-making process. Gathering information regarding what other involved clinicians recommended is key to avoid providing the patient with confusing and conflicting information.

Being well informed about the patients' history and their relationships with other professionals become particularly complex when patients have co-morbidities or complex conditions. For instance, professionals working with patients affected by heart failures attributed aggressive and non-beneficial care to failures in the communication across physicians (Hutchinson et al., 2020[117]). Studies have found lower care co-ordination at the end of life, which leads to higher costs of care and more aggressive care (Hafid et al., 2022[37]; Sharma et al., 2009[38]).

Furthermore, end of life decision-making covers a diverse set of choices. A review of studies performed in Australia, Canada, Netherlands, New Zealand, Norway, Sweden and the United States found that people at the end of life wish to participate in a number of decisions regarding their end of life, which span from choosing the place of death and selecting what treatment to receive, to saying goodbye to their loved ones and organising follow up care after death (Kuosmanen et al., 2021[103]). Organising a multidisciplinary conversation can thus be useful. Involving different experts in the conversation can ensure that patient's needs, and wishes are considered holistically (Mark Pfeifer, 2018[118]). This is particularly important for some people (e.g. people with dementia) who might present comorbidities and have contacts with different care providers. In a multidisciplinary effort, ensuring that one professional is responsible to co-ordinate care for the patient could avoid discontinuity of services and disagreements around end-of-life decisions (Bamford et al., 2018[6]).

As decision making at the end of life is a continuous process that develops with the person's health status, the health care workers involved in this process might also vary and alternate when needed. In the early stages, trained non-physicians can facilitate and initiate advance care planning in either health care or non-health care settings, building on established relationships with the individual. Physicians then need to step in and support decision making regarding health care procedures. According to a consensus building exercise on the definition and recommendations regarding advance care planning, 91% of professionals agree that trained non-physicians can be functional in supporting advance care planning, particularly in the initial stages (Rietjens et al., 2017[119]).

3.3.4. Patient reported measures can be used to measure the quality of end-of-life care conversations

To make sure that EOLC conversations improve the quality of life of the patient and provide them with care in line with their wishes, the quality of such conversations needs to be measured through indicators (Sinuff et al., 2015[120]). Including questions regarding conversations with clinicians within Patient Reported Experience Surveys (PREMS) can serve this scope. The 2015 Quality of Death Index Ranking palliative care across the world measures the existence of the option for Do Not Resuscitate (DNR) policy and whether shared decision-making is applied (Murray, 2015[18]).

Among surveyed OECD countries, seven out of 12 included questions around EOLC discussion within PREMS. In Iceland, surveys target relatives who have lost a loved one in the two to three months prior the survey. Questions are asked about whether the deceased person had discussed their preferences around the place of death. Results of the survey showed that most patients did not discuss their preferences of place of death. Results from the latest survey available, in 2021, focused on people in Palliative Home Care Services and reported that 74% of patients (N=99) did not discuss their preferences. Among those who expressed their wishes, 64% preferred to die at home and 36% in palliative care units (OECD, 2020-2021[16]). In Ireland, in 2016, the survey “Have your say” was conducted online and included 3 000 respondents. It included questions regarding conversation at the end of life. Results from the survey showed that people recognise the importance of receiving information regarding their end of life and of being involved in the decisions regarding their death and dying. In addition to the survey, as part of the “Have your say series”, relatives of deceased or dying people have access to a free bereavement support phone line (Irish Hospice Foundation, 2016[121]). Ireland developed other surveys on EOLC since 2010, but questions regarding end-of-life conversations are missing. In 2017, in Japan, a survey aimed at measuring attitudes on the end of life asked a random sample of 23 500 adult Japanese (aged 20 or older) whether they had discussed their EOLC preferences with their families and/or with professionals.

Some countries apply international surveys that include questions regarding EOLC discussion. This is the case of Canada, which used the Commonwealth Fund’s 2017 International Health Policy Survey of Older Adults. Norway used the CODE international survey in 2017-18 and the United States use the abovementioned CAHPS Hospice Survey since 2015.

The measurement of the quality of communication at the end of life needs to be prioritise as a method to assess how people-centred EOLC is. The current situation shows room for improvement across OECD countries. Chapter 4 of this report will provide more information regarding the use of specific EOLC PREMS in OECD countries.

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Annex 3.A. Programmes to improve awareness and knowledge around end of life

Annex Table 3.A.1. Programs to improve awareness and knowledge around end of life

Country	Year	Title of the programme	Length of the programme	Main topic of the programme
Australia	2015	Dying to Talk	>2 years	Encouraging the general population to talk about death and dying
Australia	2017	Greater Choice for At Home Palliative Care	>2 years	Pilot programme to support a select number of Primary Health Networks (PHNs) to improve linkages across the sectors, including health, aged care, and primary health care, to support access to and co-ordination of palliative and end-of-life-care for patients, regardless of where they live, including in residential aged care facilities (RACFs).
Australia	2017	Specialist Palliative Care and Advance Care Planning Advisory Services (delivered through a project called 'End of Life Directions for Aged Care')	>2 years	Improve palliative care and advance care planning skills of aged care providers and GPs providing health care for recipients of aged care services
Australia	2017	My End-of-Life Care	1-2 year(s)	Australian Government campaign to raise awareness of what palliative care, end-of-life-care and advance care planning is. Included starting the conversation.
Australia	2018	What Matters Most	1-2 year(s)	Raising awareness of palliative care
Australia	2019	Comprehensive Palliative Care in Aged Care Measure	>2 years	Improve palliative and end-of-life service provision and care co-ordination for older Australians living in residential aged care facilities.
Australia	2020	National Palliative Care Programs	>2 years	National projects that focus on education, training, quality improvement and advance care planning.
Australia	2020	Palliative care – it's more than you think	1-2 year(s)	Raising awareness of the benefits of quality palliative care
Iceland	2015	The art of dying	<1 month	To open discussions about death and dying
Iceland	2016	The art of dying	1-6 months	About the importance of talking about death and dying
Iceland	2016	Death Café	1-2 years	Discussing death and dying
Iceland	2016	Palliative care service in the northern part of Iceland	<1 month	Evaluation and future of palliative care service
Iceland	2016	Seminar of PC in north Iceland	<1 month	Attitudes around death and dying
Iceland	2021	Everyone dies	1-6 months	Attitudes around death and dying
Ireland	2010	Palliative Care Week	<1 month	To guide members of the public to discuss and record their end of life and health care preferences in the event of loss of capacity due to illness or accident and after death
Ireland	2014	Palliative Care Week	<1 month	Palliative Care: Making the most of life – aim to increase understanding of palliative care
Ireland	2015	Palliative Care Week	<1 month	Palliative Care: Quality Care – where it's needed, when it's needed – aim to increase understanding of palliative care
Ireland	2016	Palliative Care Week	<1 month	Palliative Care: Enabling Living – aim to increase understanding of palliative care
Ireland	2017	Palliative Care Week	<1 month	Palliative Care: What have you heard? – aim to increase understanding of palliative care

Country	Year	Title of the programme	Length of the programme	Main topic of the programme
Ireland	2018	Palliative Care Week	<1 month	Palliative Care: Because Every Moment Matters – aim to increase understanding of palliative care
Ireland	2019	Palliative Care Week	<1 month	Palliative Care: Surrounding You With Support – aim to increase understanding of palliative care
Ireland	2020	Palliative Care Week	<1 month	Palliative Care: In This Together – aim to increase understanding of palliative care
Japan	2014	EOLC enhancement initiative	1-2 year(s)	Fostering multidisciplinary care team for EOLC, including co-ordinators who provide consultation and support for patient and family to make better decision on EOLC, as well as facilitate co-ordination between relevant parties as necessary.
Japan	2017	Orange Balloon Project	>2 years	Dissemination of correct information on and raise awareness on the necessity of palliative care
Japan	2020	National campaign to disseminate the idea of ACP, ("Jinsei-kaigi" (life meeting) in Japanese)	1-2 year(s)	Provide opportunities for the public to understand "Jinsei-kaigi", or ACP.
Korea	2007	Pain Management Campaign	>2 years	Increasing awareness for hospice palliative care (production and distribution of various PR materials such as educational materials, leaflets, and videos, Yes or no quiz to know cancer pain correctly, Regional pain management campaigns)
Korea	2013	Hospice Day Campaign	>2 years	Encouraging workers in hospice palliative care, increasing awareness for hospice palliative care (Hospice and palliative care practitioners' encouragement and awards, hospice, and palliative care symposium)
Luxembourg	2009	Guide des soins palliatifs	-	Information to the citizens about the new legislation about end of life introduced in March 2009
Luxembourg	2019	My will at the end of life	-	To provide citizens impartial information about end-of-life legislation and the options available to them
Norway	1999	Campaign: The Value Commission	>2 years	Values at the end of life
Norway	2013	Campaign: Death Cafe	>2 years	Increase awareness about death
Norway		Campaign: Death shakes us all	1-2 year(s)	Increase awareness about death
Norway	2021	Openness about death	>2 years	Facilitate conversations about death, dying and end-of-life care
Slovenia	2012	Campaign: At home	2 years	Availability and access of opioid medication
Slovenia	2018	Campaign: Last aid	1-2 year(s)	Education about the EoL
United States	2010	Palliative Care: Conversations Matter Campaign	-	Evidence-based communications campaign to increase awareness of and improve communications around pediatric palliative care
United States	2014	End of Life Module for NIHSeniorHealth.gov	-	Providing information about the most common issues faced by the dying and their caregivers
United States	2014	The Conversation Project	>2 years	A public engagement initiative with a goal that is both simple and transformative: to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected

Source: (OECD, 2020-2021[16]).

Annex 3.B. Legislation, initiatives, guidelines, and training on Advance Care Planning

Annex Table 3.B.1. Countries that have legislation, governmental initiatives, guidelines and/or training on ACP

Country	Legislation on ACP	Governmental initiatives (Central or local government) on ACP	Guidance on ACP	Training or workshops on ACP for professionals
Australia	X	X	X	X
Austria	X			
Belgium	X		X	
Canada	X	X	X	X
Costa Rica	X		X	
Denmark	X			
Finland	X		X	
France	X		X	
Germany	X			
Greece	X			
Hungary	X		X	
Iceland	X		X	
Italy	X		X	
Japan	X	X	X	X
Korea	X	X	X	X
Latvia	X		X	
Lithuania	X			
Mexico	X			
Netherlands	X		X	
New Zealand	X		X	X
Norway	X		X	
Poland	X		X	
Portugal	X	X		
Slovenia	X			
Sweden	X			
Switzerland	X			
United Kingdom	X	X	X	X
United States	X		X	X

Source: OECD secretariat, 2020.

Notes

[1] This report conceptualises end-of-life care (EOLC) as the care provided to people who are in the last 12 months of life. It refers to the terminal stage of palliative care, as well as including some elements of curative care and help with mobility limitations. Chapter 1 of this report provides a more detailed definition of EOLC.

[2] Palliative care entails physical, emotional, social, and spiritual support with a particular emphasis on symptoms management such as pain, but also emotional support, mental health care and bereavement care for families.

[3] Similar results emerge from staff who were asked to rate the quality of care. Nearly 70% of respondents rated care as excellent or very good.

[4] The United States reported seven professional associations, but a comprehensive list is currently not available, hence they are not reported in Figure 3.13.

4

Renewing focus on high-quality end-of-life care

This chapter analyses the quality of end-of-life care across countries. It shows that people at the end of life suffer from an array of physical, psychological, and spiritual symptoms that are not always adequately addressed. Efforts to sustain life may sometimes result in overtreatment and not be beneficial for quality of life. To improve quality, the chapter highlights that symptoms should be adequately managed balancing measures to minimise the misuse of opioids and reducing barriers to pain relief for those with high needs, while also providing holistic care that encompasses all physical, psychological, and spiritual symptoms. Supporting professionals and families to overcome ethical dilemmas and make difficult decisions can reduce the risk of overtreatment and align care with people’s needs. Improving care guidelines, quality standards and indicators and their monitoring would contribute to better assess the quality of end-of-life care services and allow for international benchmarking.

Introduction

Providing high-quality care to those who need it is a core principle of high-performing health and social care systems, and end-of-life care is no exception. Quality end-of-life care (EOLC)[1]services should allow dying patients – and their families and loved ones – to best prepare for the end of life and to experience a good death, one which relieves their pain to the maximum extent possible and takes into account and accommodates their preferences, including where they die and what treatments they receive. High-quality end-of-life care is also important to ensuring families and loved ones can best come to terms with and process the loss of their loved one.

In many countries, high-quality end-of-life care remains accessible to too few but expanding access to end-of-life cannot come at the expense of quality. Health and social care systems that deliver end-of-life care must have mechanisms in place to ensure the end-of-life care people receive is of consistently high quality, complemented monitoring systems for driving further improvement.

This chapter offers a review of the current state of the quality of care for people receiving palliative and end-of-life care services, including the extent to which people experience pain, discomfort, and mental distress at the end of life, the kinds of care they receive, and decisions around choosing to provide or withhold life-sustaining treatments when the end is near. It looks at how ethical dilemmas and disagreements on care choices can be dealt with and how guidelines and standards affect the quality of end-of-life care. The chapter further examines how the quality of end-of-life care is measured and monitored across different OECD countries, including the extent to which patient- and carer-reported measures are systematically incorporated into regular data collections and monitoring.

The chapter is organised as follows. Section 4.1 highlights the sub-principles of high-quality end-of-life care. Section 4.2 illustrates the consequences of current health systems lacking such focus while 4.3 explores policies and best practices to ensure appropriate, comprehensive, and accountable end-of-life care.

Key findings

- People at the end of life do not always receive appropriate symptom relief. People can experience high levels of emotional distress, depression, and anxiety at the end of life, yet adequate psychosocial support at the end of life is also lacking. The share of people experiencing emotional distress is more than double among older people with high needs compared to older people without them. Only 14 of surveyed countries include psychologists within EOLC multidisciplinary teams and 7 included psychotherapists. The rise in opioid abuse has in some cases led to a decrease in the prescription of opioids and exacerbated the challenge to access pain relief at the end of life. Around 8% of people who died at the age of 65 or older reported receiving too little pain medication, around 15% too little help breathing and 24% too little help with anxiety.
- Alongside the under-treatment of their symptoms, people at the end of life sometimes receive aggressive treatment that is not likely to provide comfort, prolong life or be cost-effective. Around one-third of older patients with advanced irreversible diseases who are hospitalised at the end of life receive interventions unlikely to provide benefits in terms of survival or quality of life. Data shows that across all countries for which data is available, 22% of patients were readmitted within 30 days from discharge during the last year of life, between 30% and 65% of people visited emergency department during the last 30 days before death and patients were admitted more than once to ICU in the last 30 days of life.

Policy options

- Countries should balance the need to fight opioids abuse with that of ensuring that people can experience a comfortable life until the end. Measures could aim at increasing the pool of health care professionals who can prescribe pain relief medications, together with an improvement in the training and clinical guidelines on the use of opioids. For instance, the United Kingdom has increased the availability of prescribers by giving non-medical professionals (e.g. specialist nurses and pharmacists) the possibility to prescribe pain relief, while in Canada palliative drug programs have been put in place in several territories and provinces.
- Training for health care professionals, early provision of palliative care and advance directives appear to reduce the likelihood of overtreatment and aggressive care at the end of life. The United States have developed the Physician Orders for Life-Sustaining Treatment (POLST), which has proven to align the care received to people’s wishes. When difficult decisions need to be made, guidelines, ethical consultations or ethics committees can support health care professional through the decision-making process. In Australia and Canada there are guidelines to support health care professionals through decision making regarding withholding and withdrawing treatment and in case of disagreement with patients and/or their families. Ethics committees in France offered phone line services during COVID-19.
- Comprehensive services need to be available for all patients and their relatives. For instance, in England, guidelines report the importance of multidisciplinary teams that can take care of the person at the end of life holistically and they underline the crucial role played by advance care planning and electronic records sharing within the multidisciplinary team. It is also important to address the needs of relatives during and after the end of life. In Ireland, the Irish Hospice Foundation has set up a help line – the Bereavement Support Line – available to support people facing grief.

- Ensuring that people receive high-quality end-of-life care also requires that quality guidelines and standards are set, measured, and monitored. While 63% of countries have quality standards, they are rarely binding and they are rarely internationally comparable, nor linked to measurable indicators. Some countries have more advanced indicators collection, such as the United States and Denmark, but usually focus on measuring access to services rather than the experiences and outcomes of those services, or they are limited to specific services or providers. Less than half of the surveyed countries have mandatory patient- or carer-reported experience or outcome surveys to help inform the quality of end-of-life care. Furthermore, more than one in four countries do not have programmes of audit and evaluation to monitor quality.

4.1. Why delivering high-quality end-of-life care is so important?

What constitutes high-quality end-of-life care has been subject to extensive debate and policy scrutiny by researchers and policy makers across OECD countries. The OECD People-Centred End of Life Care Framework (see Chapter 1) identified three domains applicable across end-of-life care – regardless of where it is delivered – that are critical to ensuring the delivery of high-quality end-of-life care.

Firstly, care must be delivered in a manner that is *appropriate* to the circumstances and preferences of the patient – and in many cases their families and carers – nearing the end of life. Allowing patients to receive adequate symptom control to help maximise their comfort and well-being at the end of life. In too many circumstances, patients nearing the end of life still lack access to adequate pain relief (Knaul et al., 2018[1]). Even in circumstances where supply constraints do not represent a major challenge, policies put in place by governments to help prevent excessive opioid consumption and addiction can complicate access to pain relief even where such treatments could be made widely available. Furthermore, ethical dilemmas and disagreements between patients and clinicians, families and clinicians or patients and their families can complicate decision making at the end of life, risking providing inappropriate care to the dying person.

Care must also be *comprehensive*, taking into account all the needs of the person at the end of life and their relatives. The end of life represents a mentally distressing moment for the dying person and their relatives, and multidisciplinary teams have proven to improve continuity of care and hospital discharge (NICE, 2019[2]), but only a minority of countries report including psychologists and psychotherapists in EOLC multidisciplinary teams. Addressing the psychosocial and spiritual needs of people at the end of life is particularly important given that mental health worsens at the end of life and people might experience a loss of meaning in life (Kozlov et al., 2019[3]; Mossman et al., 2021[4]; Wilson et al., 2007[5]). Furthermore, bereavement care improves the families' experience of the end of life, but several barriers still hamper its provision (McAdam and Puntillo, 2018[6]).

Lastly, quality of care cannot be assured – or improved upon – if the delivery of care and services are not held *accountable*, through the development of clear standards, the collection of relevant indicators and regular monitoring, inspection, and regulation of end-of-life care services. While many countries have developed standards of care and guidelines for the delivery of end-of-life care, these guidelines and standards are not always accompanied by metrics that are routinely monitored to ensure the end-of-life care people receive lives up to them. Moreover, despite the importance of appropriate and patient-focused care at the end of life, the routine collection of patients- and carer-reported measures, including on their experiences and outcomes, is often ad hoc where it is collected at all.

4.2. What do we know about the quality of end-of-life care in OECD countries?

4.2.1. Symptom relief is not always sufficient

When people reach the end of their life, they often experience symptoms that span from physical suffering to psychological and spiritual distress (Knaul et al., 2018[1]). Mental ill health and lower quality of life are also common among the relatives of the dying person (Götze et al., 2016[7]; Kustanti et al., 2021[8]). Nevertheless, evidence highlighted below shows that symptom management is often insufficient. Access to pain relief is unequal, with symptoms management showing unequal distribution across countries, settings of care and disease type and, while acute shortages are a concern in low and middle income countries, lack of access has also been signalled in many OECD countries (Knaul et al., 2018[1]; ONS, 2015[9]; Reid et al., 2020[10]). Concerns also exist on symptoms management in older people (Dalacorte, Rigo and Dalacorte, 2011[11]; Fineberg IC, 2006[12]). Unmet needs of psychosocial and spiritual support for people at the end of life and their relatives are also common across the OECD (OECD, 2020-2021[13]).

Prevalence of physical, psychological, and spiritual discomfort is high at the end of life

Patients experience a wide variety of physical, psychological, and spiritual symptoms at the end of life. Half of the people who die in high middle-income countries and high-income countries experience serious health related suffering (Knaul et al., 2018[1]). A systematic review including studies from 20 OECD countries shows the prevalence of physical, psychological, and spiritual symptoms for patients with cancer, chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), end-stage renal disease (ESRD), dementia and AIDS (Table 4.1). Weakness, appetite loss, nausea/vomiting, pain, dyspnoea, and insomnia are frequent physical symptoms in the advanced stage of life-threatening diseases, such as cancer, COPD, CHF, and dementia. For instance, up to 100% of people living with cancer or ESRD can experience fatigue and weakness towards the end of life. Between 30% and 98% of people with cancer or AIDS report physical pain. Furthermore, Etkind et al. calculated for 67% of people dying for diseases classified as organ failure[2] experience pain requiring physical care, while this amounts to 84% for people with terminal illness and 60% for people with dementia (Etkind et al., 2017[14]).

Table 4.1. Symptom prevalence in palliative care

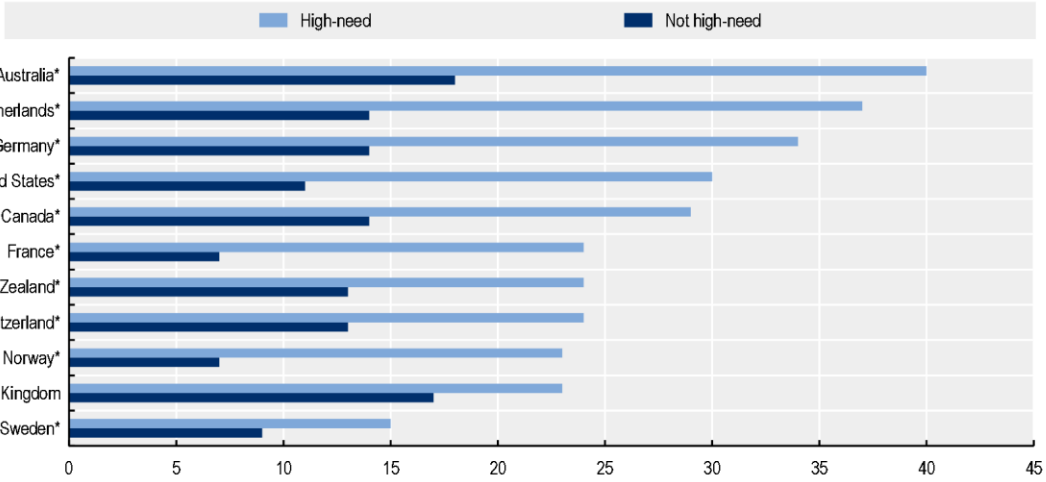
	Problems/Symptoms	Prevalence of each problem/symptom					
		Cancer	COPD	CHF	ESRD	Dementia	AIDS
Physical	Fatigue/tiredness/weakness	23-100%	32-96%	42-82%	13-100%	22%	43-95%
	Anorexia	76-95%	64-67%		38-64%		82%
	Pain	30-94%	21-77%	14-78%	11-83%	14-63%	30-98%
	Nausea-vomiting	2-78%	4%	2-48%	8-52%	8%	41-57%
	Breathlessness/dyspnoea/shortness of breath/respiratory distress	16-77%	56-98%	18-88%	11-82%	12-52%	43-62%
	Insomnia/poor sleeping/difficulty sleeping/sleep disturbance	3-67%	15-77%	36-48%	1-83%	14%	40-74%
	Confusion/delirium/cognitive failure/cognitive symptoms	2-68%	14-33%	15-48%	35-70%		
	Constipation	4-64%	12-44%	12-42%	8-65%	40%	19-35%
	Diarrhoea	1-25%		12%	8-36%		
Psychological	Depression/depressive mood/sadness/low mood	4-80%	17-77%	6-59%	2-61%	46%	17-82%
	Anxiety/nervousness/agitation	3-74%	23-53%	2-49%	7-52%	8-72%	13-76%
	Worry	3-71%	65%		32-55%		51-86%
Spiritual	Well-being	91%	14%	5%			
	Spiritual pain	44%					
	Spiritual well-being			6%			

Note: Data from studies on Africa Austria the Netherlands Germany France Italy Spain Switzerland, United Kingdom, Ireland China, Korea, Japan India, Australia, New Zealand Canada, Sweden, Norway, Denmark, Romania, Hungary, South Africa, Israel, United States.
Source: Are There Differences in the Prevalence of Palliative Care-Related Problems in People Living With Advanced Cancer and Eight Non-Cancer Conditions? A Systematic Review (Moens, Higginson and Harding, 2014[15]).

The end of life can be an emotionally distressing moment, which affects the mental health and overall well-being of people at the end of life and evidence shows that mental health deteriorates towards the end of life. Depression, anxiety, and worry are common among people with COPD, dementia, and AIDS, while spiritual symptoms seem to be assessed mainly among people with cancer (Moens, Higginson and Harding, 2014[15]). Another study focused on people with metastatic cancer found that around 24% of patients experienced depression and 27% anxiety disorders (Mossman et al., 2021[4]), while an analysis of palliative cancer patients found that around 21% of the sample experienced depression and around 15% anxiety disorders (Wilson et al., 2007[5]). The 2017 Commonwealth Fund International Health Policy Survey of Older Adults reveals that overall emotional distress in older adults is much higher for those with high-needs, namely having three or more chronic conditions or a functional limitation, compared to non-high-needs. The share of people with emotional distress in 11 OECD countries ranges between 7% and 17% in older people without high needs, while it is much higher among older people with high needs, ranging between 15% and 40% (Figure 4.1). A study performed on a population-based survey explored the trajectory of depression over the last year of life and showed the increase in depressive disorders during the last period of life. Symptoms of depression increased gradually from 12 to 4 months before death and more sharply in the last 4 months of life. In the last month before death, nearly 60% of the surveyed sample had depression (Kozlov et al., 2019[3]).

Figure 4.1. Older adults with high-needs experience higher emotional distress

Share of older adults experiencing emotional distress

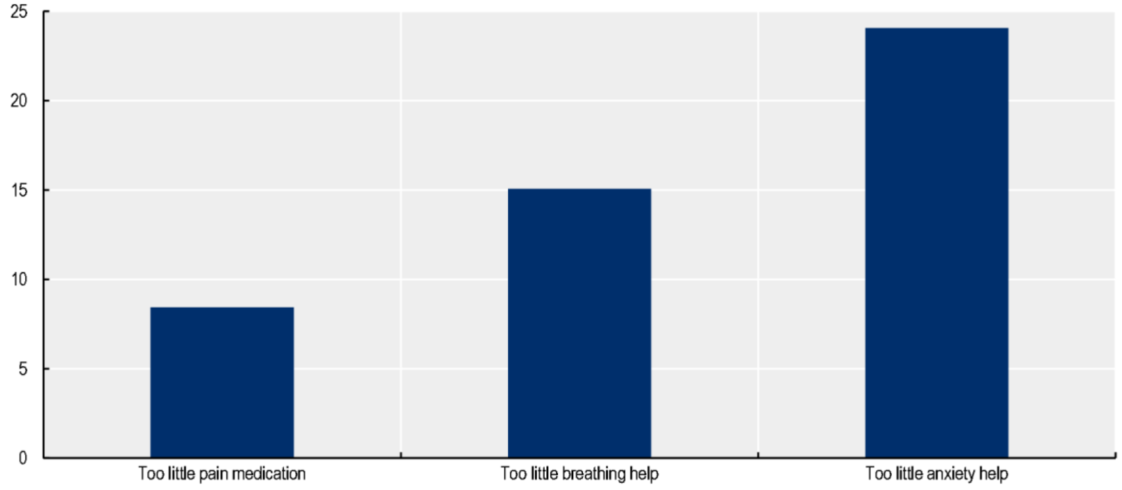


Note: Emotional distress includes anxiety or depression in the past year. Population: High-need older adults are defined as having three or more chronic conditions or a functional limitation. Asterisk (*) indicates that the differences between high need and not high need are significant below p<0.05.
Source: (Commonwealth Fund, 2017[16]).

Family members and relatives also experience mental ill health and lower quality of life during the end of their loved ones' life. A study assessed the results of the Palliative Care Outcome Scale, an international instrument to measure the quality of life of patients at the end of life and their relatives. It looked at results for a sample of adult Portuguese palliative care patients screened between 2015 and 2016 and found family anxiety, patient anxiety and feeling depressed to be the most overwhelming symptoms for respondents (Antunes et al., 2020[17]). In Canada, 30% of family caregivers for palliative care reported distress (e.g. anger and depression). Distress appeared particularly high in caregivers of dementia patients (45%) and lower in caregivers caring for people that do not receive palliative care (27%) (CIHI, 2018[18]). Further research has found that around 20-30% of family caregivers experience psychological distress at the end of their relative's life, followed by a slight decrease in the psychological distress after the person's death. More broadly, family caregivers show a significantly lower mental health and a somewhat lower physical health compared to the general population (Götze et al., 2016[7]). A meta-analysis of studies on the grief disorders in families of cancer patients recorded that between 7% and 39% of participants experienced grief disorders (Kustanti et al., 2021[8]).

Physical and psychological needs at the end of life are not always met. According to the Survey of Health, Aging and Retirement in Europe, across 28 European countries (including 23 OECD countries), on average around 8% of older people who died at the age of 65 or older reported receiving too little pain medication, around 15% reported receiving too little help breathing and 24% reported receiving too little help with anxiety (Figure 4.2).

Figure 4.2. Share of older people reporting receiving little help with symptoms at the end of life



Note: Weighted using cross-sectional weight from last core interview.
Source: Analysis based on data from SHARE (Waves 7-8).

Lack of access to medications to manage symptoms represents a challenge in some countries and for some groups

Ensuring that physical symptoms are treated adequately entails to find a balance between minimising the misuse of opioids among the general public and ensuring that there is sufficient pain relief for those with high needs. Across all ages, analgesic opioids appear to be far more used than benzodiazepine and dopamine receptor antagonist in the last 30 days of life (Table 4.2). Benzodiazepine is used to treat dyspnoea or anxiety, while dopamine receptor antagonist is used to prevent nausea. Analgesic opioids are one of the main medications to relieve pain, highlighting that this is more widely prescribed at the end of life than medication to relieve other symptoms.

There are concerns around possible under treatment of pain at the end of life for older patients (Dalacorte, Rigo and Dalacorte, 2011[11]; Fineberg IC, 2006[12]). Specific medication use illustrates that older adults receive fewer pain-relieving medications when looking the defined daily doses (DDDs) in the last 30 days before death (Table 4.2). Although DDDs per 1 000 population report much higher values for older populations, this gap disappears or overturns when DDDs are standardised by the number of deaths. In particular, the rate of DDDs per number of deaths due to cancer, cardiovascular diseases, chronic respiratory diseases, Alzheimer’s, and other dementias is lower in people aged 60 or older, compared to the 40-59 age group.[3] Such difference could partly be explained by a more common quick deterioration process among older people.

Table 4.2. DDDs of analgesic opioids, benzodiazepine, and dopamine receptor antagonist during the last 30 days of life

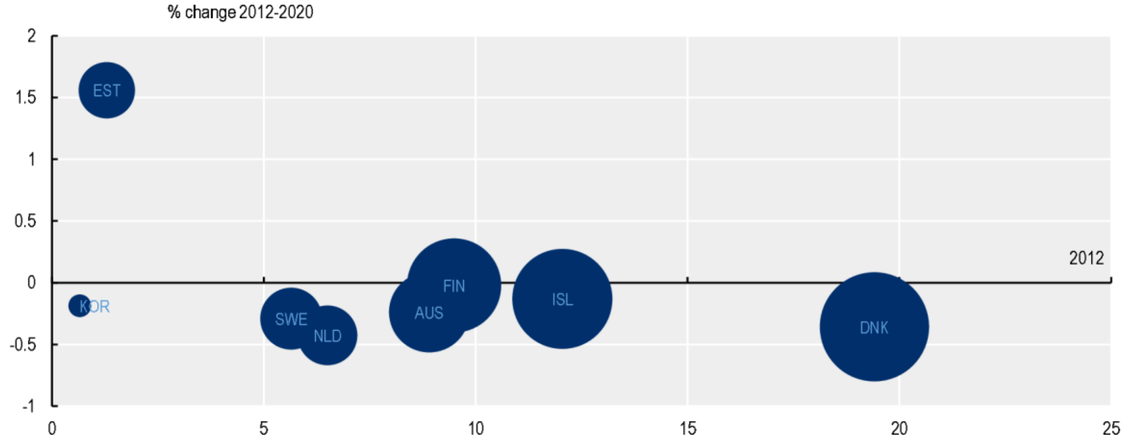
Country	ANALGESIC OPIOIDS (N02A)			BENZODIAZEPINE (N05BA, N05CD, N05CF)			DOPAMINE RECEPTOR ANTAGONIST (A04AD (Other antiemetic) N05AD (Butyrophenone derivatives – Haloperidol, Droperidol)		
	0-39	40-59	60+	0-39	40-59	60+	0-39	40-59	60+
DDDs per 1 000 population									
Denmark	2.4	43.9	377.0	1.3	17.8	195.2	0.1	4.6	52.1
Iceland	1.1	32.9	185.4	2.3	28.0	309.4	0.1	0.6	6.3
New Zealand	0.1	1.2	11.6	0.1	0.9	10.4	0.0	0.5	4.4
DDDs/ N. deaths due to Cancer (neoplasms (C00-D49)), Cardiovascular Diseases (I00-I52), Chronic respiratory diseases (J40-J47, J96) and Alzheimer's and other dementias (F00-F03, G30, R54)									
Denmark	35.9	33.4	18.4	19.2	13.6	9.5	1.7	3.4	2.5
Iceland	19.7	37.5	14.2	89.1	31.6	23.9	0.0	0.7	0.5
New Zealand	0.8	0.8	0.6	0.7	0.6	0.5	0.2	0.3	0.2

Note: Data refers to 2017 for New Zealand, 2019 for Denmark and 2020 for Iceland.
Source: (OECD, 2021[19]).

While opioid abuse has become a major challenge across OECD countries in recent years, prescription volumes fell on average between 2012 and 2020 (OECD, 2019[20]). Considering opioids prescriptions among people aged 70 or older as a proxy of opioids prescription at the end of life, Figure 4.3 shows that DDDs for people aged 70 or older per 100 population per day have decreased in all countries with data available in the past decade, except for Estonia.

Figure 4.3. Prescriptions of opioids for people aged 70 or older decreased in the last decade

DDDs per 1 000 population per day



Note: Data for Finland refer to 2013-20, for Korea to 2013-19, for Sweden 2012-19.
Source: (OECD, 2020-2021[13]).

The troubling rise in opioid abuse and opioid-related deaths across many countries also masks what remains a reality for people in need of palliative and end-of-life care: the availability of critical pain-relieving medications, including morphine and other opioids, is highly unequally distributed worldwide. Some OECD countries are not yet able to satisfy their national needs. This is the case of Latin American countries, as Mexico where availability of opioids morphine-equivalent is able to meet only 36% of the needs. Some Central and Eastern European countries and Asian countries also show low levels of opioids' needs being met (Knaul et al., 2018[1]).

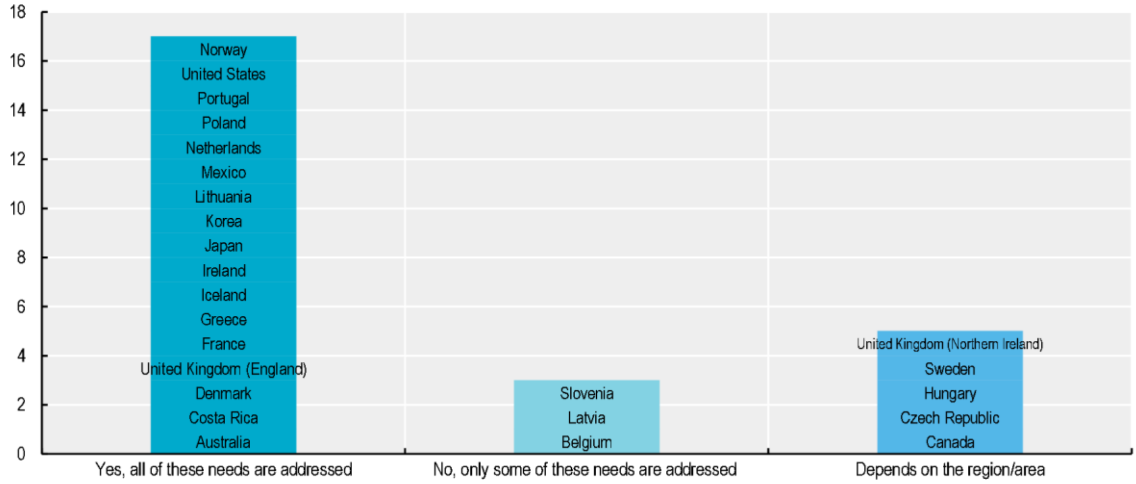
The setting of care and cause of death also seem to influence pain relief. In the United Kingdom, 63.5% of people in hospices declared receiving pain management when needed during the last three months of life, compared to only 18.6% of people at home. Around 8% of people receiving care at home reported not receiving any pain relief in the last three months of life, compared to 1.4% in hospices. Pain relief in care homes and hospitals appears to be somewhere in between, with respectively 42.7% and 39.7% of people reporting receiving pain relief when needed in the last three months of life. Cancer patients reported higher levels of pain relief compared to people with cardiovascular diseases or other diseases (ONS, 2015[9]). Similar results also come from New Zealand, where 71% of people in hospices, 69% in hospital and 61% in aged residential care facilities reported complete pain relief in the last three months of life, compared to only 17.5% of those at home (Reid et al., 2020[10]). Several randomised controlled trials showed that early referral to palliative care specialists can improve symptoms management and overall quality of life in people with life-threatening conditions (Hui, Heung and Bruera, 2022[21]).

Unmet spiritual and psychological needs are still common

Spiritual and psychosocial support are often lacking. A study from the United Kingdom, measuring access and adequacy of such services among adults at the end of life, reported that most patients did not consider the psychological services to be adequate. While most of the analysed hospices reported having in-house complementary therapist, spiritual advisor, and counsellor, only a minority have in-house clinical psychologists (19%) and counselling psychologists (9%). Hospices often also reported inadequate staff capacity and long waiting lists (McInnerney et al., 2021[22]). According to the VOICES survey for bereaved families in the United Kingdom, while nearly 70% of people agreed that the patients' emotional needs were addressed,[4] only nearly 59% of people reported that religious and spiritual support was provided. Furthermore, while 75% of people reported that emotional support was provided at home, only 60% reported so in hospitals (ONS, 2015[9]). Evidence from 2013 reported that less than half of the bereaved people who wanted to talk to health care professionals about their feelings manage to do so (Thomas, 2021[23]). While two-thirds have policies or programs that address the psychological, social, and spiritual needs of the people at the end of life, 15% of countries address at least some of those needs and in 18% such policies might vary within the country (Figure 4.4), only 14 reported including psychologists within EOLC multidisciplinary teams and only 7 included psychotherapists. Lack of spiritual support is associated with lower satisfaction with end-of-life care (O'Brien et al., 2018[24])

Figure 4.4. Most OECD countries address psychological, social, and spiritual needs of the person at the end of life

Countries' answers to the question "Are there policies or programmes to cover the psychological, social, and spiritual needs of people at the end of life?"



Source: (OECD, 2020-2021[13]).

Although patients would like to have their spiritual needs addressed, professionals do not always support them. According to a literature review, the reasons for this lack of support are related to lack of knowledge and training around spiritual care, fear of imposing personal religious beliefs and the feeling that spiritual care is not part of health professionals' tasks. Such barriers appear to be overcome when professionals are more informed regarding EOLC and spiritual care specifically (Evangelista et al., 2016[25]). Spirituality is a complex concept that goes beyond religion and the share of people defining themselves as religious and/or spiritual is changing over time. While both religion and spirituality are related to questions of meaning of human life, religion entails some connection with the transcendent, which is not necessarily included in the definition of spirituality (Lazenby, 2018[26]). Knowing about religion, spirituality and their differences is important for professionals working in end-of-life care. Evidence shows that training can play an important role in helping health care workers recognising the importance of spiritual care and improve the quality of spiritual and psychosocial support as part of end-of-life care (O'Brien et al., 2018[24]).

Bereavement care and follow ups after death seem to have a positive effect on the well-being of decedents' relatives but there is some evidence of unmet needs among bereaved family caregivers. Receiving bereavement care is associated to lower cases of prolonged grief and posttraumatic stress disorder (McAdam and Puntillo, 2018[6]). According to a study on family caregivers caring for people receiving palliative care, more than 50% of bereaved caregivers report unmet needs, particularly related to hope and symptom management (Ullrich et al., 2020[27]). Similarly, to the provision of spiritual care for people at the end of life, bereavement care faces several barriers on the health care professionals' side. Professionals express lack of knowledge and skills, together with frustration, discomfort and helplessness when dealing with bereavement care. Once again, training has proven effective in reducing the emotional barriers and burnout, while increasing feelings of self-efficacy and compassion satisfaction (Fan and Lin, 2021[28]).

4.2.2. Efforts to sustain life can lead to overtreatment at the end of life

In end-of-life care literature, overtreatment is defined as a medical intervention that is extremely unlikely to help a patient, that is, because it does not improve survival but there are potentially harmful effects. While overtreatment is challenging to measure because inaccuracies in survival probabilities, the literature has identified certain proxies to measure it and serve as potential indicators for quality. This section highlights data collected for such indicators piloted by the OECD which include, having repeated hospital admissions in the last 30 days of life, ICU admission and emergency department visits in the last 30 days of life, as well as receipt of chemotherapy within 30 days before death.

Hospital readmissions, emergency department visits, and ICU admissions during the last year of life are relatively high in some countries

While some hospital admissions at the end of life might be scheduled, emergency department visits, frequent hospital readmissions and admission to intensive care units close to the end of life are often avoidable and may result from a lack of access to community-based care. In countries where community-based palliative care is available, evidence suggests that patients who had received palliative care earlier were less likely to have multiple visits to the emergency room and less likely to be admitted into the intensive care unit in the 30 days before their death, compared with those who had not received palliative care, or received it closer to the end of their lives (Canadian Institute for Health Information, 2018[29]).

Table 4.3 indicates that, on average, 22% of patients were readmitted within 30 days from discharge during the last year of life, with wide variation across countries. Readmission rates in Slovenia and Switzerland are significantly higher than in other countries, while Lithuania's readmission rates are significantly lower than other countries. People who died due to cancer were more likely to be readmitted in their last year of life, compared to other causes of death, particularly in Slovenia and Switzerland.

Table 4.3. Share of patients readmitted within 30 days from discharge during the last year of life

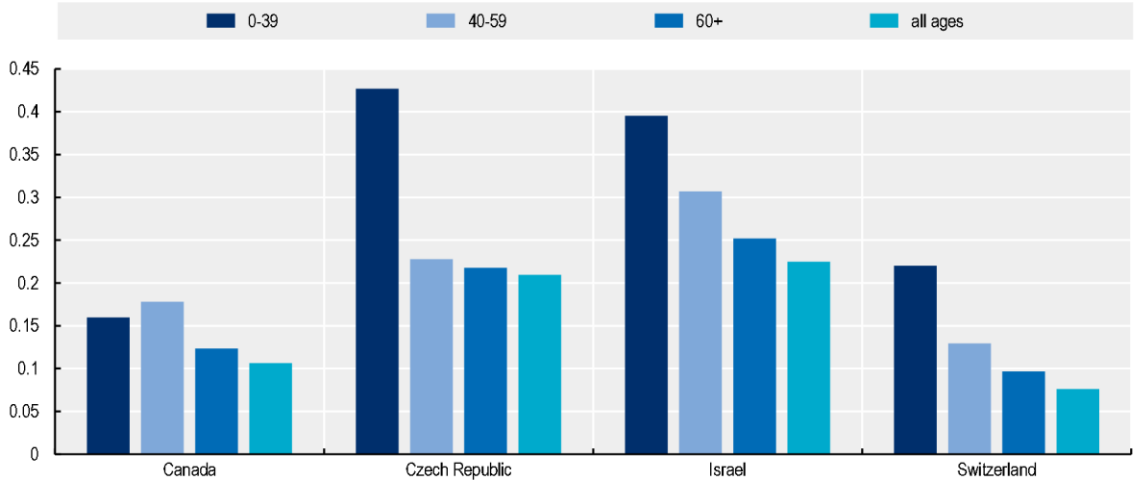
Country	Year	CANCER (neoplasms (ICD-10 C00-D49))	CARDIOVASCULAR DISEASES (ICD-10 I00-I52)	CHRONIC RESPIRATORY DISEASES (ICD-10 J44)	ALZHEIMER'S AND OTHER DEMENTIAS (ICD-10 F00-F03)	ALL CAUSES OF DEATH, EXLUDING EXTERNAL CAUSES (all ICD-10, except V00-Y99)
Czech Republic	2019	10%	6%	13%	12%	9%
Denmark	2019	17%	15%	15%	13%	16%
Israel	2018	15%	16%	15%	16%	15%
Lithuania	2020	5%	3%	6%	3%	4%
Slovenia	2019	64%	46%	54%	52%	54%
Sweden	2020	17%	14%	15%	11%	15%
Switzerland	2018	50%	25%	32%	24%	39%

Source: (OECD, 2021[19]).

Resource-intensive care within hospitals at the end of life, including admission to an intensive care unit (ICU), can also be an indicator of overall quality of health care delivery as it carries the risk of the patient receiving poor quality of EOLC and poor co-ordination and planning of follow-up care after discharge (Overbeek et al., 2017[30]). ICU interventions may include endotracheal tubes, intravascular lines, feeding tubes and restraints may reduce mobility, ability to communicate, and autonomy and may cause pain (Dasch et al., 2017[31]). ICU admission may not be aligned with patients' values and preferences for their end of life, can lead to worse quality of life for the patient including increased emotional and physical suffering, as well as caregiver distress (Bernacki and Block, 2014[32]; Leith et al., 2020[33]; Wang et al., 2016[34]; Zhang et al., 2009[35]). Figure 4.5 outlines that the ICU admission rates during the last 30 days before death are high but vary between 8% in Switzerland and 22% in Israel. In addition, the OECD survey indicated that patients tend to visit ICU more than once during the last 30 days before death, among the countries reporting data. On average, for each patient admitted to ICU in the last 30 days of life, the number of admissions ranges between 1.06 in Switzerland to 1.23 in Israel (in 2018). There is a decreasing rate of admissions as the age of the patient increases. This mirrors studies that have found that ICU and intensive treatment decrease with age (Bylicki et al., 2019[36]; Levinsky et al., 2001[37]; Menec et al., 2007[38]). This may relate to differing diagnoses between younger and older patients and consequent likely survival rates, which has implications for treatment. For instance, the five-year survival rates for invasive cancer are as low as 40% among older adults, but around 80% in children younger than 15 years old (Keegan et al., 2016[39]).

Figure 4.5. During the last 30 days before death, 15% of people are admitted to ICU on average across OECD countries with available data

Share of people admitted to ICU during the last 30 days before death among people who died in the reference year



Note: Data refer to 2018.
Source: (OECD, 2021[19]).

Close 40% of patients visited the Emergency Department (ED) during the last 30 days before death. Table 4.4 highlights the percentage of people by age group who visited the emergency department during the last 30 days of life. On average, for each patient admitted to ED in the last 30 days of life, the number of admissions is ranged between 1.23 in Sweden (in 2020) to 1.48 in Israel (in 2018). An analysis of administrative health data from New Zealand shows that people in their last year of life receive more aggressive treatments, including higher rates of ED admissions compared to people in the same age group which are not at the end of their life (Hamblin et al., 2018[40]). Furthermore, one meta-analysis focussed on lung cancer specifically found that patients receiving palliative care had few emergency department visits during the last 30 days of life (Bylicki et al., 2019[36]). For those who did access the emergency department, the most common symptoms were dyspnoea and pain (Bylicki et al., 2019[36]).

Table 4.4. Between 30% and 65% of people visited emergency department during the last 30 days before death

Share of people who visited emergency department during the last 30 days before death among people who died in the reference year

Country	Year	0-39	40-59	60+	All ages
Canada	2018	18%	31%	32%	30%
Denmark	2019	62%	56%	56%	27%
Israel	2018	42%	62%	66%	65%
Lithuania	2020	36%	42%	42%	27%
Sweden	2020	30%	39%	38%	38%

Source: (OECD, 2021[19]).

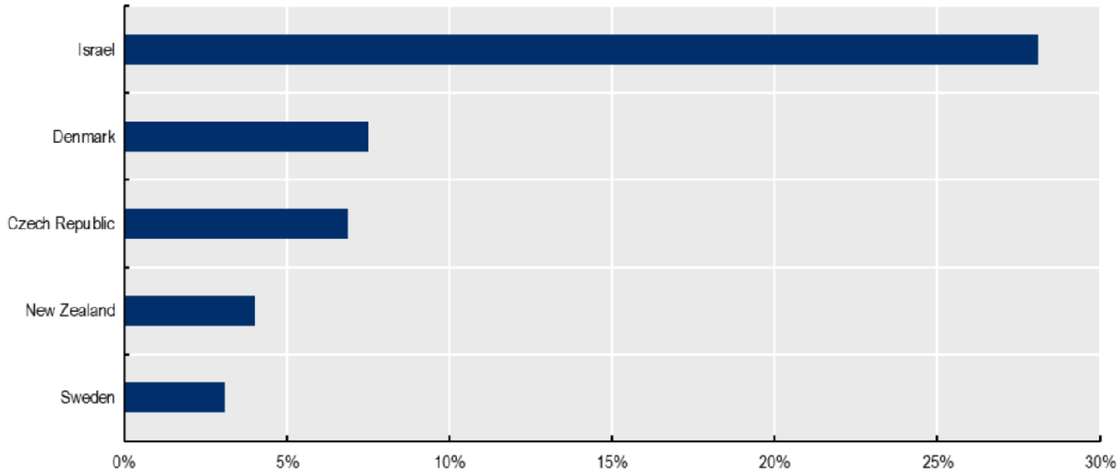
Treatment and care at the end of life may not necessarily be appropriate to the person's needs and can pose ethical dilemmas

There are concerns in some countries that a large share of resources is used on treatments that neither prolong life nor provide additional comfort to the patient. Ideally, when a patient is very close to death, this is recognised by the treating team and addressed with the patient, aggressive treatment stopped and supportive services put in place (Barbera, Paszat and Chartier, 2006[41]), although disease progression cannot always be sufficiently well assessed. Evidence from the literature suggests more than one-third (33% to 38%) of older patients with advanced irreversible diseases hospitalised near the end of life received interventions unlikely to provide either survival or palliation benefit (Cardona-Morrel et al., 2016[42]). Another concern related to care at the end of life is polypharmacy, namely the simultaneous use of high numbers of pharmacological treatments, usually more than five drugs at a time. A study on people admitted to hospital palliative care teams revealed that a median of seven drugs were prescribed at the time of admission, decreasing to four at the time of death. Polypharmacy causes high rates of side effects, 80% of people can experience side effects when they intake seven or more drugs (Peralta et al., 2022[43]).

The use of chemotherapy close to the end of life is considered a measure of poor quality of care. Evidence has shown that administering chemotherapy in the last month of life could represent a cause of unnecessary suffering while also constituting a cost to society. Studies on Canada, France and the United States reported that around 17% of people received chemotherapy in their last 30 days of life, while this percentage corresponds to nearly 12% in Switzerland (Woldie et al., 2022[44]). OECD analysis found that the share of people receiving chemotherapy during their last month of life corresponded to between 3% in Sweden to 28% in Israel (Figure 4.6). When looking at data by age group, strong inequalities appear between younger and older people among countries with available data.

Figure 4.6. Between 3% and 28% of people receive chemotherapy in the last 30-days of life

Share of people who died in the reference year, who received chemotherapy in the last 30 days before death



Note: Data refer to 2017 for New Zealand, 2018 for Israel, 2019 for the Czech Republic and Denmark, 2020 for Sweden.
Source: (OECD, 2021[19]).

People at the end of life also receive life-sustaining treatments such as cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition, and hydration. Such treatments may lead to complications and a decrease in the quality of life and might not be beneficial when a person is approaching the end of life (Akdeniz, Yardımcı and Kavukcu, 2021[45]). Withdrawal of life sustaining treatments is foreseen to provide palliation and comfort to the person dying. For instance, withdrawal of mechanical ventilation has proven to improve family satisfaction and reduce depression in family members (Gerstel et al., 2008[46]; Kross et al., 2011[47]). Nevertheless, some studies have reported that often people die while receiving mechanical ventilation and other life sustaining treatments. A study from the United States showed that one in two patients who had received mechanical ventilation received it until their death (Gerstel et al., 2008[46]).

When people’s wishes are not recorded and the patient is too ill, clinicians and families need to make treatment decisions, but decisions to withhold or withdraw life-support raise major ethical challenges for health professionals and can become a source of conflict with families. A study showed that conflict occurred between staff and family in 48% of cases when withdrawal of treatment was considered (Way, 2002[48]). Difficult ethical choices at the end of life usually concern the use of treatments such as cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration and the withholding and withdrawing of treatments (Akdeniz, Yardımcı and Kavukcu, 2021[45]). Discontinuing some treatment or providing pain relief can make death occur earlier: a retrospective study of patients who died in France in each month found that 47.7% of deaths followed at least one medical decision that may have hastened death such as withholding (14.6%) or withdrawal (4.2%) of treatments, or intensified use of opioids and/or benzodiazepines (28.1%). Evidence from a variety of countries also points to many deaths in ICU occurring after withholding or withdrawing treatment (Pennec et al., 2012[49]).

People at the end of life and their families have different preferences of care, which can cause and exacerbate conflicts during decision making. According to a literature review of studies from nine OECD countries (Australia, Canada, Denmark, Germany, Ireland, Korea, the Netherlands, United Kingdom, and the United States), family caregivers seem to value information and health care professionals’ engagement more than patients do. On the other hand, family members underestimate the patient’s preference to avoid caregivers’ burden and to organise personal affairs before death. Decisions around the type of care also represented potential cause of conflict, as family caregivers appeared more in favour of life-sustaining treatment compared to patients. Having information on the health status, the disease and care possibilities were factors associated with better alignment between people's and family's preferences (Mulcahy Symmons et al., 2022[50]).

4.3. How can quality in end-of-life care be improved?

The 2015 Quality of Death Index Ranking palliative care across the world measured quality of end-of-life care (Murray, 2015[51]). In particular, six measures are included in the assessment of such indicator: the availability of monitoring standards for organisations, the availability of opioid painkillers, psychosocial support to patients and families, do-not resuscitate policies, support for shared decision making and the use of surveys to assess patient's satisfaction. Among the OECD countries included in this assessment, the United Kingdom, Sweden, Australia, New Zealand, and France ranked in the top five, while Colombia, Greece and the Slovak Republic ranked lowest (Murray, 2015[51]). This section discusses examples of best practices across countries highlighting access to pain relief, shared decision-making and reducing unnecessary treatment, psychosocial and spiritual support, as well as monitoring and measurement.

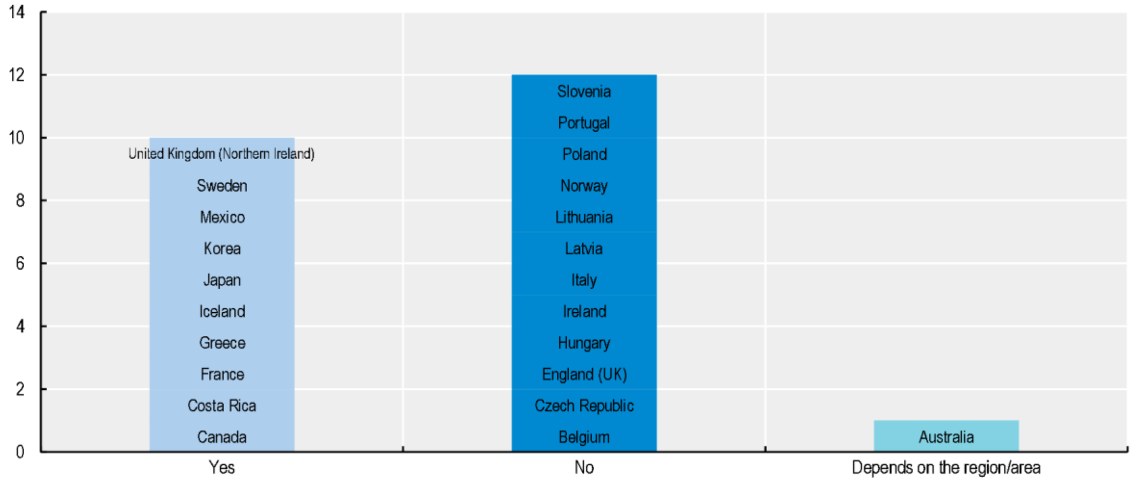
4.3.1. Reducing barriers to accessing pain relief at the end of life

Ensuring appropriate use of pain relief, including opioids, requires a fine balance between measures to minimise the misuse of opioids among the general public and ensure that there is sufficient pain relief for those with high needs. OECD countries have already put in place measures to improve the opioid-related literacy among patients, family, and providers (OECD, 2019[20]). In fact, one of the barriers to pain relief is that health care professionals do not always feel comfortable providing opioids and similar medication because of their possible risks. At the same time, patients and families can be reluctant to accept the use of opioids as they might be seen as dangerous or as an indicator that the end of life is approaching (Bhadelia et al., 2019[52]). Adequate training for health care professionals, safety protocols and monitoring of unlawful practices, without undermining the medical need for opioids, seem to justify the correct use of opioids in Germany and the United Kingdom. These countries succeeded to keep nonmedical use very low, despite the high availability and consumption of opioids (Bhadelia et al., 2019[52]). In particular, evidence from the Netherlands and the United Kingdom showed the positive impact that training has on supporting physicians to prescribe opioids appropriately (British Medical Association, 2017[53]). Among clinicians who received training, 67% report an increase in the confidence when prescribing opioids and 86% report some changes in their prescribing practices (OECD, 2019[20]).

Results from the 2020 OECD End of Life Care Policy Questionnaire suggest that specific prescribing regulations may not present the most pressing barrier to accessing opioid-derived pain relief. Across 24 OECD countries that responded to questionnaire, nearly all countries reported that opioid prescribing is allowed by all medical doctors, though specific licenses are required to prescribe opioids in nearly half (43%) of responding countries (Figure 4.7). In Japan, for example, physicians are required to process both a medical license and a license designating them as a "person licensed to administer narcotics" to prescribe opioids.

Figure 4.7. Around half of the countries require specific licenses to prescribe opioids

Countries' answers to the question "Are specific licences required to prescribe opioids?"



Source: (OECD, 2020-2021[13]).

Yet, some countries have supported the provision of pain relief through changes in the rights to prescribe opioids, allowing non-medical professionals to prescribe such medication. When changing prescription practices, countries must ensure that health care providers are knowledgeable about opioids and feel comfortable when making a decision to prescribe such pain relief. The United Kingdom has increased the availability of prescribers since 2012 by giving non-physicians (e.g. specialist nurses and pharmacists) the possibility to prescribe pain relief. The British Medical Association recommends to better promote the existing guidance on the prescription and management of opioids, to support professionals providing pain relief (British Medical Association, 2017[53]). Among OECD countries, 15 have such clinical opioid guidelines in place, usually at the national level (OECD, 2019[20]).

The regulation on medication use has also played a key role to improve access to pain relief. Countries like Germany, Austria, Belgium, Denmark, and the Netherlands show high rates of opioids availability, but low rates of overdose deaths due to opioids misuse (OECD, 2019[20]). In some cases, access to pain-relieving medicine at the end of life has been improved by developing palliative drug programs that subsidise medicines that would not otherwise be covered by health plans, or that expand access to medicines that would not otherwise be made available outside of health care settings, such as at home or in hospice. In Canada, palliative drug programs have been put in place in several territories and provinces, including Alberta, British Columbia, Manitoba, Nova Scotia, Prince Edward Island, Saskatchewan, and Yukon. Among patients in Alberta, British Columbia and Manitoba who were on a palliative drug programme in their last year of life, 81% received opioids for pain relief, compared with just 35% of patients on other public drug plans in their last year of life (Canadian Institute for Health Information, 2018[29]). In Australia, the regulatory body – Therapeutic Goods Administration (TGA) – has acknowledged and highlighted the importance of opioids for the treatment of symptoms and publicly stated that regulations "must not unduly restrict informed, rational prescribing of opioids" (TGA, 2018[54]). Furthermore, the position statement of Palliative Care Australia on Sustainable access to prescription opioids for use in palliative care provides eight recommendations[5] for a sustainable opioid management, to improve the access to such medications while minimising the risks linked to their use (PCA, 2019[55]). Among OECD countries, there has been a recent trend in adjusting regulations to enhance transparency in marketing relationships, but impact evaluations are not common[6] (OECD, 2019[20]).

4.3.2. Reducing unnecessary treatment and managing ethical dilemmas

Reducing the prevalence of unnecessary treatments as patients approach the end of life can help to improve their quality of death – by, for example, facilitating death in the home based on preference – while also reducing the high costs of care that often come at the very end of life. Supporting health care professionals facing ethical dilemmas can reduce disagreements and facilitate the provision of the most appropriate care at the end of life.

Early provision of palliative care, physicians' training and advance directives can reduce unnecessary treatment

Early palliative care, especially community-based, is often associated with reducing non-beneficial treatment. A systematic review of interventions intended to reduce unnecessary end-of-life hospital use found that the introduction of community-based palliative care interventions was associated with reductions in hospital use at the end of life (Taylor et al., 2020[56]). Among patients who had not received community-based palliative care, some evidence suggests that receiving palliative care initiated during their hospital visit may still help to reduce the length of stay (Wu et al., 2013[57]; May et al., 2017[58]). A ten-year study in Canada shows that early specialist palliative care exposure reduces the risk of hospital-based acute care, including ICU admission, in the last 30 days of life for all chronic disease groups except dementia (Earp et al., 2021[59]). Early referral to palliative care also appears to be associated with a lower likelihood of receiving chemotherapy in the last month of life, better quality of life and longer survival rates (Qureshi et al., 2018[60]; Temel et al., 2010[61]; Woldie et al., 2022[44]). Some evidence suggests that training in palliative care affects decision-making about end-of-life treatment decisions for physicians, although research on this front is scarce. Evidence has found that doctors trained in palliative care were less likely to choose to pursue more aggressive courses of treatment at the end of life, such as blood transfusions and intravenous hydration (Piili et al., 2018[62]).

Regulation establishing the right of patients to take an active role in decision making at the end of life seems to also influence treatment choices. The United States introduced the Federal Patient Self-Determination Act (PSDA) in 1991, which entails that physicians should engage in conversations on end of life preferences and support patients in decision making, but must respect the patient's autonomy to voice their choices (Karnik and Kanekar, 2016[63]). In France, a 2005 law on patient rights at the end of life expanded the involvement of patients and their families in end-of-life care decision-making while facilitating opportunities for communication between the health care team and the patient and their carers. In a study of deaths in intensive care in one health care facility in France before and after the implementation of the 2005 law and development of an end-of-life care communications strategy, the proportion of patients who died following a decision to withhold or withdraw treatment nearly doubled, rising from 45% prior to the implementation of the law and communications strategy, to 85% after it was introduced (Quenot et al., 2012[64]).

Furthermore, all physicians, regardless of whether they had received palliative care training, were more likely to pursue aggressive treatments following advocacy by family members, while the having an advance directive was associated with a lower likelihood of aggressive treatment (Piili et al., 2018[62]). A range of communication tools to help guide end of life discussions in different settings, such as intensive care units, have been developed to improve decision-making and the quality of communication. While further high-quality studies are needed, evidence suggests that the uptake of such communication tools may be associated with less intensive treatment at the end of life, in addition to improvements in how end-of-life decisions are documented (Oczkowski et al., 2016[65]). The United States developed the Physician Orders for Life-Sustaining Treatment (POLST) in the early 90s and as of 2020 POLST are adopted in most states. The POLST forms are standardised and thus transferrable across settings of care. A systematic review found that when people had POLST, in most cases there was alignment between their wishes and the care that people received. This was the case for 93% of people with stated preferences on artificial nutrition/hydration, 96.5% for antibiotics use and 97.5% for cardiopulmonary resuscitation (Tark et al., 2020[66]). POLST can also be advantageous for people with dementia. Their use appears to increase communication and documentation around end-of-life care preferences as well as the alignment between preferences of care and care provision for people with dementia. Some issues linked to POLST consist in the difficulties of nurse practitioners in discussing and explaining care options as well as a lack of understanding of POLST and issues with proxy people (Kim et al., 2015[67]).

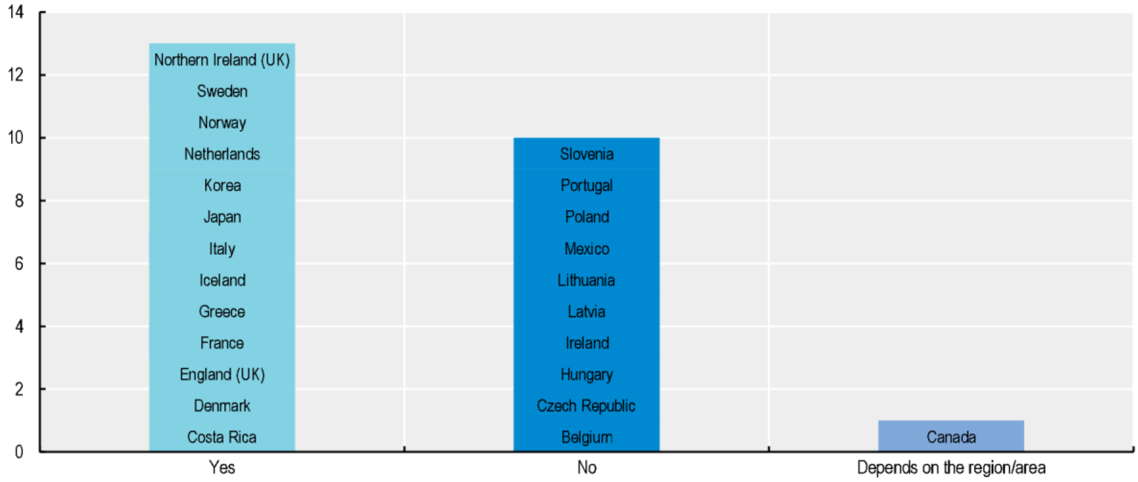
Managing ethical dilemmas and disagreements can lead to care that is effective and in line with people's preferences

While hospital use at the end of life has been associated with non-beneficial or inappropriate treatment, not all hospital treatments are unnecessary, and the likelihood of receiving non-beneficial care once admitted to hospital has been associated with whether patients had disagreements within their own family or clinical teams about their care (Carter et al., 2019[68]). Balancing over treating with withholding or stopping treatment at the appropriate time can represent a tremendously difficult balance for health professionals, both in ensuring care is not removed too hastily, and that the patient, as well as their carers and family, understand and agree with the decisions being made. Communication difficulties among and between patients, patient's families, and health professionals have been frequently identified as one of the most challenging issues confronting high-quality end-of-life care (Price et al., 2019[69]). Patients or families may be resistant or opposed to the care that health care professionals may be inclined towards, particularly around the withdrawal of life sustaining or prolonging treatments. Furthermore, patients and their families might have different preferences, generating disagreements (Mulcahy Symmons et al., 2022[50]).

In addition to general ethical principles driving decision making in health care, countries have also put in place national guidelines to help health professionals make end-of-life care decisions. There are four important ethical principles guiding end-of-life care decisions: autonomy, beneficence, no maleficence, and justice. Autonomy consists in the right of self-determination of the patient whose decisions should be respected, beneficence means that physicians need to choose the best intervention for their patients, no maleficence corresponds to avoiding unnecessary harm, while justice refers to fair and impartial distribution of health care services and resources (Akdeniz, Yardımcı and Kavukcu, 2021[45]). In addition, three-fifths of surveyed OECD countries (15 of 25) reported that they had in place national guidelines to manage situations of misalignment between patients and health care providers (Figure 4.8). Such guidelines are often embedded within broader guidelines on decision making regarding withholding and withdrawing treatment. For instance, the Australian State of Queensland issued comprehensive guidelines on decision making regarding withholding and withdrawing life sustaining measures from adult patients. The guidelines include support regarding how to manage possible disputes that might arise with patients and families, recommending having a respectful conversation, allow time, seek other opinions and assistance with conflict resolution when needed. The guidelines recommend involving an impartial third party in the discussion, for instance a senior health professional. If conflict persists, the guidelines also suggest referring to hospital ethics committees (Queensland Health, 2018[70]). The Canadian Critical Care Society also developed guidelines on withholding and withdrawing treatments which support physicians making decisions at the end of the patients' life, including guidelines on how to deal with disagreements with patents and families over the preferred care. Such guidelines also recommend seeking the opinion of an experienced third party (e.g. other health care providers, spiritual care providers) before referring to ethics committees or institutional ethics consultants (OECD, 2020-2021[13]).

Figure 4.8. Countries reporting specific guidelines to manage situations of misalignment between patients and health care professionals on ethical choices

Countries' answers to the question: "Are there specific guidelines to manage situations of misalignment between patients and health care providers on ethical choices (e.g. provision of life-sustaining or life-prolonging treatments)?"



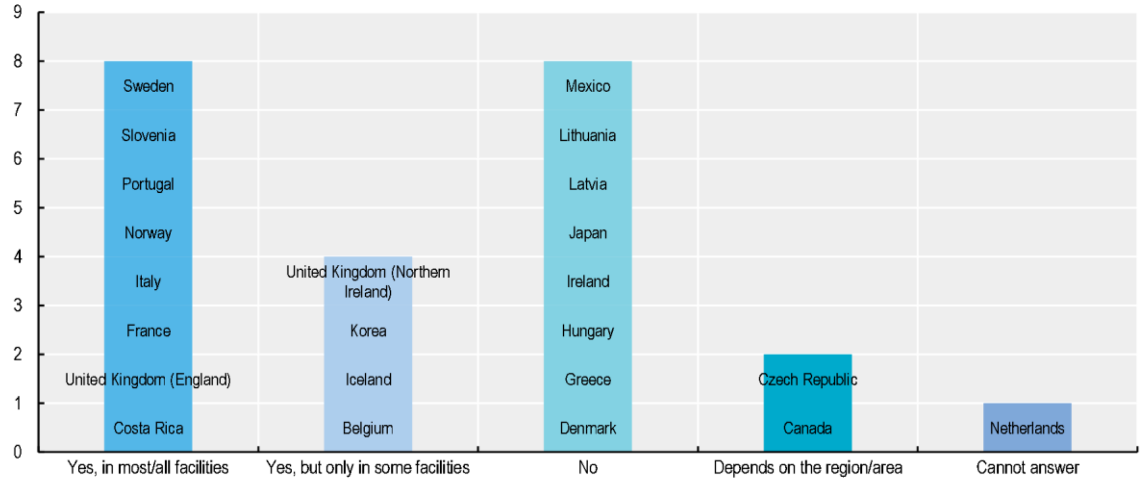
Source: (OECD, 2020-2021[13]).

Growing evidence suggests that ethical consultations or ethics committees may help to improve important measures of end-of-life care quality and the experiences of patients, their carers and health care staff. Studies of patients who did and did not receive ethics consultations in hospital at the end of life found that while mortality rates were unchanged, the number of days spent in intensive care units, as well as the provision of life-sustaining treatments, both fell for the patients who had received an ethics consultation, compared with those in the control group (Au et al., 2018[71]; Schneiderman, Gilmer and Teetzel, 2000[72]).

A majority of OECD countries report having interdisciplinary ethics committees and employee assistants who are in charge of helping employees facing difficult ethical decisions in end-of-life care, with slightly more than one-third of responding countries (9 of 24) reporting that such committees and staff members are available in most or all facilities providing end-of-life care (Figure 4.9). In Canada, regions should have formal resolution processes for health care disputes, involving multiple representatives and stakeholders. Costa Rica has Local Committees of Clinical Bioethics in public hospitals to provide case by case support for conflict resolution. Similar ethics committees and mediation services are also available in many health care settings in the United Kingdom and France. The latter has a national ethics committee and is currently setting up regional ethical support platforms. Furthermore, during the pandemic French ethics centres provided support through phone lines (OECD, 2020-2021[13]).

Figure 4.9. Countries with interdisciplinary ethics committees or employee assistants to help health care professionals address difficult ethical decisions in end-of-life care

Countries' answers to the question: "Does your country have interdisciplinary ethics committees and employee assistants in charge of helping employees facing difficult ethical decisions in EOLC?"



Source: (OECD, 2020-2021[13]).

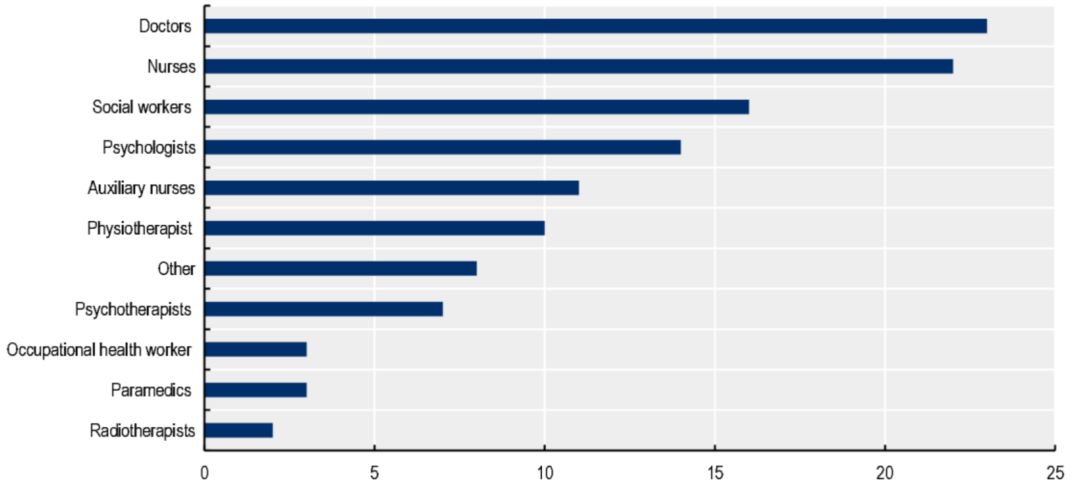
4.3.3. Ensuring a comprehensive approach to EOLC

Multidisciplinary teams can address all person's needs in a holistic approach

Taking into account all needs of the person at the end of life, holistically, requires a joint effort of several professionals. Furthermore, with people at the end of life often suffering from comorbidities, the co-ordination across different professionals is even more crucial. Multidisciplinary teams represent a way to adequately address all the person's needs. Multidisciplinary teams consist of groups of professionals with different specialisations, who can co-operate and co-ordinate in providing care to the person at the end of life. Multidisciplinary teams address physical symptoms as well as psychosocial and spiritual needs.

All surveyed OECD countries reported having multidisciplinary teams to provide EOLC services, but the number and types of professionals vary across countries. Doctors, nurses, and social workers are most often included in such teams, with respectively 23, 22 and 16 countries reporting including those professionals in EOLC teams. Radiotherapists, paramedics, and occupational workers are the least involved in multidisciplinary teams. Furthermore, despite the importance of considering the psychological needs of people at the end of their life and their relatives, psychologists and psychotherapists are included respectively in 14 and 7 out of 27 surveyed OECD countries (Figure 4.10). Pharmacists could also play a growing role in end-of-life care and be involved in multidisciplinary teams. Some OECD countries have already started to expand the role of pharmacist by allowing them to change prescriptions to generic drugs, administer vaccines for COVID-19, renew or extend prescriptions for contraceptives, order laboratory tests. Estonia has also integrated pharmacists into multidisciplinary teams (de Bienassis et al., 2022[73]). Building on the trusted relationship with patients and their pharmaceutical knowledge, they could provide advice and support to the patients and their relatives, initiate discussion on end of life, monitor the pharmacotherapeutic process and support families in the bereaved period (Wendy Archer, 2017[74]).

Figure 4.10. Professionals included in EOLC multidisciplinary teams vary across countries



Note: N=27.
Source: (OECD, 2020-2021[13]).

Interdisciplinary palliative care teams were found to improve the satisfaction of patients at home and in hospitals, especially with the communication but were also related to improved continuity of care and better hospital discharge (NICE, 2019[2]). Interdisciplinary teams at the end of life can include a range of professionals such as a doctor, nurse, social worker, an occupational therapist but also a psychologist and a home care worker. Case management is beneficial for patients with progressive life-threatening illnesses and complex needs as it can reduce the likelihood of gaps in care, time in hospital, the use of aggressive care and caregiver burden. Case managers help patients and their families with assessment, planning, implementing, co-ordinating, monitoring, and evaluating the options and services required to meet the client's health and service needs. As people at the end of life often experience transfers across settings, someone helping with communication across settings can be beneficial. Evidence from the Netherlands shows that the percentage of patients who die at home is higher and the number of hospitalisations in the last 30 days of a patients' life is lower when a case manager is involved offering advice and support (van der Plas et al., 2015[75]). An early and integrated approach that joins up different services has the potential to improve quality of life and symptom intensity (Healthcare Improvement Scotland, 2019[76]).

Some countries include multidisciplinary teams in the guidelines for the provision of end-of-life care. In 2019, the English National Institute for Health and Care Excellence (NICE) published guidelines on the EOLC services delivery. Guidelines report the importance of multidisciplinary teams that can take care of the person at the end of life holistically and they underline the crucial role played by advance care planning and electronic records sharing within the multidisciplinary team, to ensure care co-ordination. The guidelines do not define precisely what professionals should be included in the team, but rather list the type of support that the team must be able to provide (NICE, 2019[2]). In France since 2004 the guidelines require that when a patient starts an EOLC programme multidisciplinary teams must meet to discuss the patient's needs. The teams must also care and support the relatives of the person reaching the end of life (French Ministry of Health, 2008[77]).

Other countries have introduced programs and projects for the provision of end-of-life care that foresee the use of multidisciplinary teams. In Canada, the composition of multidisciplinary teams varies across the country. Doctors, nurses, auxiliary nurses, and social workers are the minimum requirement, but other professionals can be part of such teams. The Canadian Society of Palliative Care Physicians has designed a model to calculate the staffing needs for multidisciplinary teams providing palliative care (OECD, 2020-2021[13]). In the Czech Republic, the Ministry of Health has funded a pilot project to implement multidisciplinary palliative care teams in acute care setting. The project started in 2017 and is currently ongoing in 6 large hospitals across the country. At the end of the implementation phase (i.e. 2026), it is expected that at least 5 of the 6 pilot hospitals will continue using such multidisciplinary teams.

Ireland, Japan, and the United States are addressing the need of multidisciplinary teams through training initiatives. The All-Ireland Institute of Hospice and Palliative Care has launched the ECHO AIIHPC project to provide nursing home staff with occasions of mentoring and development on palliative care. The project brings together nursing home staff and multidisciplinary teams from specialist palliative care services, which engage in case studies discussion and exchange on difficult patient scenarios (National Clinical & integrated Care Programmes, 2019[78]). Such interdisciplinary interaction has proven to improve professionals' confidence to provide palliative care (Dowling et al., 2020[79]). Japan launched in 2012 the "Care for Life-threatening Illnesses" programme, which provides paediatricians with palliative care education (Murray, 2015[51]). In the United States, since 2002 the Department of Veterans Affairs provides training about palliative care to a plethora of professional figures (i.e. chaplains, nurses, pharmacists, physicians, psychologists, and social workers) to prepare them to work as part of EOLC multidisciplinary teams. The programme, the VA Interprofessional Fellowship in Palliative Care, lasts one year and combines clinical and academic training opportunities. The academic training includes treatment of physical symptoms, EOLC conversations, ethical and legal issues and psychological issues related to the end of life. At the end of each programme, several indicators are calculated to measure the success of the programme (Weller et al., 2019[80]).

Some countries have included spiritual support in guidelines and include actions for relatives

Spiritual care complements and overlaps with psychosocial support. Already in 1998, the WHO included spiritual needs as an essential domain of life and included it into quality-of-life measurements (The Whoqol Group, 1998[81]). Spirituality at the end of life does not exclusively refer to religion, but it encompasses everything that provides meaning to life. Spiritual care provides meaning and purpose to the life of people that, in the dying process, suffer from a loss of meaning. Such care has proven effective in helping people cope with grief and ill health. It entails the assessment of the person's believes and needs to provide the best support in line with their wishes (Colleen Doyle, 2016[82]). Growing evidence has shown that spiritual care improves people's experience of the end of life, across age groups and disease groups. When spiritual care is missing, people are more likely to experience dissatisfaction with care and more aggressive care, higher costs of care. This is particularly the case among ethnic minorities (Gijsberts et al., 2019[83]).

The Netherlands included spiritual care within palliative care guidelines in 2006. In the same period in Rotterdam there was the first course to train experts in palliative care and spiritual care, which involved international experts, including German experts who drew upon their previous experience with palliative and spiritual care training. Although spiritual care is currently not integrated system-wide in the Netherlands Palliative Care National Programme, some progress has happened. The government of the Netherlands has recognised the importance of spiritual care and currently has multidisciplinary guidelines on spiritual care and an inventory of competencies for spiritual care. Furthermore, in 2011 the European Association for Palliative Care (EAPC) established a taskforce on spiritual care in palliative care, including primary caregivers, spiritual care providers, researchers, psychologists, social workers, and policy makers (van de Geer and Leget, 2012[84]).

Helping caregivers manage their emotions, accept the end of life of their relatives and more generally improve their mental health is an emerging policy area in the field. A systematic review including studies from Australia, Canada, the Netherlands, United Kingdom, and the United States has reported interventions to support family caregivers of people with dementia reaching the end of life. Interventions adopted included provision of information, psychoeducational programs, family meetings, psychosocial support, and education. The best results were obtained through structured psychoeducational interventions and regular family meetings (Gonella et al., 2021[85]). Similar evidence also comes from Japan, where a survey of bereaved families showed that family members who had end-of-life conversations were less likely to experience depression and complicated grief. In turn, they reported a better quality of death and dying (Yamaguchi et al., 2017[86]). Furthermore, respondents to the Veterans Affairs' Bereaved Families Survey in the United States reported high appreciation for the support received by health care staff during grief, through expressions of condolence. The Veterans Affairs' inpatient facilities also provide bereaved families with booklets reporting information on benefits entitlement after the Veteran's death, recommendations for local lodging, restaurants, and funeral arrangements. Bereaved families have reported high appreciation for this set of support actions (Gray et al., 2020[87]).

4.3.4. Improving quality monitoring for end-of-life care

As outlined earlier in this Chapter, for too many people high-quality end-of-life care is not the reality. This section describes efforts from some countries to have a stronger focus on monitoring and measuring the quality of end-of-life care which are critical to show quality improvements.

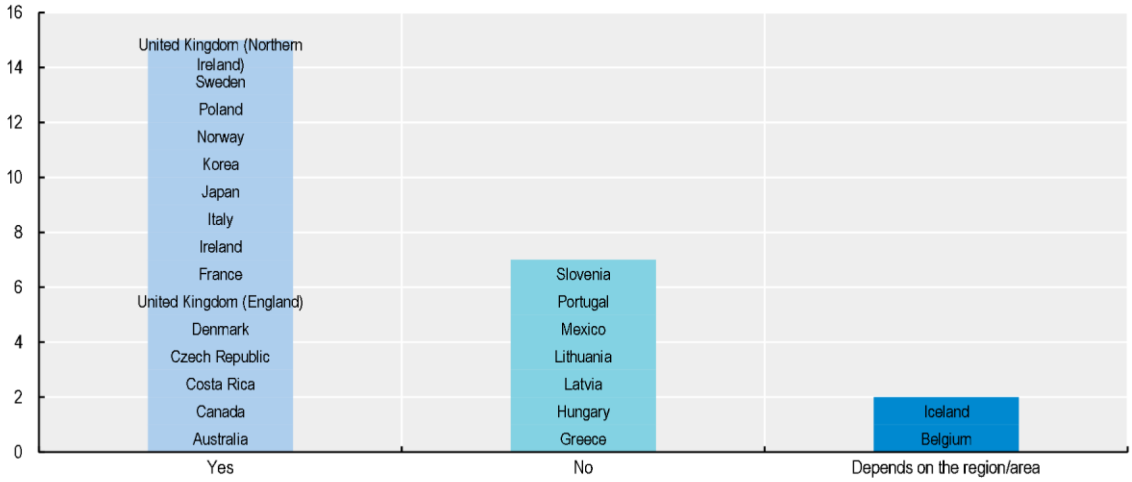
More efforts could be made to ensure widespread use of quality guidelines and standards

Well-defined care guidelines and standards can help drive improvements in care quality. By setting a benchmark for high-quality, evidence-based care, they can provide guidance on the interventions that patients should receive, can make gaps between best practice and care delivery more apparent, and they can promote person-centredness by increasing transparency about the treatments and interventions to which patients and their families are entitled.

While many countries have some form or care guidelines or standards, greater efforts are needed to ensure that they are well-framed to drive tangible and meaningful improvements in care quality. Most of the countries report having quality standards, norms, or guidelines in place to inform quality palliative and end-of-life care, though many are voluntary. Across 24 responding OECD countries, more than three-fifths (63% – 15 of 24 countries) responded that they had specific quality standards or norms to guide end of life care services on a national level, with a further two countries reporting that quality standards or norms existed on the regional level (Figure 4.11). While most of the countries report having developed palliative care or end-of-life care standards and guidelines, however, not all national quality standards are mandatory, monitored or enforced through review. The approach to care guidelines varies across countries: in some countries there are specific care guidelines for end-of-life care, whilst in other countries, guidance with respect to end-of-life care is embedded in clinical guidelines for the treatment of specific conditions, such as cancer.

Figure 4.11. Most countries have national quality standards or norms guiding end-of-life care

Countries' responses to "are there specific quality standards or norms for EOLC in your country (e.g. programmes, guidelines)?"



Source: (OECD, 2020-2021[13]).

Clinical care guidelines

Care guidelines could provide one mechanism by which to begin to tackle the challenges of over and under-treatment outlined in this chapter by providing clear guidance on interventions that are effective and cost effective. Norway, Denmark, and England stand out for having dedicated care guidelines for end-of-life care that are applicable in a broad range of care settings, and that touch on both medical and social care needs. In Norway, for instance, there is a national clinical guideline on palliative care in the final stages of life. While it is primarily focussed on guidance to effectively meet patients' physical needs and symptoms, it also contains guidance on effective end-of-life conversations that recognise physical, mental, social and spiritual needs, and on person-centred care planning (The Norwegian Directorate of Health, 2018[88]). In Denmark, there are two national recommendations for palliative care for adults and for children and young people. They provide guidance on holistic needs assessments, end-of-life conversations, patient and relative involvement and support for survivors, and emphasise a multidisciplinary approach (Danish Health Authority, 2017[89]). Denmark's care guideline also stands out for making several recommendations around quality monitoring, assurance, and improvement. In the United States, the National Coalition for Hospice and Palliative Care, an independent organisation comprised of 12 national hospice and palliative care organisations, publishes consensus-based clinical practice guidelines for quality palliative care that include guidelines on culturally competent communication.

In the United Kingdom (England), the National Institute for Health and Care Excellence (NICE) has published four clinical care guidelines on end-of-life care which are accompanied by care indicators and appear to be binding. The four guidelines focus on i) end-of-life care for adults, ii) end-of-life care for adults in the last days of life, iii) end-of-life care for children and young people, iv) on the use of opioids for pain relief. They are oriented to commissioners, providers, and practitioners, as well as adults approaching the end of their life, their carers, and families (NICE, 2014[90]). England's care guidelines stand out for being accompanied by a range of care quality standards which contain specific and measurable indicators of care quality (outlined in Table 4.5 below). Specific guidelines or recommendations on end-of-life care are also under development in a number of other countries, for example in Ireland, where the Clinical Effectiveness Committee has authorised the National Clinical Programme for Palliative Care to develop a national guideline on care for the dying adult (HSE Ireland, 2019[91]).

In several countries, guidance on aspects of end-of-life care is also embedded in clinical guidelines for the treatment of specific conditions, such as cancer, for example in Ireland, clinical guidelines on the management of cancer pain and constipation include guidance on managing symptoms toward the end of life. In England, Norway and Denmark, national care guidelines on end-of-life care are also accompanied by a range of specific guidelines for the treatment of certain conditions, which include components of end-of-life care such as symptoms management. For example, in England there is a national guideline on improving supportive and palliative care for adults with cancer and in Norway there is a guideline on palliation in cancer care. In Denmark, it is expected that the national recommendations for palliative care will be embedded in relevant care guidelines, for example in relation to the treatment of specific conditions. In addition to these national recommendations, several professional organisations have also developed clinical guidelines with respect to palliative care (Danish Health Authority, 2017[89]).

Several countries have taken steps to ensure a consultative approach to the development of care guidelines, and these efforts are to be welcomed. Developing care guidelines with input from the providers and users of services provides a valuable tool by which to ensure buy-in to recommendations, and the involvement of patient and carer representatives is one way by which to promote person-centredness in care. In several countries – such as Denmark, Norway, Ireland, and England – care guidelines have been developed in close consultation with a broad set of stakeholders.

Care quality standards

Care standards can drive care quality by setting a standard for care systems to aspire and to, and by making gaps between best practice and care delivery more evident. Care standards for end-of-life care typically focus on early identification of people who are reaching the end of their life, shared decision-making with patients and their relatives, symptoms and pain control, holistic care that includes support to patient's relatives, advance care planning, multidisciplinary and co-ordinated care provision. However, there is variation across countries as to the breadth and depth of care standards, in terms of the settings and interventions covered, and the extent to which they are measurable. While many countries have care quality standards for end-of-life care, they are sometimes limited to specific care settings or institutions – or where they are not – are often not mandatory or measurable.

Several countries, such as the Netherlands, Canada, and England, have developed comprehensive care quality standards for end-of-life care. For example, in the Netherlands, in 2017 Palliative Care Netherlands (PNZL) – with the support of the national Ministry of Health Welfare and Sport – published an expansive Quality Framework for Palliative Care, together with a conceptual framework setting out shared and unambiguous definitions of key concepts. The framework was developed through consultation with patients, families, health care professionals and insurers to develop a joint vision and criteria for the quality of palliative care in the Netherlands and aimed to define high-quality care from the perspective of those who receive it. The Dutch framework stands out for its breadth and depth, with a focus on ten specific quality domains that cover core values and principles, structures and processes, and physical, psychological, social, cultural, ethical and legal components of care (IKNL/Palliactief, 2017[92]). A patient version of the framework was published by the Dutch Patient Federation in 2019 to provide further transparency about the standards of care that patients can expect, and is available as both an e-book and PDF (Palliaweb, 2019[93]). Whilst the framework defines care quality, it does not – by its own design – set out how high-quality care can be monitored or achieved: it defined what care should be provided and when, but not how, and work is ongoing to translate these principles into specific and measurable actions that drive care quality (IKNL/Palliactief, 2017[92]).

In Canada, a new standard for palliative care services for adults was published in 2020, broadening the scope of care standard beyond facilities to include home and community care. The care standards are focussed on staff capacity, the provision of safe and effective services, ensuring enabling and supportive environments, care co-ordination, and care continuity (Health Standards Organisation, 2020[94]). Similarly in Australia, the commission on safety and quality in health care has published standards that focus on two areas: i) the process of care (i.e. patient-centred communication, shared decision-making, care co-ordination, recognition of patients reaching the end of life); and ii) organisational prerequisites (governance, education and training, support to multidisciplinary teams, monitoring and evaluation) (Australian Commission on Safety and Quality in Health Care, 2015[95]).

England stands out for having measurable care quality standards, aligned to a national vision for care quality. In 2014, the Leadership Alliance for the Care of Dying People – a national coalition of 21 organisations including Public Health England, NHS England, NICE and the Care Quality Commission – published *One Chance to Get it Right,* a joint national vision on the approach to and quality of care for dying people. The national principles have been translated into clear, measurable standards by being embedded into relevant clinical care guidelines and care quality standards. The National Institute for Health and Care Excellence (NICE) has published several comprehensive quality standards for end-of-life care which contain structure, process, and outcome measures of care quality (National Institute for Health and Care Excellence, 2022[96]). The quality standard for end-of-life care for adults, for instance, contains five quality statements with accompanying quality measures of care quality (Table 4.5).

Table 4.5. Care standards in the United Kingdom (England) contain specific, measurable statements that can be used to assess care quality

Quality standard for end-of-life care for adults [QS13] in England

Quality Domain	Quality Statement	Type of measure	Measure
Quality Statement 1: Identification	Adults who are likely to be approaching the end of their life are identified using a systematic approach	Structure	Evidence of local systems established to systematically identify adults who are likely to be approaching the end of their life
		Outcome	The proportion of adults who have died with progressive life-limiting conditions who were on the palliative care register or had evidence of end-of-life care planning
Quality statement 2: Advance care planning	Adults approaching the end of their life have opportunities to discuss advance care planning	Structure	Evidence of local arrangements to ensure that adults approaching the end of their life have opportunities to discuss advance care planning
			Evidence of local arrangements to ensure that advance care planning for adults approaching the end of their life takes into account their holistic needs assessment
		Process	Proportion of adults approaching the end of their life who have documents discussions about advance care planning
			Proportion of adults approaching the end of their life whose documented advance care plan takes into account their holistic needs assessment
		Outcome	Satisfaction of adults approaching the end of their life with the support they have to plan their future care

Note: Only two out of five quality statements are listed here, to provide an indication of the types of measures attached to care quality standards.
Source: (NICE, 2021[97]).

In other countries, care quality standards are limited to specific care settings or providers or have not yet been fully developed. For example, in the United States, care standards are limited to hospice care provided through Medicare. All Medicare hospice providers are required to assess and address patient's needs in a written plan within 48 hours of election of hospice care, including their physical, psychosocial, emotional, and spiritual needs. The Centres for Medicare and Medicaid Services also select hospitals that can participate to the PPS-Exempt Cancer Hospital Quality Reporting (PCHQR) Program. Currently 11 hospitals participate to the programme collecting and publishing data on: i) Proportion of Patients Who Died from Cancer Receiving Chemotherapy in the Last 14 Days of Life; ii) Proportion of Patients Who Died from Cancer Admitted to the ICU in the Last 30 Days of Life; iii) Proportion of Patients Who Died from Cancer Not Admitted to Hospice; iv) Proportion of Patients Who Died from Cancer Admitted to Hospice for Less Than Three Days. In Ireland, there are well-defined quality standards for end-of-life care, but these are limited to hospitals. The care standards emerged from a 2008-09 national audit on end-of-life care in hospitals and are focused on four key areas: the hospital (governance, communication and records, physical infrastructure), the staff, the patient, and the family (Hospice Friendly Hospitals, 2013[98]). In some countries, such as Estonia, care standards are very limited whilst in other countries (Greece, Hungary, Latvia, Lithuania, Mexico, and Slovenia) care standards on end-of-life care have not yet been developed. In Portugal, care standards for palliative care are expected to be published by the end of 2022. In Portugal, a designated group of experts is developing by the end of 2022 the first set of standards to be applied by all specialised palliative care teams.

Even in countries which have defined what high-quality end-of-life care looks like, there remains scope for improvement. Care standards are often normative or principles-based, and not measurable, and as such there is a limit to the extent which they might be expected to drive improvements in the quality of care. In Ireland, for instance, one measure of care quality is that hospitals' service plans should reflect a 'clear ethos' of end-of-life care. Similarly in the Netherlands, the national quality framework defines what high-quality care is, but quality standards are not measurable. For care standards to drive meaningful improvements in care quality, it will be critical that they are translated into concrete expectations, and that there are adequate processes and mechanisms in place to ensure that these standards are met.

While some countries have developed national standards and norms for the practice of end-of-life care, many standards and guidelines have been prepared by or in co-operation with associations of health care workers and professionals, with the intention of strengthening the delivery of quality care among members of that profession, such as the Palliative and End-of-Life – Entry-to-Practice Competencies and Indicators for Registered Nurses issued by the Canadian Association of Schools of Nursing (Olsson et al., 2021[99]). Despite the high quality of many of these standards and guidelines, studies have found that the guidelines governing quality end-of-life care across professions that work together at the end of a patient's life are not always co-ordinated, possibly introducing challenges to the provision of person-centred, integrated care through multi-disciplinary teams. In a review of applicable standards and guidelines governing end-of-life care in Saskatchewan, Canada, researchers found relevant standards produced by 11 health care professional organisations, which were not always aligned in terms of even the definition and concept of end-of-life care (Buness et al., 2021[100]).

Auditing and evaluation of care standards can drive care quality and some countries are assessing new levers

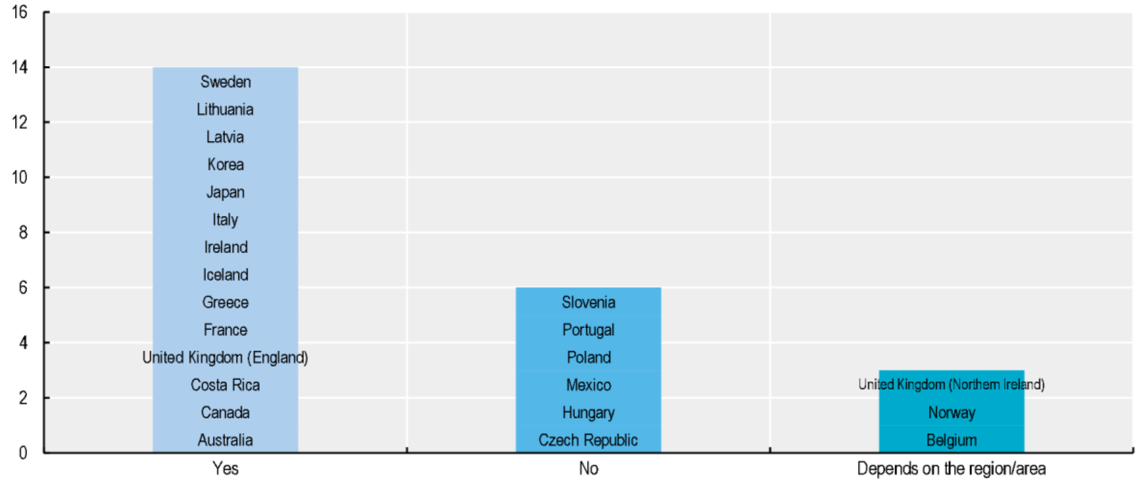
As outlined earlier in this Chapter, there is a limit to the extent to which care standards can be expected to drive care quality unless there are appropriate mechanisms in place to ensure that those standards are met. A range of approaches have been adopted across OECD countries to ensure the quality of end-of-life care, from recommendations or requirements for internal and external scrutiny and assurance, and a range of other levers to monitor, enforce and improve the quality of end-of-life care.

Auditing or evaluation programmes are important to monitor quality

Most countries report that audit or quality evaluation programs are in place to monitor palliative care, though too many countries have no mechanisms in place to ensure the quality of care. Across the 23 countries that responded to the OECD End of Life Care Policy Questionnaire, more than one in four countries (6 of 23) reported that there were no audit or quality evaluation programs in place to monitor palliative care services. Three-fifths (14 of 23) reported that a system of audit and quality evaluation was in place for palliative care services, with a further three countries reporting that audits or other quality evaluation programs depended on the region (Figure 4.12).

Figure 4.12. Audit or quality evaluation programs for monitoring palliative care services

Countries' answers to the question "Is there a system of audit and quality evaluation for palliative care services?"



Source: (OECD, 2020-2021[13]).

Three-fifths of OECD countries have audit or quality evaluation programs in place for end-of-life care, but they do not always cover all care settings, or care providers. For example, the United States have a monitoring process for hospice settings, with all Medicare-certified hospices required to have a quality assessment and performance improvement programme in place (Centers for Medicare and Medicaid, 2021[101]). End-of-life care that occurs outside of certified hospice programs, however, are not included in the quality measures, which focus specifically on the hospice setting.

Where audit or quality evaluation programmes are in place, there is variation across countries as to whether there is a recommendation, requirement, or opportunity for internal or external assurance. In some countries care providers are encouraged or required to have appropriate internal assurance measures in place, whilst in other countries there is also a broader system of external assurance and inspection. In Ireland, for instance, extensive guidance has been provided to support care providers in conducting a self-assessment of the quality of their services. A series of quality assessment and improvement workbooks have been developed as part of the 'Towards Excellence in Palliative Care' initiative, designed to help specialist palliative care service providers self-asses the quality of care against national health care standards. However, whilst incredibly comprehensive, the quality elements contained in the workbooks are not always measurable (HSE Ireland, 2014[102]).

Conversely in other countries – such as England and the Netherlands – there are comprehensive systems of external assurance. In England, for instance, the Care Quality Commission (CQC) – an independent regulator of health and adult social care – provides external assurance over the quality of end-of-life care services. The Care Quality Commission conduct inspections of end-of-life care services as part of their inspection regime, and use National Institute for Health and Care Excellence (NICE)'s quality statements to inform their assessment of care quality (National Institute for Health and Care Excellence, 2014[103]). The Care Quality Commission publish inspection ratings for acute hospitals, community hospitals and independent hospices in an online 'end-of-life care ratings map' (Care Quality Commission, 2022[104]). A National Audit of Care at the End of Life (NACEL) is also conducted annually, though this is focussed only on hospital care, and evaluates hospital performance vis-à-vis existing quality standards and principles (NHS, 2022[105]). The audits are informed by input from providers, patients, and their families.

In the Netherlands, the Inspectorate for Health and Youth Care provide external assurance over the quality of care in nursing homes, hospitals, and district nursing including palliative care. There is also a voluntary inspection programme for hospice care, attached to the ‘PREZO quality mark’; a voluntary accreditation programme open to members of the Association of Hospice Care in the Netherlands (Associatie Hospicezorg Nederland, AHzN). The PREZO quality mark for Hospice Care certifies best-practice EOLC in accordance with the Dutch Palliative Care Quality Framework, and is focussed on the last three months of life and after care (The Association of Hospice Care Netherlands, 2022[106]; Perspekt, 2022[107]).

Levers for driving service improvement

Alongside the establishment of care standards and the development of internal and external systems of assurance, countries have trialled several different levers to drive care quality, for example through specific clinical quality programmes or by leveraging payment systems to drive care quality. For example, In Denmark, data from the Danish Palliative Care Database is used at a regional level to monitor and manage the quality of care, aligned to both national-level health system goals and individual-level measures of the outcomes of care (Box 4.1). In addition to the quality improvement mechanisms attached to the Palliative Care Database, there are several specific quality improvement programmes. For example, in 2017 the Learning and Quality Team (LKT) for specialised palliative care brought together a group of clinical experts in the field of palliative care and quality improvement to improve the quality of palliative care, improve quality of life, improve support for support networks and reduce the number of patients who are referred to care but do not have time to receive it (Danish Regions, n.d.[108]; Danish Health Authority, 2017[89]). The project led to the development of new treatment packages, as well new ways to measure their efficacy using existing and newly developed indicators in the Palliative Care Database. The packages include a number of measures focused on meeting the physical and mental needs of service users and their families, including a focus on pain relief, shortness of breath, depression, constipation and delirium, ACP conversations and support for relatives – especially families with teenagers (Danish Health Authority, 2017[89]).

Box 4.1. Aligning national, regional, and individual measures of the quality and outcomes of care

The approach to quality improvement for specialist palliative care in Denmark

As outlined earlier in this Chapter, the Danish Palliative Care Database contains quality data on a range of indicators related to specialised palliative care. The Danish approach stands out for its data-driven programme of quality improvement, and for its alignment of national, regional, and individual measures of care quality.

Alignment

Denmark stands out for its alignment of national, regional, and individual measures of the quality and outcomes of care. The National Goals of the Danish Health Care System (2018) contain a specific goal on care quality and measure the extent to which Danish regions fulfil quality goals in clinical quality databases. The Danish Palliative database contains a range of indicators related to the provision of specialised palliative care, including an indicator on the share of patients who have completed a patient-reported survey on their symptoms at several points throughout their care (these are outlined in further detail below). Aligning national, regional, and individual measures of care quality can help to ensure that efforts are pulling in the same direction.

Data-driven quality improvement

The Danish Clinical Quality Program – National Clinical Registries (RKKP) aims to spur continuous improvement in care quality. The data entered in the Danish Palliative Care Database – which covers 100% of specialist palliative care services – is analysed by clinical epidemiologists, and monthly/quarterly feedback is provided to all clinical departments, with risk-adjusted data provided once a year. The analysis can spur regional or national-level clinical audits and can help to inform specific quality improvement initiatives.

Source: (Danish Ministry of Health, 2018[109]; The Danish Clinical Registries (RKKP), n.d.[110]).

Several countries have trialled or are considering mechanisms to leverage payment systems to drive care quality. In the Netherlands, the newly-developed Quality Framework contains a recommendation that health insurers develop reimbursement criteria for palliative care that incorporates the standards and criteria set out in the quality framework – but suggests that this be phased in gradually (Palliaweb, 2019[93]). In England, there are several pay-for-performance measures already in place in primary care, to encourage the early identification and management of palliative care needs in General Practices (GPs). England’s Quality and Outcome Framework – a voluntary framework with upside incentives – contains two measures related to palliative care, namely that GPs maintain a register of all patients in need of palliative care/support irrespective of their age, and that the GP has a regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

There is a need to strengthen quality indicators patient- or carer-reported experience or outcome measures

Quality and outcome indicators provide one useful way by which to translate high-level care quality standards into specific, tangible measures of care quality that can provide an insight into health system performance and individual care outcomes. Quality and outcome indicators provide an invaluable tool by which to understand and drive improvements in care quality and systems performance. Well-defined quality and outcome indicators can be used as a governance and accountability tool to understand and manage system and provider performance, and as a clinical tool to measure individual care outcome. Measuring the quality of end-of-life care in a systematic and comparable way requires a strong data infrastructure, with comprehensive health data governance, legislation, and policies that allow health data to be linked and accessed (see Chapter 6).

The indicators operationalised to measure the quality and outcomes of end-of-life care across countries are limited in both their scope and coverage. Measures of care quality and outcomes – where indeed they are collected at a national level – tend to be narrow in focus. This is due in part to data availability. The indicator for which most countries have available data is place of death (14 OECD countries provided available data, results are reported in Chapter 2), followed by hospital admissions in the last year of life (12 countries), hospital 30-day readmission (9 countries) and visit to the emergency department in last 30 days of life (7 countries). Data for other indicators of negative quality such as use of chemotherapy in the last days of life or positive quality indicators such as numbers using palliative care, recording advanced directives, or being referred for palliative care appear to be less widespread.

Greater efforts are required to monitor the quality of end-of-life care: very few countries have national-level indicators of care quality that apply across different care settings and populations. The literature has identified multiple studies relying on survey or focus group data, which record the perceptions of care and most of them concerned the processes and outcomes of palliative care, whereas there were few indicators dealing with the organisational structure of palliative care. Moreover, not all domains of palliative care were covered to the same degree: there was an underrepresentation of psychosocial, spiritual, and cultural domains. Finally, most indicators were restricted to one setting or patient group, often cancer patients (Daryl Bainbridge and Hsien Seow, 2016[111]).

In several countries – England, Italy, and Norway – isolated indicators of EOLC quality are embedded in broader health care quality frameworks and tend to be focussed on particular conditions or care settings. For example, in January 2020 Italy launched 88 national health quality indicators as part of its new system for monitoring the equity, effectiveness and appropriateness of health care ('Griglia LEA / Nuovo Sistema di Garanzia'), with performance data published online. There is one core quality indicator on access to palliative cancer care, namely the number of deaths due to cancer assisted by the palliative care network (Italian Ministry of Health, 2022[112]). In England, there is one national-level indicators with respect to the quality of end-of-life care, namely the share of people with three or more emergency admissions in the last three months of their life, which is used to provide an indication of the quality of services and community-based support. There are also two quality indicators focussed specifically on primary care, which form part of England's Quality Outcomes Framework for General Practitioners (GP). These are discussed in further detail below. Similarly in Norway, activity-based data on the provision of palliative care services is collected, connected to activity-based (DRG) payments. There are a number of indicators related to admissions to inpatient care and the provision of outpatient care, and there is also one indicator which focuses on counselling and collaboration between palliative care centres and municipal health and care services (Norwegian Directorate of Health, 2020[113]). In other countries, such as Estonia, there are no national quality indicators specifically for end-of-life care, though broader national health care quality indicators touch on some components of end-of-life care. For example, Estonia has several care quality indicators related to timely access to cancer care (Estonian Health Insurance Fund, 2022[114]).

Even in countries with more advanced systems of quality and outcome measurement for end-of-life care – such as Ireland, the United States and Denmark – quality and outcome indicators remain geared toward measuring access to services rather than the experiences and outcomes of those services, or they are limited to specific services or providers. In Ireland, a national set of key performance indicators for palliative care are included in the HSE's Annual Service Plan, and all service providers are required to submit performance data monthly. An annual management report then provides benchmarking results with national average and breakdown by Community Health care Organisation). However, the quality indicators are mostly focussed on measuring timely access to care (see Table 4.6).

Table 4.6. National key performance indicators for palliative care in Ireland

Service area	Type of indicator	Indicator
Inpatient palliative care	Access	Share of persons receiving access to specialist inpatient beds within seven days during the reporting year
	Access	Number of persons receiving access to specialist inpatient beds within seven days during the reporting year
	Access	Share of persons triaged within one working day of referral (inpatient unit)
	Person-centredness	Share of patients with a multidisciplinary care plan documented within five working days of initial assessment (inpatient unit)
Community palliative care services	Access	Access to specialist palliative care services in the community provided within seven days (normal place of residence)
	Access	Share of patients triaged within one working day of referral (Community)
	Access	No. of patients who received specialist palliative care treatment in their normal place of residence in the month
Children palliative care	Access	No. of children in the care of the Clinical Nurse Co-ordinator for Children with Life Limiting Conditions (children's outreach nurse)
	Access	No. of children in the care of the acute specialist paediatric palliative care team (during the reporting month)

Note: KPIs relate to the reporting period December 2019.
Source: (HSE Ireland, 2019[115]).

In the United States, there is a comprehensive quality framework which captures data on access, experience, and outcomes, though it is limited to Medicare-provided hospice care. All Medicare-certified hospices are required to submit provider-level quality data to the Centers for Medicaid and Medicare (CMS) (Box 4.2). Several other tools to measure care quality are in use in the United States, covering different care settings or aspects of care. For example, the Bereaved Family Survey (BFS) for inpatient care – to be filled in by family members – comprises 19 items on the same areas as the HIS and CAHPS and is available in English and Spanish (National Care Experience Programme, 2021[116]). The QUAL-E tool was developed in 2002, includes 25 questions and aims at measuring symptoms, preparation to the end of life and the relationship with the health care provider.

Box 4.2. Measures of the quality of hospice care in the United States

Quality and outcome measures for hospice care in the United States stand out for their breadth and depth, covering a range of patient outcomes and experiences based on three separate data sources:

- Data from the Hospice Item Set (HIS), submitted by hospices, is used to calculate the Hospice and Palliative Care Composite Measure – Comprehensive Assessment at Admission (HIS Comprehensive Assessment at Admission Measure). The measure is a composite of seven process-based measures which capture the share of patients for whom hospices performed seven essential care processes, including: addressing patient's beliefs/values, treatment preferences, pain screening, pain assessment, dyspnoea treatment, dyspnoea screening, and patients treated with an opioid who are given a bowel regimen. The HIS has been endorsed by the National Quality Forum
- Medicare claims data is used to inform two quality measures on the number of hospice visits in the last days of life, and the 'Hospice Care Index'. The Hospice Care Index is itself a composite measure of ten separate process indicators focussed on the period between admission and discharge, calculated based on Medicare claims. The indicators cover: continuous home care (CHC) or general inpatient care, gaps in skilled nursing visits, early live discharges, late live discharges, burdensome transitions, per-beneficiary spending, skilled nursing care minutes per routine home care (RHC) day, skilled nursing minutes on weekend, and visits near death.
- Additionally, the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey containing several experience measures, for family members of those who receive hospice care, focussed on a range of different topics: communication with family members, timely support, respectful treatment, emotional and spiritual support, symptom and pain management, and perceptions of/willingness to recommend the relative hospice. Results from the CAHPS® survey are published online.

Source: (Centers for Medicare and Medicaid, 2021[101]).

In Denmark, there is a quality-framework for end-of-life care, though it is limited to specialised palliative care and does not contain any data for patients who require basic palliative care. The Danish Palliative Database was developed to monitor, evaluate, and improve the clinical quality of specialised palliative care in Denmark, and contains data on several indicators with accompanying care standards, based on data from the national patient register, and data registered by treatment units (Table 4.7). A report on the database is published annually, and further indicator development is ongoing, let by the database's steering group. The data is disaggregated at regional level and allows some disaggregation by condition, enabling constructive comparisons. Tracking care quality and outcomes across regions and over time can facilitate constructive comparisons and help policy makers understand whether systems performance and individual outcomes are improving over time. The Danish Palliative Database also contains socio-economic data, enabling research into socio-economic variations in symptoms and outcomes.

Table 4.7. Quality Indicators in the Danish Palliative Care Database

Type of indicator	Indicator	Care standard
Timely access	Proportion of referred patients who do not die or become too ill before contact with specialised palliative care	80%
Timely access	Proportion of patients admitted who have their first treatment contact within 10 calendar days of receiving a referral	90%
Access	Proportion of cancer patients who had been in contact with a specialised palliative care unit / team / hospice before death	35%
Process	Proportion of patients admitted who have completed the European Organisation For Research and Treatment of Cancer (EORTC) screening form	50%
Process	Proportion of patients admitted who have been discussed at an interdisciplinary conference	80%
Process	Proportion of patients admitted with a minimum survival of 1 week who have completed the follow-up EORTC screening form	N/A

Note: Reference to the 'EORTC screening form' refers to the EORTC QLQ-C15-PAL, a patient-reported questionnaire of symptoms for patients receiving palliative care, developed as part of a pan-European collaboration in 9 European countries.
Source: (The Danish Clinical Registries (RKKP), 2019[117]).

In several other countries – such as France, Germany, and the Netherlands – there are no nationally-defined quality and outcome indicators, though efforts have been made in recent years to publish comprehensive national data on a range of relevant indicators, typically utilising and aggregating existing data from a range of sources. In France, the National Center for Palliative and End-of-Life Care publishes an Atlas of Palliative and End-of-Life Care in France every two years, which contains a range of relevant indicators, disaggregated by metropolitan areas (Fin de vie Soins Palliatifs, 2019[118]). It contains data on a range of indicators, such as the place of death, palliative care beds and human resources in palliative care, and models end-of-life trajectories. However, there is currently little data available on the experiences or outcome of care. Similarly in the Netherlands, development of the quality and outcomes framework spurred renewed focus on filling a significant gap in the availability of data on the quality and availability of palliative care (Palliaweb, 2022[119]). In 2019, PZNL published for the first time national palliative care figures drawing on a range of data sources and using a range of indicators to provide insights into the needs for palliative care, potential overtreatment in the last month of life, and the deployment of care providers in specialised in palliative care (Table 4.8). Additionally, PZNL publishes national-level data on several indicators with quality components, such as the number of palliative care teams in hospitals. PZNL's data collection utilises data from existing sources and is regularly updated (Palliaweb, 2022[119]). Germany is currently conducting the PallCompare project, a six-year project aiming at collecting surveys on the use of palliative care in the country, its quality and cost (Gemeinsamer Bundesausschuss, 2022[120]).

Table 4.8. First insights into a range of indicators on the quality and accessibility of palliative care in the Netherlands

Quality domain	Indicator	Sub-indicator	Results
Needs for palliative care	Location of death (as a percentage of expected deaths)		
Potential overtreatment in the last month of life	Potential overtreatment in the last month of life, cancer patients	Share receiving chemotherapy	
		Share with admission to intensive care	6%
		Share with more than 14 days of stay	8%
		Share with more than one hospitalisation	9%
		Share with more than one emergency room visit	12%
		Died in hospital	20%
		One or more of the above	
	Hospitalisation in the last month of life (persons with expected death)		
Deployment of care providers specialised in palliative care within hospitals	Number of palliative care teams		
	Disciplines present in palliative care teams	Oncologist; nurse; anaesthetist; specialised nurse (with expertise in palliative care); pulmonologist; mental health professional; family doctor; specialist in geriatric medicine	
	Who can request a consultation with a palliative care team	Medical specialist; doctor in training; nurse; family doctor and other first-line providers; co-assistant; pharmacist; paramedic; patient/family	
	Share of non-oncological patients for whom a palliative care team is consulted		
Consultations with KNL – Integrated Cancer Center the Netherlands (Integraal Kankercentrum Nederland)	Distribution of the number of telephone consultations per function		
	Topics discussed in telephone consultations		
	Involvement of care providers with specific expertise (expected deaths)	Psychiatrist or psychologist; mental caretaker; specialist in pain relief; palliative counsellor or consultant	
	Proportion of expected deaths in which a palliative care team or consultant was involved in the care in the last month of life	Disaggregated by region	
Consultations with 'Palliarts' – an advice app for health care providers	Screen views in Palliarts app	Guidelines; bed free; medication; organisation; consultation; checklists; information leaflets; other	Screen views on: Guidelines 28% Bed free 22% Medication 17% Organisation 8% Consultation 7% Checklists 9% Information leaflets 4% Other 5%

Note: The publication reports on several indicators, including needs for care. Only the indicators with some link to care quality are reported here.
Source: (Palliaweb, 2022[119]).

Patient-reported indicators in end-of-life care are limited

Where there are national-level indicators of care quality, they are often focussed on access to services rather than the experiences or outcomes of care. Even ‘top performers’ in terms of data infrastructure have considerable scope for improvement: currently, no country has national-level data which provides a holistic overview of access to, experience of, and outcomes of end-of-life care across all care settings, and there is considerable variation across countries as to the breadth of care quality indicators. Many of the key domains and principles that constitute high-quality end-of-life care – including ensuring end-of-life care is *patient-focused* and *appropriate* – cannot be achieved without good knowledge of the patient’s preferences, background, experience, and other concerns. Without getting the input of the patient – and their families and carers – directly, much of the information valuable to making informed choices that would improve the quality of their care is lost (OECD, 2021[121]).

Less than half of OECD reported that they have put in place mandatory patient- or carer-reported experience or outcome surveys to help inform the quality of end-of-life care (OECD, 2020-2021[13]). Just two of 25 countries, France and Korea, report that such patient- or carer-reported measures are required at the national level, while a further 10 countries (40%) report that requirements for collecting patient- and carer-reported measures in end-of-life care are dependent on the region or area. More than half (52%) of countries report that collecting patient- or carer-reported measures in end-of-life care is not required (OECD, 2020-2021[13]).

Around half of the responding countries (13 out of 25) held no system in place to monitor and evaluate palliative care experiences and outcomes such as patient reported outcomes and measures. In Australia, Ireland and New Zealand, the Palliative Care Outcomes Collaboration collects patients’ outcomes to measure quality of end-of-life care. The indicators measure responsiveness to urgent needs, pain management and timely commencement of palliative care, among other things. Between 2020 and 2023, Australia will expand PCOC into residential aged care, embedding a framework and protocol for routine clinical assessment and response across all aged care settings (PCOC, 2022[122]). Internationally comparable quality indicators are still rare, making cross-country benchmarking difficult to perform. Some efforts are in place to collect internationally comparable indicators.

Beyond systems and provider-level quality and outcome measures, several country-level initiatives have been developed to collect patient reported data and provide insights into individual outcomes of care. For example, in Australia, the government-funded Palliative Care Outcomes Collaboration is open to all providers of palliative care services and aims to improve the quality of palliative care through the development of a framework intended to be integrated into regular clinical assessment (University of Wollongong Australia, 2022[123]). The Palliative Care Outcomes Collaboration (PCOC) in Australia is a national palliative care outcomes and benchmarking programme that aims to improve patient outcomes, including pain and symptom control. PCOC involves a framework and protocol for routine clinical assessment and response. By embedding the framework into routine clinical practice, it develops a common clinical language that helps identify and respond to needs; improves access to palliative care; and generates consistent information to plan and deliver care. The Palliative Care Outcomes Collaboration (PCOC) has produced an improvement in patients’ outcomes in Australia. The framework regularly measures indicators of the patient’s physical and psychological outcomes, as well as carer-related measures. Since its introduction in 2006, the Palliative Care Outcomes Collaboration has increased its coverage from about 30 sites covering fewer than 30 000 patients, to nearly 180 sites providing palliative care services, with a reach of over 150 000 patients (Palliative Care Outcomes Collaboration, 2019[124]). The success of the Palliative Care Outcomes Collaboration has led to further adoption of the programme outside of Australia, including in Ireland – where it has been launched on a voluntary basis – and New Zealand.

In Italy, while national-level quality indicators for palliative care are not yet widely used, there have been some local innovations in the use of patient-reported outcome and experience measures. In the region of

Toscana, the local hospital of Biella and the research centre of Istituto Superiore Sant'Anna di Pisa collected PROMs and PREMs from people with cancer between 2019 and 2021. The hospital collected PROMs and PREMs entirely digitally and from their homes. The forthcoming national cancer care also recommends the collection of further quality indicators of palliative care (e.g. early access to palliative care, quality of life, pain prevalence) (Ministry of Health Italy, forthcoming[125]).

Further efforts are necessary to agree on comparative international measures of care quality at an individual level. As mentioned in Chapter 1 of this report, countries are lacking a shared definition of end-of-life care. Efforts should thus include reaching a common understanding regarding the definition of end-of-life care, to ensure the design of internationally comparable indicators. The United Kingdom has created (first in 1999 and then updated over time) the Palliative Care Outcome Scale. It consists of questions on outcomes of care, but it also includes questions around communication and quality of care, and it is available in three versions, one for the patients, one for the caregivers and one for health care staff. 1 274 individuals, groups or organisations from 74 countries have registered to use POS, yet it appears to be used for specific population with limited sample size rather than a country-wide and systematic use of the tool (Collins et al., 2015[126]). The McGill Quality of Life Questionnaire (MQOL) was first developed in 1995 and it was later revised and expanded. It measures four domains: physical, psychological, existential/spiritual, and social. The four domains are balanced, and the physical aspects are not predominant, an element that distinguishes the MQOL from other similar questionnaires. Another instrument is the Cambridge Palliative Assessment Schedule (CAMPAS-R), which is specifically built for people receiving palliative care at home. In 2022, the National Care Experience Programme in Ireland developed the first national end-of-life care survey, which will ask relatives of people who died no more than three months before the survey about the experience of people who were cared for in hospitals, nursing homes, hospices or their own homes during the last months of life (National Care Experience Programme, 2021[116]).

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Notes

[1] This report conceptualises end-of-life care as the care provided to people who are in the last 12 months of life. It refers to the terminal stage of palliative care, as well as including some elements of curative care and help with mobility limitations. Chapter 1 of this report provides a more detailed definition of EOLC.

[2] For the classification of diseases see Chapter 2 of this report.

[3] The only exception can be found in the dopamine receptor antagonist DDDs for Males, in Iceland.

[4] Questions referred to the last two days of life.

[5] i) providing access to opioids without unnecessary regulatory barriers, ii) compulsory education on this topic for all undergraduate degrees for health care professionals, iii) adequate supply and stock of opioids, iv) nationally consistent policies for opioids prescribing, v) national digital monitoring of opioids prescriptions, vi) improved co-ordination between palliative care teams and acute care for the provision of opioid, vii) review the Palliative Care Schedule of the Pharmaceutical Benefit Scheme (PBS), viii) review the Medicare Benefits Schedule (MBS) for palliative care.

[6] Pharmaceutical companies have played a significant role in increasing the (mis)use of opioids, through the use of marketing campaigns directly targeting physicians and patients, sometimes dismissing the risks linked to the use of opioids (OECD, 2019[20]). According to the Lancet Commission, the use of opioids could become safer through policies that ban the direct marketing of opioids between pharmaceutical companies and health care providers (Bhadelia et al., 2019[52]).

5

Ensuring that end-of-life care is appropriately financed

This chapter discusses the public and private financing of end-of-life care. It highlights that there are gaps in public coverage of certain services, leading to high out-of-pocket (OOP) expenses for families and a heavy burden on informal carers. Current models of care can also result in heavy hospital use and potentially higher costs. Avenues for improvement discussed include more prioritisation of cost-effective interventions, especially community and home-based palliative care and adapting payment mechanisms to incentivise more integrated care (between curative and palliative care). Finally, better support for informal or family carers in terms of combining work and care is essential to avoid high societal costs.

Introduction

End-of-life care[1] (EOLC) refers to the health and social care provided to persons who are very ill and most likely will die in the near term from their illness. Such care involves acute care provided in the days or months prior to death and/or palliative care, which focuses on relieving the patient's suffering and improving quality of life. Costs of care at the end of life can be paid by public social protection schemes, but individuals also often have significant out-of-pocket payments or might rely on private health care insurance in some countries. Even where family members or others close to the person needing end-of-life care may also provide an important part of the care, some individuals fail to have their needs met because of inadequate financing, leading to unnecessary suffering at the end of life.

Expenses at the end of life have also raised concerns about their high costs for public budgets. Several studies have highlighted that the bulk of per capita health care costs are concentrated in the last years of life, as more health services are needed and therefore more is spent on an individual close to death (Lorenzoni et al., 2019[1]).There is evidence of high variability in the costs of dying, related to the type of illness but also to the location and type of services provided. For instance, increases in spending at the end of life are driven primarily by increases in emergency rather than planned treatment (Lee and Stoye, 2019[2]). Evidence from several countries shows that in the last three months of life, more than 80% of the total health and social costs were attributable to hospital care. In contrast, the cost of palliative care amounted to 10% (Yi et al., 2020[3]).

As countries prepare for increasingly ageing populations and more individuals with chronic conditions who require complex care before dying (see Chapter 1), there will likely be substantial increases in the need for high quality end-of-life care services, and consequently more sustainable financing solutions for such services. A central policy question is whether to expand the role of the government in providing support to individuals and families to assist with end-of-life care. Equitable financing of end-of-life care services means that care will be affordable and adequate, as well as the care burden being fairly shared and not unduly burdensome upon relatives and other informal carers.

The remainder of the chapter is organised as follows. Section 5.1 highlights the principles of appropriately financed end-of-life care. Section 2.2 illustrates the consequences of not having appropriate financing for end-of-life care. Section 5.3 explores policies and best financing practices to ensure adequate and effective care, whose cost is fairly shared, and without undue financial burden on family and informal caregivers.

Key findings

- In most countries end-of-life care services are publicly funded, mostly through health benefits or insurance (in 70% of countries), but public funding varies widely across settings of care. Medical spending in the 12 months prior to death ranges from 8.5% of aggregate spending in the United States to 11% in Denmark. Public funding of end-of-life care services is more predominant in hospitals which could influence the place of death and have an upward impact on public expenses. Across OECD countries, hospital expenditure constitutes 32% to 67% of end-of-life care expenditures across countries.
- Public social protection systems do not cover some of the health and social care expenses to alleviate symptoms at the end of life. Partial coverage of expenses occurs in a third of the countries for some services such as opioids and other forms of pain management, for nutrition support and for medication to alleviate vomiting and nausea. This can lead to substantial out-of-pocket medical expenses, which amount to a mean of EUR 3 200 in a year for households.
- Gaps in public coverage can lead to an overreliance on informal and family carers. Currently, two-thirds of individuals receive informal care at the end of life. Informal carers can face a heavy burden which can generate additional societal indirect costs because of reduced employment and financial costs, especially because one-third of countries do not provide financial support for carers.

Policy options

- Modifying payment systems for end-of-life care should focus on ensuring sustainable funding given growing demand. While more, more stable, and predictable funding would allow for better planning of care, only 7 out of 25 countries have policies in place to control the budget on EOLC. In Australia, England and Switzerland, the amount of reimbursement received per patient is being set to vary by performance status, phase of illness, care setting and age to ensure that payments are more adequately reflecting needs. Countries also need to find a balance between sustainable funding and affordable care. Belgium, France, Germany, and Korea have put in place policies to reduce out-of-pocket expenditures for end-of-life care.
- Incentivising early access to palliative care services is paramount as palliative care is found to be cost-effective, improving quality of life and reducing length of hospital stays, re-admissions, and visits to intensive care units. Improving care co-ordination can incentivise earlier access to palliative care, but current funding schemes do little to incentivise care models that improve co-ordination. Bundled payments have been suggested as an alternative option to integrate curative and palliative care. The United States are moving towards value-based payments which might favour more palliative care, while the United Kingdom has applied pay-for-performance systems incentivising GPs to identify and manage palliative care needs.
- Incentivising the use of palliative care outside hospitals can lead to better cost-effectiveness and higher quality of end-of-life care. Evidence from Australia, Belgium, Canada, the United States and the United Kingdom showed cost-effectiveness of palliative care at home, and evidence on the cost-effectiveness of palliative care in nursing homes has started to emerge. France has increased funding for out-of-hours palliative care and increased mobile teams with the aim of promoting palliative care at home, while Australia has announced increased funding for home palliative care. Furthermore, Luxembourg has started to allow medical devices in nursing homes, while France has implemented a hospital at home protocol to avoid the transfer of people from nursing homes to the hospital.

- Supporting informal or family carers who provide end-of-life care remains an essential element of overall end-of-life care policy. This includes appropriate training, information services, the provision or adequate benefits and sufficient leave for keeping carers in employment. Flexible work arrangements can also support caregivers by allowing them to balance professional and caring responsibilities. Norway and the United States for instance provide opportunities for training and counselling, while in Denmark, employees have the statutory right to leave for the care of someone close dying, and there is no fixed time limit for the leave. Furthermore, in Belgium informal caregivers can obtain part time work arrangements for up to five years and in Norway people who care for a dying person can work from home.

5.1. Why is it important for end-of-life care to be appropriately financed?

Good end-of-life care has an enormous impact on the quality of a person’s last weeks or months of life, by reducing unnecessary suffering and providing a supportive, caring environment. End-of-life care should therefore be a right afforded to everyone equally. This requires *adequate* financing of services so that people can receive the care they need, both specialist and non-specialist, irrespective of their background and where they live. Palliative care and hospice services need to be affordable to families, without resulting in excessive out-of-pocket costs. Timely access is also critical. Palliative care teams connected to every hospital helps minimise waiting times and ensure access across different localities. In many countries, given demographic changes, without more resources for social, community and home care, it will remain challenging to respect people’s preferences to die at home and for care to be of high-quality.

Informal carers are an important source of care in many countries. They constitute the foundation of care for many relatives and friends, can help contain the overall costs to the health system but also suffer from financial costs themselves, especially because of the time invested. Without proper support, informal carers often struggle to combine caring with work and other personal commitments. Informal carers need both financial and non-financial support, including sufficient formal care to ensure that the burden is *fairly shared*. Respite care, initial training and provision of equipment, and bereavement care are all critical support components for informal carers and the person they are caring for.

From a financial and human perspective, it is also important for end-of-life care to be (cost) *effective*. Concern about high cost at the end of life raise ethical dilemmas about how to balance appropriate interventions and spending. This is fundamentally challenging because it remains difficult to predict the timing of mortality. Individuals with high likelihood of dying account for only a small share of total spending-less than 5% of spending (Einav et al., 2018[4]). Ensuring an appropriate balance of treatments with curative and palliative care and avoiding inappropriate treatments is likely to be not only desirable for patients and families in terms of quality of life but also cost-effective. This requires accessible, high quality palliative care home care teams, including knowledgeable palliative nurses and palliative care physicians who can advise other professionals on appropriate treatment and psychological support (Service Publique Fédéral Santé Publique, 2020[5]). Investing in palliative care knowledge among staff in nursing homes should also contribute to have more palliative care delivered in such institutions without the need to transfer patients.

5.2. The consequences of inadequate financing at the end of life

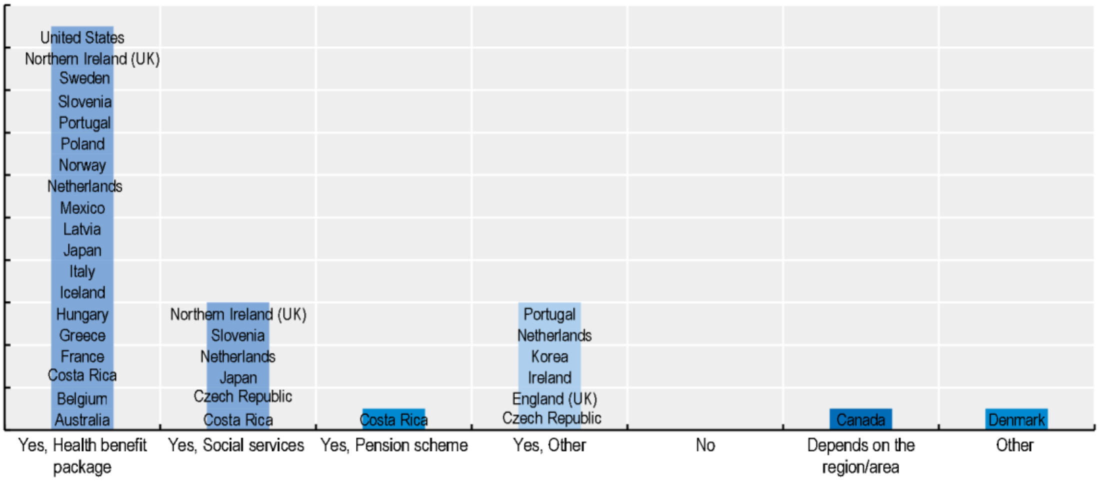
5.2.1. Inadequate models of care can lead to high expenditures, with detrimental impacts on government budgets and households

The cost of end-of-life care has received a great deal of attention and there have been concerns about the high level of public expenditures for people at the end of life. Such focus started with the publication that in the United States 5% of people on Medicare represent patients in the last year of life while they amount to 25% of the costs of Medicare (Banarto et al., 2004[6]). More recent cross-country analysis has confirmed that EOLC spending is substantial on a per capita basis, yet expenditures as share of public health spending appear to be much lower than 25. In the United States, average medical spending from all payers was USD 80 000 in the last 12 months of life (in 2011, measured in 2014 US dollars), and the share of medical spending in the 12 months prior to death ranges from 8.5% of aggregate spending in the United States to 11% in Denmark (French et al., 2017[7]). Such spending appears to be driven by the high costs of managing chronic conditions prior to death since a country's medical spending in the last three years of life usually exceeds 2% of its GDP and spending in the last three years of life accounted for as much as 24.5% of overall costs (French et al., 2017[7]).

End-of-life care costs benefit from public funding across all OECD countries. In 18 out of 25 countries which provided data, services are funded in part through health benefits and in 5 of these countries or regions the funding comes from both health and social care packages (Figure 5.1). In most countries, there is a dedicated palliative care budget, but the funding system is mixed (Groeneveld EI, 2017[8]). In Costa Rica, funding is covered through health care social insurance, government budget, and special sources such as lottery revenue. Several countries pointed to other sources of funding. For instance, in England (United Kingdom), EOLC is funded through the National Health System (NHS) or in hospices through a mix of NHS and charitable funding. In the Czech Republic, a significant part of the funding is coming from social services, funded through municipalities but there is also an important share of expenditure from families. In Australia, the budget is shared between the Department of Health and the Treasury. In Denmark, all health and social services, including EOLC, are financed by general taxes and are supported by a system of central government block grants, reimbursements, and equalisation schemes (OECD, 2020-2021[9]).

Figure 5.1. EOLC services are covered in part by health and social security schemes

Countries' answers to the question "Are EOLC services covered by national schemes of social protection or social security? (e.g. health benefit package, social services, pension scheme)"

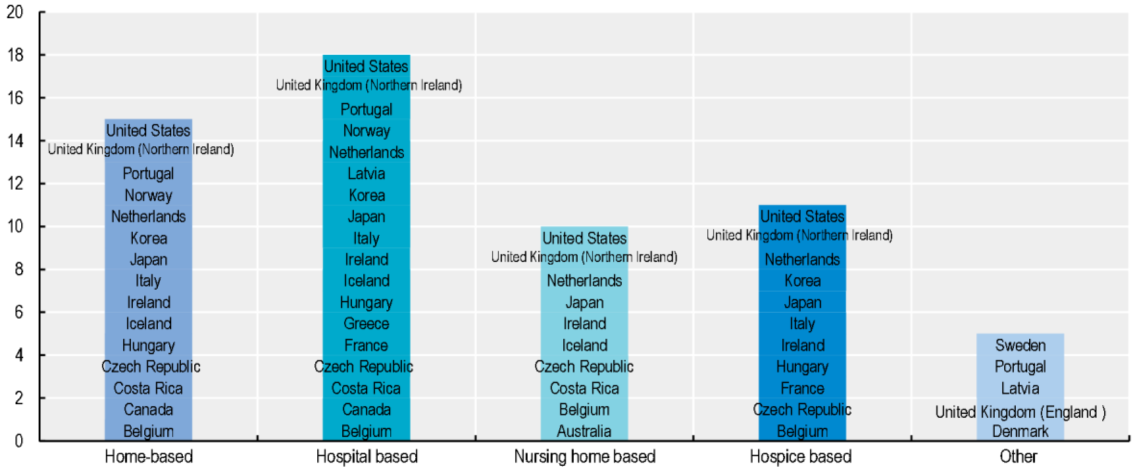


Source: (OECD, 2020-2021[9]).

Public funding for end-of-life care varies by setting, affecting place of death. Most OECD countries provide funding for end-of-life care in hospitals (18 out of 25), but an important share (14) has home-based care financing (Figure 5.2). Hospice-based care is publicly financed in less than half of countries. In the United Kingdom, between 25 to 40% of hospice funding comes from the government (UK Hospice, 2021[10]). Hospices also rely heavily on volunteers. In the United States, hospice care is covered for the elderly through Medicare but there are usually some capped co-payments for medication, for respite care inpatient and board and lodging is not covered if live in a facility, while it is an optional plan for people on Medicaid who need to select it and wave other cure or treatment. Nursing home end-of-life care funding is less widely available and overall use of long-term care is subject to high out-of-pocket costs in several OECD countries. Exceptions include, for instance, Luxembourg, where it is legislated that nursing homes need to have certain share of personnel with palliative care expertise at different levels. In Poland, there is insufficient end-of-life care in long-term care (LTC), both for institutions and home care as specialist hospice palliative care services by law are excluded from LTC facilities (Krakoviaw, 2020[11]). This can have unintended consequences on the quality of EOLC and on place of death. There is also, for instance, an association between high levels of public financing and organisation of long-term and lower hospitalisations and a higher share of out-of-hospital deaths (Orlovic, Marti and Mossialos, 2017[12]).

Figure 5.2. Public funding for EOLC services is predominantly hospital-based

Countries' answers to the question "Is there a specific public financing mechanism for EOLC services in the following care settings?"



Source: (OECD, 2020-2021[9]).

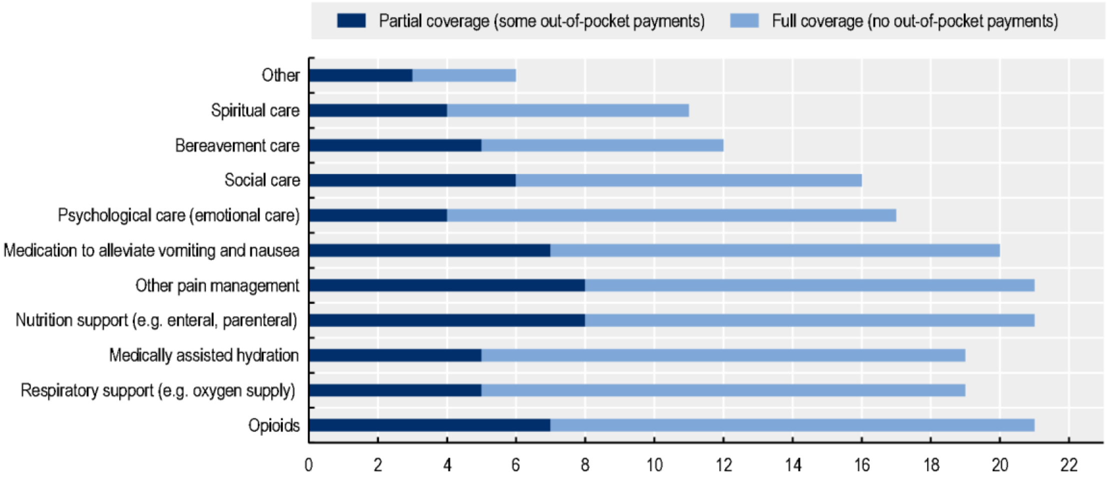
Hospital care, especially acute care, is an important component of end-of-life care expenditures. This represents 67% of expenditures in the last 12 months of life in France, 58% in Germany and Denmark, 44% in the United States but 32% in the Netherlands where expenditures from long-term care represent the most important item (French et al., 2017[7]). An international study revealed that more than 80% of the costs in the last three months of life were attributable to hospital acute care while the costs of palliative care were only close to 10% (Yi et al., 2020[3]). However, not all of hospital care is necessary or appropriate. Differences in medical culture could influence patterns of treatment intensity as shown by the variation in hospital admissions across countries in the last year of life. Similarly, variability in end-of-life health care is dependent on a range of patient characteristics, including gender, age and the type of disease or chronic conditions and the presence of limitations, with one of the most consistently important factors is age at death) illustrated by the fact that those being 60+ are less likely to be hospitalised (see Chapter 3). OECD data in Chapter 3 also finds that men and individuals with cancer are more likely to be hospitalised at the end of life and data from the United Kingdom confirms that this results in higher costs for those groups (Luta et al., 2020[13]).

Similarly, several studies have highlighted regional variation in the use of inpatient care and in costs at the end of life. This suggests that the high cost of EOL may also be partially the result of a failure of community-based services to support the person at home (Luta et al., 2020[13]). Evidence from the literature suggests more than one-third (33% to 38%) of older patients with advanced irreversible diseases hospitalised near the end of life received interventions unlikely to provide either survival or palliation benefit (Cardona-Morrel et al., 2016[14]). Regional variation in surgical interventions and other treatments suggest that treatment is influenced by external factors such as the number of hospital beds per head and availability of local practices (Kelley, 2011[15]). A ten-year Canadian study has indicated that early specialist palliative care exposure reduces the risk of hospital-based acute care, including Intensive Care Unit (ICU) admission, in the last 30 days of life for all chronic disease groups except dementia (Earp et al., 2021[16]).

5.2.2. Not all service costs are covered, leading to gaps and high expenses for families

Public social protection for EOLC does not cover all health and social care expenses. Across counties, partial coverage occurs in a third of the countries for some services such as opioids and other forms of pain management, similarly to nutrition support and for medication to alleviate vomiting and nausea (Figure 5.3). This is the case for instance in Australia, Belgium, Hungary, Iceland, Ireland, Japan, Korea, and Portugal. Australia, Belgium, Ireland, Japan, and Korea do not fully cover respiratory support nor medically assisted hydration. Six countries do not fully cover social care nor bereavement support. In Poland, the reimbursement rate from the National Health Insurance fund covers between 50% and 75% of all drug purchases and so the hospices must find additional funds to ensure access to all essential medicines (Pawłowska et al., 2016[17]).

Figure 5.3. Certain EOLC services are not fully covered



Note: N=19.
Source: (OECD, 2020-2021[9]).

In addition, the financing mechanisms designed to reimburse palliative and end-of-life care impact how palliative care is delivered and can lead to insufficient care and/or inequalities. A review of funding mechanisms across 14 OECD countries found that payment mechanisms for palliative care often maintained inequalities in access to palliative care, and often did not structure reimbursement models to deliver on the needs of individual patients (Groeneveld EI, 2017[8]). In some countries, statutory funding does not always appear to lead to sustainable funding for the services and funding meeting population needs. In the United Kingdom, researchers found a limited correlation between the palliative care needs of the population and the budget allocated to palliative care services while more than two-thirds of hospices had their statutory funding frozen or reduced in recent years (Ryan, 2018[18]).

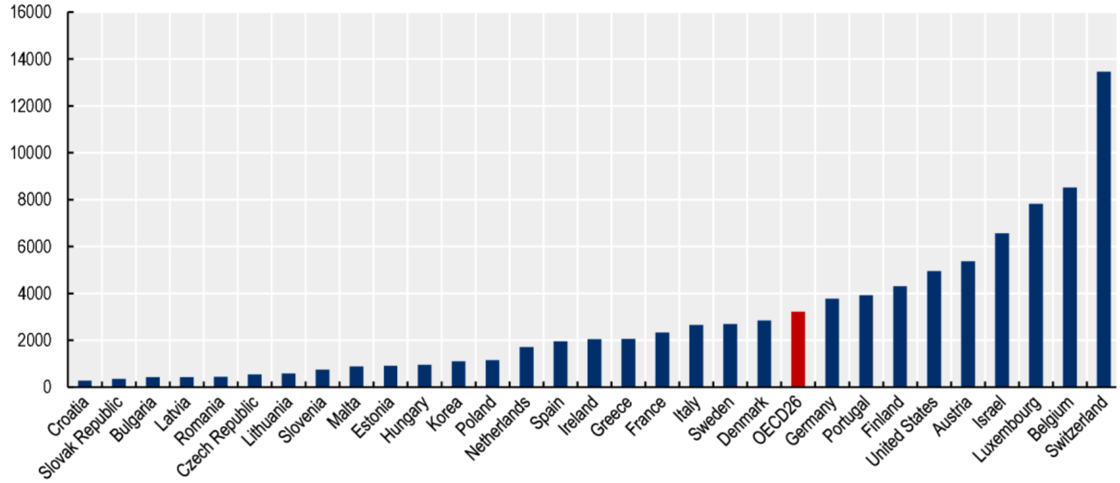
There are sizeable reimbursement limits in some countries which can lead to gaps. In the United States, there are limitations on reimbursements related to the timing of treatments or interventions, which can only be reimbursed in the last six months of life. This can constrain access to end-of-life care for those with conditions that are more difficult to identify the end-of-life phase, such as dementia, or who require palliative care services towards the end of life for more than the reimbursed period (OECD, 2018[19]). For instance, in Hungary, palliative care is restricted to 150 visits. In addition, in Hungary, outpatient palliative care services do not receive government funding and rely on funding to be made available from the general hospital budgets. Home and community-based care services in some countries rely to a certain extent on contributions by the charitable sector (Groeneveld EI, 2017[8]).

In addition to partial coverage, other regulations such as prescription drug caps might affect access to symptom management services across countries. For instance, due to the large increase in opioid in some OECD countries, efforts to curb the opioid abuse are also having an unintended effect of reducing access to pain medication for terminally ill cancer patients in the United States, among other countries (Andrea C. Enzinger, 2021[20]). In the Unites States, while Medicare appears to cover 80% of those at the end of life, for those on Medicaid, states can choose whether to include a hospice benefit at all and some do not cover hospice while some can limit the number of prescriptions for Medicaid patients, impacting pain management and other symptoms (Wachterman and Sommers, 2021[21]). In France, there are restrictions to provide midazolam outside hospital settings, making long and continuous sedation outside hospitals very rare (Senat, 2021[22]).

If public social protection does not cover all end-of-life costs, families can face significant costs at the end-of-life. Out-of-pocket health care expenses at the end of life for elderly households represent a substantial amount. According to comparative data, the mean out-of-pocket medical expenses in OECD countries can be significant at around EUR 3 200, ranging from around EUR 300 per year in the Slovak Republic, to more than EUR 13 000 per year in Switzerland (Figure 5.4). The amount of out-of-pocket spending depends on whether EOLC financing is predominantly private or public, the type of cost-sharing arrangement and the financial protection mechanisms in place (such as caps on patients' out-of-pocket contributions). In the Slovak Republic for instance, 40-60% of the cost of inpatient palliative care is paid for by patients and families, as the health insurance companies do not consider hospices to be necessary medical facilities while for outpatient care, patients must contribute to the cost of medications (Krizanova and Skripekov, 2015[23]).

Figure 5.4. Summary of OOP expenditure in the last year of life, 2008-17

Total major expenses for deceased who died at the age of 65 or older, 2008-20



Note: Mean Health Expenditures (Normalised to a Twelve-Month Period). Values are in 2010 Euros computed based on the CPI for country and year of death. For details, refer to the codebook for SHARE EoL dataset.
Source: Analysis based on data from SHARE EoL wave 2-7 interview (SHARE, the Survey of Health, Ageing and Retirement in Europe, 2020[24]), HRS (wave 8-14), KLoSA (wave 2-7).

Overall out-of-pocket expenditures are highly related to the place of death, the financing of long-term care and the availability of informal care support (Orlovic, Marti and Mossialos, 2017[12]). Previous analysis shows that the largest expenditure item at the end of life tends to be hospital care, especially in the last months, and long-term care (French et al., 2017[7]; De Nardi et al., 2016[25]; Marshall, McGarry and Skinner, 2010[26]). Indeed, some end-of-life expenditures on formal medical services are reasonably well covered by public systems while, by contrast, the extent of coverage and cost-sharing for long-term care (LTC) varies substantially. Data from the last year of life from the Survey of shows that it represents 30% on average of out-of-pocket expenditures. Data for Israel focusing on cancer patients highlights that 84% have out-of-pocket expenditures and that such expenditures represent mostly spending on medicines and private caregivers (USD 5 800 and USD 10 800 respectively during the last half-year of life) (Tur-Sinai et al., 2022[27]).

In addition to expenditures to meet health needs, many people with terminal illnesses need other social services such as long-term care, housing adaptation and technical aids. People at the end of life may need help with support with daily living such as washing, dressing, and preparing meals which represent long-term care. OECD analysis shows that the reported total costs of LTC represent between one-half to as much as five times the median disposable income of individuals of retirement age or older and that even for as little as 6.5 hours of care per week for people with low needs, the total costs of home LTC services would represent more than half of the disposable income of an older person with a low income. In seven jurisdictions, older people with severe needs receiving care at home would face out-of-pocket costs that are higher than the median income among elderly people (Oliveira Hashiguchi and Llena-Nozal, 2020[28]).

High out-of-pocket medical and long-term care expenditures at the end of life may strain the finances of households. Data from the United Kingdom shows that two-third of households affected by terminal illness experience financial strain and that the cost of additional expenses can amount to 98% of income for disadvantaged families (Marie Curie, 2019[29]). An international study based on information from GPs reported that 43% of patients and families in Italy, 36% in The Netherlands, 14% in Belgium and 8% in Spain had difficulties in covering the costs of care at the end of life (Pivodic et al., 2014[30]). High expenses at the end of life may even influence the capacity to pay other expenses, and people might need to use their savings or assets. Data from several studies points out that households can struggle to pay important living expenses or choose to forgo or delay treatment (Marie Curie, 2019[29]). It can also drain a couple's assets when one spouse gets sick and leaving little for the other spouse later in life. Data from the United States show that for 25% of households the total out-of-pocket spending over the last 5 years of life exceeds total household assets and for 40% it exceeds their financial assets (Kelley and al., 2010[31]).Older households appear to save in order to use their financial wealth in the last years of life when there is insufficient public support for long-term care (Nakajima and Telyukova, 2018[32]).

5.2.3. Overreliance on informal carers can generate high societal costs

Because of both public funding and service delivery gaps, much of the burden of providing EOLC falls on informal carers. Two-thirds of all people dying at age 65+ received informal care (Table 5.1), ranging from 46% in Switzerland to 86% in Finland. A high proportion of people dying at age 65 or over received some form of informal care. Moreover, a relative, most often children or grandchildren, provides most of the informal care. These data are in line with sources estimating that informal caregivers provide 75-90% of home-based care for people who are near the end of life (Gardiner et al., 2020[33]). In Canada, there are about 1.5 to 2 million end-of-life informal caregivers (Lung et al., 2021[34]).

Table 5.1. Proportion of deceased who died at age 65 or over who received informal care, 2008-20

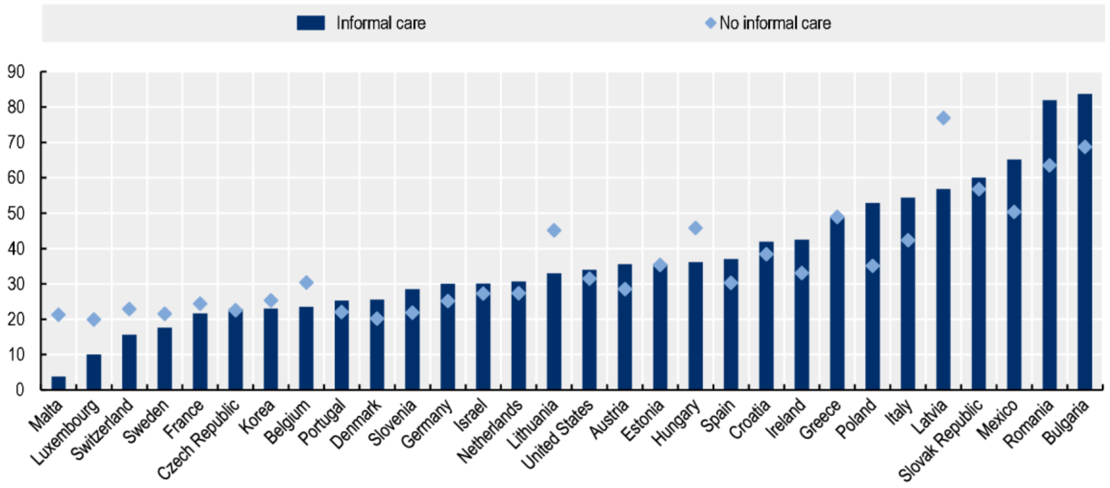
Country	Received Informal Care	Relationship to the Deceased			
		Spouse	Children/ Grandchildren	Relative	Non-relative
Austria	62.95	31.13	48.19	8.81	13.87
Germany	61.54	40.85	54.13	4.35	12.60
Sweden	48.24	24.03	43.39	5.75	9.11
Netherlands	59.09	42.56	45.08	9.26	9.94
Spain	69.10	26.75	62.77	10.31	14.13
Italy	72.00	25.80	67.27	8.73	10.36
France	63.43	37.23	45.62	8.47	11.11
Denmark	59.64	25.75	52.34	7.33	11.39
Greece	69.61	24.78	67.47	10.98	12.77
Switzerland	45.96	31.96	36.96	5.78	8.86
Belgium	71.88	39.00	54.88	8.45	12.28
Israel	57.49	28.07	45.10	3.52	5.05
Czech Republic	66.99	33.95	67.99	5.37	14.78
Poland	67.95	32.49	78.45	7.51	8.31
Ireland	59.77	16.57	73.46	23.38	0.00
Luxembourg	73.01	26.65	52.81	12.97	9.62
Hungary	71.52	28.23	70.30	8.66	14.64
Portugal	66.23	24.01	65.10	14.83	5.79
Slovenia	73.03	33.43	71.23	8.92	10.84
Estonia	66.78	30.43	48.39	7.83	11.20
Croatia	68.79	24.90	71.81	8.49	16.04
Lithuania	71.21	32.71	58.96	11.68	17.83
Bulgaria	56.38	29.55	63.12	5.74	7.99
Cyprus	70.55	24.49	51.63	0.00	12.12
Finland	86.47	41.45	53.25	11.30	2.18
Latvia	65.96	53.07	38.60	4.49	14.32
Malta	62.98	34.44	66.26	0.00	6.36
Romania	65.12	35.68	53.90	13.45	18.09
Slovak Republic	82.64	41.69	73.05	7.37	3.62
United States	81.39	31.28	52.97	10.38	14.01
Korea	54.83	35.21	47.23	3.68	5.66

Note: Weighted using cross-sectional weight from last core interview. Data not available for SHARE Wave 5. It is possible that the deceased received informal care from multiple sources.
Source: Analysis based on data from SHARE (EoL wave 2-4, 6-8 interview), HRS (wave 3-14), MHAS (wave 2-5), KLoSA (wave 2-7).

Not only do informal caregivers provide the bulk of care, but they might also influence the end-of-life experience (e.g. the place of death). According to the Survey of Health, Ageing and Retirement in Europe (SHARE), the Mexican Health and Aging Study (MHAS), the Korean Longitudinal Study of Aging (KLoSA) and the Health and Retirement Study (HRS) on the United States, in most countries people who receive informal care are slightly more likely to die at home (36% versus 33% see Figure 5.5).

Figure 5.5. Older people who received informal care are more likely to die at home

Mean percentage of home deaths for the deceased died at age 65 or over, by informal care receipt



Note: Data weighted using cross-sectional weight from last core interview.
Source: Analysis based on data from SHARE (EoL wave 2-8 interview), HRS (wave 3-14), MHAS (wave 2-5), KLoSA (wave 2-7).

The *financial costs of informal caring* for a person approaching the end of life can be substantial. Such costs stem from three main areas: work-related costs (due to stopping work or reducing hours), carer time costs (cost related to time investment required by carers) and out-of-pocket costs. Caregivers can incur a number of out-of-pocket costs which include the cost of special food, travel expenses, additional care supplies and medication, and extra household costs to support the care recipient and this can represent 7%–13% of total caregiver costs (Coumoundouros et al., 2019[35]). Estimates suggests that the overall cost of caregiving ranges across countries from 26.6% to 80% of total costs at the end of life (Gardiner et al., 2014[36]). In the United Kingdom, 43% of people caring for someone at the end of life struggle financially and average out of pocket costs are GBP 3 300 per patient and GBP 1 500 per carer, every year (Marie Curie, 2019[29]).

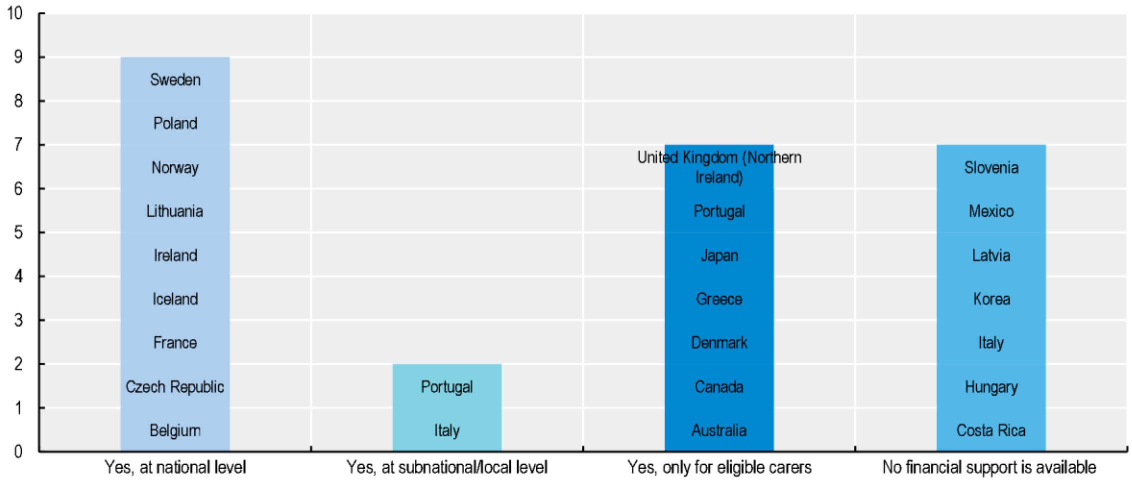
Households experience high *indirect costs* from end of life due to the heavy burden of care undertaken by family carers. There is limited evidence on the impact of caregiving at the end of life on employment, but some studies report that caregivers have reported giving up work, reducing hours of work, or using up annual or sick leave to cope with the demands of caregiving. Data from Korea shows that those caring for someone with a terminal illness were 2.4 times more likely to be not working compared with the general population (Kim et al., 2013[37]). Changing jobs and accepting a low-paid occupation which might be more compatible with caregiving can also occur, as can early retirement. Caring for terminally ill loved ones often results in diminished lifetime earnings (O'Brien, Yang and Jankauskaite, 2020[38]) and/or reduced retirement savings (Girgis et al., 2013[39]). Even when caregivers could combine work and care, the situation could still be demanding, especially with the progression of illness leading to unpredictable care needs and work interruptions (Bijnsdorp et al., 2021[40]). Scheduling can become challenging when dealing with doctor's appointments. More than half of the caregivers had one employment transition (between full-time employment, part-time, on-leave and not employed) and 29% had three or more over a period ranging between 2.6 and 6.4 months (Guerriere et al., 2020[41]). All employment changes and challenges accumulate and result in difficulties for career advancement (O'Brien, Yang and Jankauskaite, 2020[38]). Employment changes can result in an income loss which adds to other expenses. For instances, studies of cancer patients found that it was associated with an income loss of 1 000 per year for the spouse (Coumoundouros et al., 2019[35]).

Time spent on informal or family caregiving is especially intense in the last three months of life: caregivers of cancer patients provided an average of 70 hours per week of informal care (Rowland and al., 2017[42]). A study from Ireland, the United Kingdom and the United States found that when considering the hours that informal carers were on duty and valuing them average hourly wages and unit costs for nursing care, the costs to informal carers are larger than those to formal care services (health, social and voluntary combined) for people in the last three months of life. Costs of informal carers represent 58% of total societal costs (Higginson et al., 2020[43]). Costs are higher when death occurs at home: informal care costs at home were found to be USD 6 144 per month compared to USD 4 168 per month in the hospital (Yu, Guerriere and Coyte, 2015[44]).

Limited support is provided to informal carers at the end of life. In particular, Figure 5.6 shows that not all countries provide financial support for carers. Yet, a Eurobarometer survey had found that financial remuneration was perceived as the most important support to informal caregivers (Gardiner et al., 2019[45]). Furthermore, when financial support is available, informal caregivers report difficulties navigating the bureaucratic application process to obtain such support. Eligibility criteria consider the hours of care provided, the income and employment status, as well as the relationship with the person cared for. According to a survey covering 6 OECD countries (Australia, Canada, Ireland, New Zealand, the United Kingdom, and the United States), eligibility criteria and application processed tend to discourage people from applying. This results in eligible people not receiving such benefits. For instance, only 12% of Canadian caregivers have used financial benefits. A further issue consists in people not defining themselves as caregivers and thus not applying for benefits they would be eligible to (Gardiner et al., 2019[45]).

Figure 5.6. Not all countries provide financial support for carers

Countries' answers to the question "Is there financial support for informal carers?"



Source: (OECD, 2020-2021[9]).

Caregiving takes a toll on the physical and mental health of caregivers which is particularly prominent for those accompanying someone at the end of life. Several studies report on the emotional strain of caregiving at the end of life and the great deal of loss and grief experienced by caregivers (Williams, Wang and Kitchen, 2013[46]). A Canadian study comparing EOL caregivers with those providing short-term care and those providing long-term care to someone with an illness or dependency, found EOL caregivers are more negatively impacted by the often-additional role of caregiving, financially, in terms of employment and especially in terms of their health.

5.3. How can countries improve the financing of end-of-life care?

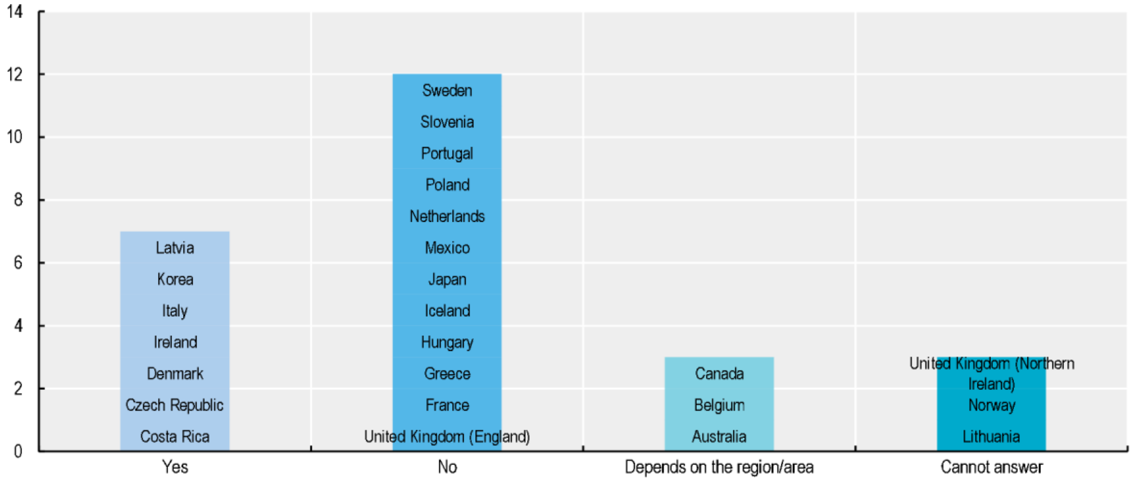
5.3.1. Ensuring sufficient funding for end-of-life care

A stable and predictable funding that allows end-of-life services to be planned and developed in a coherent way is needed. A growing demand will place a challenge on the sustainability of funding in most countries for not having a policy to control the budget on end-of-life care (see Figure 5.7) This can create pressure on budgets as additional resources may still be required. Funding such investments requires finance and health ministries to agree solutions that combine raising additional funding with efforts to free up current resources by reducing wasteful spending in health systems. Such solutions require forward-looking, multi-year commitments (OECD, 2015[47]). They are also likely to involve a trade-off with other priorities, especially in terms of exploring the possibility of reallocation and allocating possible additional resources to this specific area of health.

A more effective public financing should improve the alignment of EOLC services with EOLC needs. This requires budgets or reimbursement mechanisms that adequately fund priority EOLC services. Critical in this regard is better pricing, so that provider payments are set at accurate levels to cover the costs of service provision. Yet in some cases, payments are set below the average costs of service provision for palliative care patients. For examples, studies of palliative care wards in Poland show that payments from the national health system cover only 60% of the costs incurred by the units – thereby providing insufficient incentives for promoting such palliative care wards for providers (Ciałkowska-Rysz et al., 2016[48]). Changing the reimbursement amount of palliative care services by the National Health Insurance is likely to promote access to palliative care. As well as pricing, reimbursement rules are also important. For example, in Hungary, a single payment is received for each day on which the community-based palliative care team visits the patient, irrespective of the number or length of visits (Groeneveld EI, 2017[8]). As previously discussed, funding for each patient is limited to 150 visits over a longer period, but approximately 5% of patients require more than 150 days of care. In England, to improve the pricing of palliative care and reduce variation in funding, the NHS tested the introduction of a national "currency" for Specialist Palliative Care Providers. A "currency" is used to describe a consistent unit of health care, that is, interventions that are carried out in a health care setting and the complexity of the patients that are using that care, which may also be used as the basis for payment (NHS England, 2017[49]).

Figure 5.7. Most countries do not have a policy to control the budget on EOLC

Countries' answers to the question "Is there a policy to control the overall budget envelop of EOLC in the country?"



Source: (OECD, 2020-2021[9]).

With strong pressures to increase public spending, some governments have considered if the private sector can absorb some of such increases in health spending needing for end-of-life care. Currently options for private insurance in this area are limited. In the United States, most private insurance companies have a hospice benefit which covered 12% of end-of-life care expenditures (Raphael, Ahrens and Fowler, 2001[50]). An interesting example in severe disability in old age was Eldershield in Singapore where citizens were automatically enrolled at the age of 40, unless they explicitly chose to opt out and was provided by private insurers (this was replaced by a new system CareShield in 2020 which is now mandatory for recent cohorts).

Because cost-sharing appears to be sizeable, countries need to find an appropriate balance between the financial sustainability and the affordability of end-of-life care. Countries could consider target universal care benefits where needs are the highest, especially for those with low-income. Caps and exemption for those with low income might be relevant while considering some degree of means-testing to ensure that those with higher income contribute more. It would be important that thresholds set by public social protection systems are close to or above relative poverty levels to prevent that economically vulnerable care recipients are not eligible for increased public support. Some countries have introduced policies to limit out-of-pocket costs. Korea adopted a new insurance system from 15 July 2015, based on diagnosis-related groups (DRG) and per diem payment to support patients through a multidisciplinary approach and lighten their economic burden. Out-of-pocket expenses for patients decreased in the new payment system while length of stay is similar and there is no negative effect on quality of life (Lee et al., 2018[51]). Belgium and Germany have policies to decrease the out-of-pocket costs of GPs, physiotherapists, nursing home visits and/or pharmaceuticals. In Belgium people can obtain the legal palliative status, in which case they are not charged any out-of-pocket cost, while people with chronic diseases who are care-dependent and live at home can fulfil the criteria to obtain EUR 130 per month. In Germany out-of-pocket is fixed to 1% of the annual household income for care dependent people. In France such policies are not in place, but the French health care system fixes an annual cap of EUR 50 for out-of-pocket expenditure per person (Maetens et al., 2017[52]).

5.3.2. Prioritising the most cost-effective interventions

Firstly, palliative care interventions have been associated with improvements in patient quality of life and symptom burden. Several studies have supported that palliative care reduces symptom burden, improves quality of life and mood and in some cases increased longevity or survival rates (Institute of Medicine, 2015[53]). A meta-analysis of randomised control trials further provided robust evidence of quality of life and symptom improvement (Kavalieratos et al., 2016[54]). In addition, specialist palliative care has been shown to bring further benefits for patients, including a reduction in the likelihood of costly and often aggressive treatments such as chemotherapy in the last days of life (Hunter, 2018[55]).

Secondly, evidence from several countries shows that the introduction of better access to palliative care can result in more cost-effective outcomes (Public Health England, 2017[56]). A literature review including studies from nine OECD countries (Belgium, Canada, France, Greece, Israel, Italy, Spain, the United Kingdom and the United States) performed over ten years and with different characteristics has found consistent results on the cost-effectiveness of palliative care across settings (Smith et al., 2013[57]). Evidence from the United States found that transferring people into inpatient palliative care units resulted into 25% cost reduction (Isenberg et al., 2017[58]). Hospital palliative care teams can be cost-effective, for instance, especially with early introduction and integrated with other treatments, such as oncology (KMPG, 2020[59]). Care co-ordination at the end of life is also important to manage care transitions and avoid discontinuities in care. Preventable hospital readmissions are frequently a consequence of poorly managed transitions. Care managers should be of prime importance at the end of life (Institute of Medicine, 2015[53]).

Comparing the costs of end-of-life care in hospital with the cost of equivalent care outside

Several studies have found that palliative care outside inpatient settings can enhance patient satisfaction, improve symptom control and quality of life, and reduce health care costs (Public Health England, 2017[56]). Some studies also show that hospice enrolment and care in nursing homes results in better quality at the end of life with lower public health expenditures (Abernathy et al., 2011[60]). An analysis of people at the end of life living with dementia found that being cared for in nursing homes seems to reduce the likelihood of using hospital care and ICU at the end of life, with same spending levels (Nicholas et al., 2014[61]). Evidence from Australia suggests that specialist palliative care in nursing homes reduced hospital admissions (KMPG, 2020[59]).

Several studies from Australia, Canada, the United Kingdom and the United States found that providing palliative care at the person's home can be cost effective (Luta et al., 2021[62]; Higginson et al., 2003[63]; Gomes et al., 2013[64]), while additional literature has also found that palliative care in nursing homes can reduce costs and hospital use, as well as increasing the quality of life (Abernathy et al., 2011[60]). Evidence has shown that home care is cost-effective and provides potential benefits for people receiving care and their relatives, together with lower health care costs (Luta et al., 2021[62]; Higginson et al., 2003[63]; Gomes et al., 2013[64]). The effectiveness of palliative care stems mainly from reducing length of hospital stays, re-admissions, and visits to intensive care units (Hodgson, n.d.[65]). In Belgium, for instance, patients using palliative home care support had lower ICU and emergency visits (Maetens et al., 2019[66]).

Home-based palliative care appears to have a sizeable impact on expenditures, depending on the country. In the United States, a proactive, community-based palliative care programme engaged participants several months before death, resulted in dramatically lower hospital usage and lower health care expenditures, achieved with modest programme costs (Cassel and al., 2016[67]). In Ontario, Canada, an in-home palliative team care was cost-effective; it increased the chance of dying at home by 10%, increased the average number of days at home (6 days) and quality-adjusted lifedays (0.5 days), and it reduced costs by approximately USD 4 400 per patient (Pham and Kram, 2014[68]). An analysis on the effectiveness of the Australian Palliative Care Extended Packages at Home (PEACH) pilot found that it increased at-home stay by one day. The mean direct cost of PEACH was AUD 3 489 per patient, which was largely offset by cost savings amounting to AUD 2 450. Although a lower share of people died at home when receiving care as part of the pilot compared to usual care (McCaffrey et al., 2013[69]), in 79% of cases this was in line with their wishes (Agar et al., 2022[70]). A study from the United Kingdom found that the estimated cost of a day of community care at the end of life is GBP 145 compared to the cost of GBP 425 for a specialist palliative care bed day in hospital. Overall, a meta-analysis concluded that home-based palliative care may contribute to an improvement in quality of care by reducing medicalisation at the end of life and therefore reducing costs (Luta et al., 2021[62]). This indicates that changing the setting of care of a patient at the end of life has the potential to reduce the daily cost by GBP 280 (Marie Curie, 2012[71]). At the same time, the extent of cost-savings cannot be determined with confidence because many studies did not consider the additional community costs and informal cost to carers (Hunter, 2018[55]).

The literature has also explored the potential cost savings at the end of life linked to the use of advance care planning, showing mixed results. A literature review including studies from Canada, Singapore, the United Kingdom, and the United States found that around half of the studies showed cost savings attributable to the use of advance care planning. The studies showing a reduction in health care costs linked to advance care planning also reported reductions in the use of hospital care and acute care (e.g. ICU) at the end of life. Further analysis of the potential cost savings – and cost effectiveness – linked to advance care planning may be beneficial (Dixon, 2015[72]).

5.3.3. Adapting health financing mechanisms to incentivise a more appropriate mix of end-of-life care services

Improving provider payments

While countries use a variety of payment systems, better linking provider payments to population needs will be important. In most countries, a mix of activity-based and non-activity-based payment exists for EOLC. In the United States, Medicare payment for hospices has a fixed per diem rate. In England, Ireland, New Zealand and Norway, block contracts are often used to pay for services, while Spain uses capitation-based resource allocation (Groeneveld EI, 2017[8]). In Germany, experts in clinical care and health care financing identified weaknesses in both reimbursement mechanisms used for palliative care, per-diem payments and payments based on the diagnosis-related group (DRG) (Schildmann et al., 2019[73]). DRGs do not sufficiently classify palliative care and may fail to fully account for the unique needs of the individual patient, instead looking at the broader definitions around their official disease diagnosis (Schildmann et al., 2019[73]). In an analysis of patients who received palliative care in two German hospitals, researchers found that existing DRG categories did not sufficiently capture the true costs of palliative care, with the cost of the extra health care staff time needed to provide quality palliative care, in particular, not reflected in existing DRGs (Vogl et al., 2018[74]) In contrast, in Australia, a patient characteristic-based payment model has been rolled out nationally. The amount of reimbursement received per patient varies by performance status, phase of illness, care setting and age (Groeneveld EI, 2017[8]). Similar patient-characteristic payment models are currently being explored in England and Switzerland.

Different funding streams between curative care and palliative care can impede early access to palliative care. Designing funding to recognise the complementarity of different care services and their integration would be beneficial. Currently, payment systems do little to support new care models that for instance improve care co-ordination as health service provision is predominantly financed in a “silo”. For instance, it has been found that in Canada, acute-care beds are substantially more expensive than hospice or in-patient palliative-care beds, long-term care (LTC) beds or homecare and, if budgets were global, then efficiencies would be found by increasing capacity in lower-cost settings to reduce backlogs in higher-cost settings (Kieran Quinn, 2021[75]). Frequently, this results in fragmentation of care with poor patient experience and poor health outcomes.

Recommendations for improved funding in end-of-life care include thinking about integrated funding – with some form of bundling of the palliative and curatively oriented components of care (Duckett, 2018[76]). Bundled payments have been used for specific diseases but are complex to implement, particularly in setting tariffs (OECD, 2016[77]). Yet, a bundled payment for those with a diagnosis of advanced illness may provide strong incentives to provide care in teams, thereby reducing fragmentation. It would be important to signal that choosing palliative care should not necessarily mean giving up on seeking a cure but rather on improving quality of life and possibly, even living longer. Medicare is testing a new model of care –Medicare Choices – that would allow patients to continue receiving curative care once they enter hospice care – an option that has been unavailable until now (May et al., 2021[78]).

In the United States, there has been progress towards value-based payments which might favour more palliative care. In general, the use of fee-for-service payment might encourage providers to have more curative care instead of palliative care which requires more time-intensive care. Medicare has seen growth in Medicare Advantage (MA) which pays private insurers a risk-adjusted fee to administer bundled inpatient, outpatient and typically prescription drug benefits to Medicare beneficiaries who opt into these plans and makes providers likely to gain financially from promoting palliative care as it has been shown to reduce overall expenditures. It also promotes Medicare’s hospice benefit because the MA plan is no longer responsible for the expenses, but costs are borne by original Medicare under the hospice benefit. Medicare also has moved toward value-based care that is more consistent with palliative care through the growth of accountable care organisations (ACOs) and other special payment models in original Medicare. These models provide incentives for co-ordinated care by investing in data infrastructure and offering providers a share in any savings (and increasingly in any loss) to Medicare relative to projected targets and subject to meeting quality guidelines. Nevertheless, evidence of the effectiveness of ACOs is mixed. One of the issues related to their use consists in the difficulty to define when a person is likely to die. People whose likelihood to die soon is easy to predict only represent a small share of the total number of people who are nearing the end of their life (Gilstrap et al., 2018[79]).

Quality measures related to end-of-life care are needed to transform the payment system to a system where there is payment for quality or value. In England (United Kingdom) there are pay-for-performance systems to incentivise GPs to identify and manage palliative care needs. For instance, the Quality and Outcome Framework incentivised GPs to keep a register of patients who need palliative care and to have regular multidisciplinary reviews where the cases of people in need of palliative care are discussed.

Incentivising care outside hospitals

Given the evidence pointing to cost- effectiveness of palliative care outside hospitals, rethinking payment systems to incentive such care might be useful. In this sense, it is important to avoid uncapped funding for hospital-based palliative care while home-based care is capped. Similarly, separate funding for different places of death can create negative incentives and would require funding to be aligned for services in different locations. Allowing the benefits to follow the patient would ease problems with transitions and give patients a broader range of options. Improving the adequacy of payment levels for health care in nursing homes might contribute to more desirable outcomes overall, and at the end of life, although further cost-effectiveness analysis would be beneficial.

Several countries have introduced funding changes to incentivise the use of home-based palliative care. England has introduced personal health budgets for end-of-life in five areas with the goal of having more personalised care (HSJ solutions, 2017[80]). The use of personal health budgets has resulted in 82% of people dying in their preferred place while allowing people to purchase services which were not previously available and resulting in a cost neutral or reduced cost compared with the traditionally commissioned care. A personal health budget is in place in The Netherlands as well (persoonsgebonden budget (PGB)), for people who need help at home due to illness or disability or for palliative care needs (Government of the Netherlands, 2022[81]). France has introduced as part of the action plan on end of life in 2022 additional funding for out-of-hours palliative care and a reinforcement of mobile teams to promote palliative care at home. Mobile palliative care teams (EMSP) are funded by global budgets. The price is set by the Regional Health Office (ARS) according to the number of full-time-equivalent persons working in the team and considers the travel costs. The payment also includes a contribution to the structural costs of the hospital that the team is attached to. The amount of payment for organisational costs may be assessed by the ARS based on hospital accounting data (WHO/OECD, 2021[82]). The Australian Government has announced in December 2021 an investment of AUD 56 million to improve the provision of palliative care at home. AUD 37 million will be invested in scaling up the Greater Choice for At Home Palliative Care programme – which has so far been successful as a pilot programme to improve access to palliative care at home (Department of Health and Aged Care, 2021[83]). Since 2007 in Germany GPs can refer people to specialised outpatient palliative care services (SAPV), which include medical, nursing, and psychological services. The SAVOIR project analysed people's satisfaction regarding SAPV services and found a general positive attitude towards SAPV across the country, despite regional differences in the characteristics of the services provided (Gemeinsamer Bundesausschuss, 2019[84]).

Countries are also implementing policies to improve the provision of end-of-life care in nursing homes. In Luxembourg, for instance, up until now nursing homes were not allowed to have medical devices onsite (like stocks operated by pharmacists). As of end of 2022, new legislation to allow stocks operated by pharmacists in nursing homes has passed and its implementation is foreseen in January 2023. The impact of such change on hospital admissions will be monitored. In France, to avoid hospitalisations and improve the quality of care at the end of life, the hospital at home (HAH) protocol is available in nursing homes so that nursing homes can provide palliative treatments that require material and medical services that are not normally available. The palliative care in HAH, is paid by an activity-based payment scheme using palliative care DRGs (WHO/OECD, 2021[82]). As part of the AUD 56 million investment for end-of-life care in Australia, the government has announced an investment of AUD 19 million on improving end-of-life care in residential aged care (Department of Health and Aged Care, 2021[83]). Furthermore, the European Union has funded the Palliative Care for Older People in Care and Nursing homes in Europe (PACE) project in six countries (Belgium, Finland, Italy, the Netherlands, Poland, and the United Kingdom). The project aims at producing toolkits and guidelines for governments to improve the provision of palliative care in nursing homes.

5.3.4. Countries need to find a better balance between supporting and relying on family carers

Policies to support informal carers such as cash benefits, respite care, leave and training heavily influence the availability and burden of informal cares. Such policies are particularly important in case of a shift towards more home EOLC which may also have unintended consequence on caregivers, especially if formal home services are insufficient. Indeed, informal caregivers of patients dying at home spent more than twice as much time on unpaid caregiving compared with those caring for patients dying in hospital (Gardiner et al., 2020[33]).

Because financial issues are often a major barrier in the provision and receiving of palliative home care, specific allowances, or other financial incentives to both patients and informal caregivers are important. As mentioned in Section 5.3.3, several countries do not provide such benefits for carers. Cash benefits could help to expand the supply of otherwise unpaid carers, but there are also important trade-offs for both carers and care recipients which need to be considered. It is important that cash benefits are not used to substitute the formal care providers, thereby impacting the quality of care. They are an adequate tool to prevent poverty and social exclusion and should be made more widely available but should not trap family carers into a low-paid unwanted role. For instance, in Belgium informal caregivers can receive EUR 786.76 per month. Informal caregivers who work in the Flanders are also entitled to the Flemish encouragement allowance for up to two years (EUR 123.95 per month), which serves as an incentive to remain attached to the labour market and return to their jobs. Furthermore, 82% of Flemish municipalities offer an allowance of an additional EUR 30 per month on average. In France, people who are accompanying a relative to death can receive a daily allowance of around EUR 56 for up to 21 days per year. Parisian residents are also entitled to an additional allowance of up to EUR 610 per month for up to 3 months (12 months if the terminally ill is a child) (Maetens et al., 2017[52]).

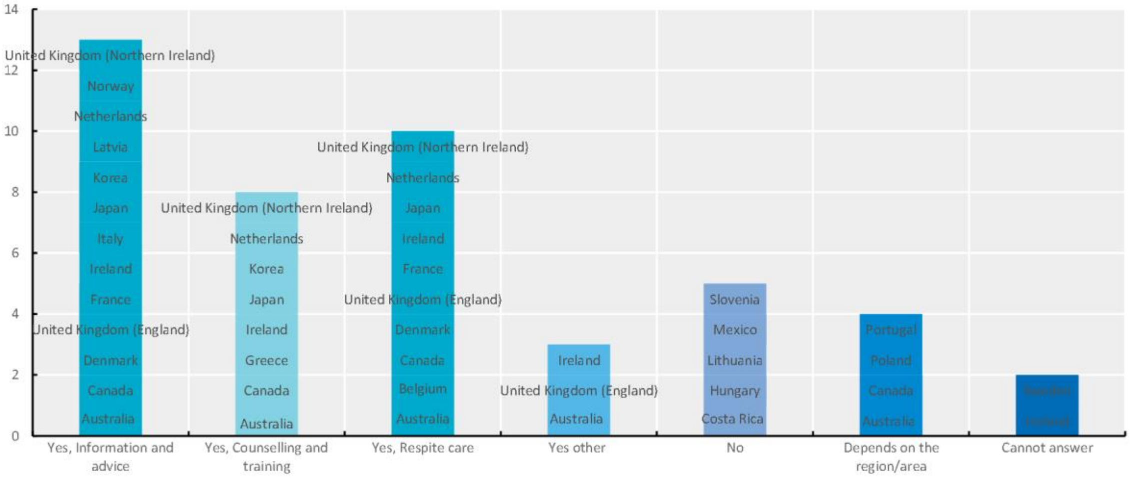
The design of the eligibility criteria for carers' allowance should be carefully weighted to ensure an adequate trade-off between the generosity of the cash benefit and the size of the eligible population. Typically, such cash allowances involve several eligibility requirements with a view to define an eligible carer, the level of care effort, and the relationship between the carer and the care recipient (e.g. certain relatives, co-residency). Countries also use very different compensation and eligibility conditions. Two main approaches, discussed below, emerge: i) countries providing remuneration to family carers who are formally employed; and ii) countries with means-tested allowances. In most Nordic countries, remuneration is subject to a contract with the carer and can last a maximum amount of time. For instance, in Denmark, the eligibility requirements specify that the caree receives palliative care and is expected to die in 3-6 months. In English-speaking countries, allowances are subject to means-testing and eligibility conditions may result in disincentives to work as there are often not combined with several work hours.

Caregiving may have detrimental effects on the health and well-being, especially at the end of life. Likewise, bereavement may be associated with excess risk of mortality, a decline in health and higher rates of medical use and hospitalisation. Integrating relative and family in end-of-life care decisions and increasing understanding of the end-of-life process appears to be beneficial for both the patient experience and the psychological recovery of the relatives. Addressing emotional strain by providing coping strategies such as self-care, stress management, problem-solving and decision-making guidance are fruitful avenues to reduce caregiver stress and improve quality of care (Brimblecombe et al., 2018[85]). Such policies are likely to have a financial impact as well as there is evidence that counselling results in lower health care utilisation for caregivers and that assisting caregivers can reduce their productivity losses (KMPG, 2020[59]).

Yet, while information and advice are available in just over half of the countries, only 8 counties provide counselling and training (Figure 5.8). Availability of training services is often fragmented across OECD countries. Most training is typically provided through local initiatives and relies heavily on the voluntary sector. In Luxembourg, an NGO Omega 90 is providing follow-up support for informal carers after bereavement. In some countries, training is tied to a cash benefit specific to informal carers. In Norway, municipalities have the obligation to deliver training to caregivers providing intense care, under specific conditions, while in the Netherlands both volunteers and informal carers receive training on end-of-life care through a well-established national programme (OECD interviews, 2021). In the United States, there is a broad programme for all type of carers for the elderly, the National Family Caregiver Support Program (NFCSP). It is administered by the Administration for Community Living of the US Department of Health and Human Services. States and territories receive funding based on the proportion of their population age 70 and older and are required to offer various core services in partnership with local public centres ("Area Agencies on Aging") and local service providers, including individual counselling, support groups, and caregiver training.

Figure 5.8. Support is focused on information, but specific counselling and training is lacking

Countries' answers to the question "Are there policies/programmes to support informal carers of people at the end of life?"



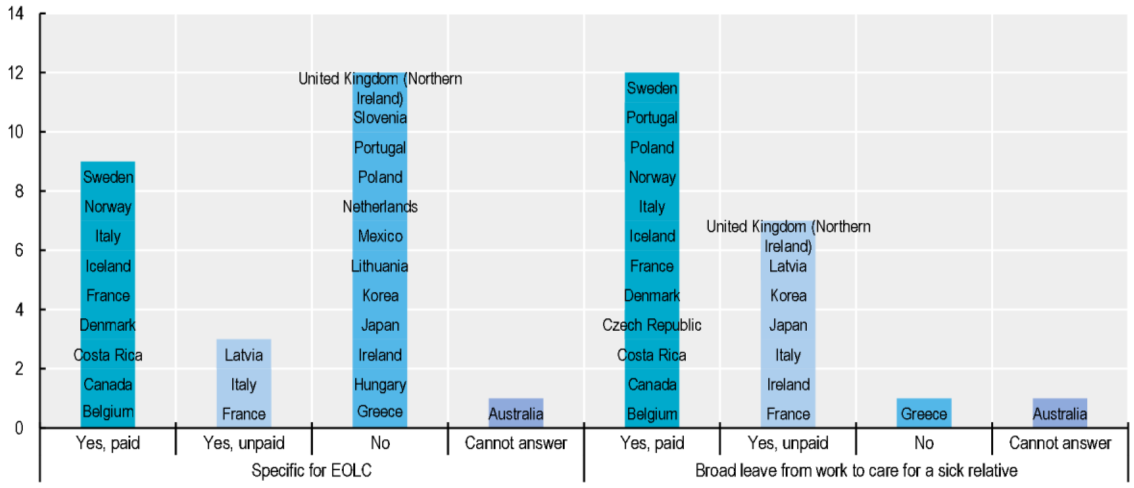
Source: (OECD, 2020-2021[9]).

Respite care, which is designed to offer caregivers a break from their regular duties, is viewed as a policy that helps carers to overcome some of the physical and psychological challenges from their caregiving role. It is often perceived as the most important and common form of support to alleviate caregiving burden (COFACE, 2017[86]). A review covering 11 OECD countries (Austria, Belgium, Czech Republic, Denmark, France, Germany, Luxembourg, Slovenia, Spain, Sweden, and Switzerland) found respite care to be the most effective support measure to improve the mental well-being of in-house informal caregivers (Calvó-Perxas et al., 2021[87]). Carers of people with advanced and terminal illnesses face considerable uncertainty over the length of time for which they are committing themselves to care, and what may be involved in delivering that care. Respite care could be provided as inpatient care, for instance in hospices, as day care or at home. In the United Kingdom, several types of respite care are available, including day care centres, homecare from a paid carer, short stays in care homes, respite holidays and sitting services. Respite care in the United Kingdom can be paid out-of-pocket or its cost can be covered by a charity or public funding. In the last case, both the person in need of care and their informal caregiver must undergo a needs assessment to qualify for the funding (NHS, 2019[88]). Often, there is restricted availability of respite care at home but there is some limited evidence that the service appears to be associated with better quality home care (Ingleton et al., 2003[89]). Yet, respite care is not always fully funded or available. In Belgium, respite care centres are reimbursed only for caregivers of terminally ill minors (Maetens et al., 2017[52]). In Germany, respite care is available for up to four weeks per calendar year if the caregiver is temporarily unavailable to provide home care and accommodation and food costs are paid by the patient or their family (Maetens et al., 2017[52]).

Across OECD countries, there is growing commitment to support informal carers combining work and caring but paid leave is not widely available, especially for terminal illness. Among EU countries, this is well exemplified by the Work-life Balance Directive, which entered into force in 2019 and must be adopted by member states within three years. The directive includes a carers' leave: workers providing personal care or support to a relative will be entitled to five days of leave per year. Three-quarters of OECD countries (30 countries) provide some rights to leave to care for a family member – either paid or unpaid – up from two-thirds of countries 10 years ago (Rocard and Llena-Nozal, 2022[90]), while 12 OECD countries have specific care leave for end-of-life care, 9 of which have paid leave (Figure 5.9). In the future, countries need to find a way of promoting a better work-life balance care leave because it allows employees to provide care without having to worry about income loss or job security. Currently, leave entitlements vary starkly across countries in terms of duration, eligibility criteria and degree of compensation.

Figure 5.9. Only half of OECD countries have a special statutory leave from work for EOLC

Countries' answers to the question "Is there a special statutory leave from work or flexible work for informal carers?"



Source: (OECD, 2020-2021[9]).

Several countries have a more generous duration for palliative care paid leave. This is the case for Denmark, where employees have the statutory right to leave for the care of someone close dying, according to the Act on Leave from work due to Special Family reasons (March 2006) and there is no fixed time limit for the leave. In France since 2 March 2010 Law, family solidarity leave is available for three months (renewable once), but financial support for palliative care is only available for a maximum of 21 days. Sweden allows both family and relatives of a dying person to obtain leave for up to 100 days

(Observatory for Sociopolitical Developments in Europe, 2016[91]), while 60 days of paid leave are available in Norway for informal caregivers (OECD interviews, 2021). Furthermore, the employer had a legal obligation to ensure the return to work after palliative care leave. Canada implemented in 2004 the Compassionate Care Benefit, which allows family caregivers to obtain up to six weeks of leave from work to care for a relative at the end of life. During the leave, informal caregivers receive up to 55% of their average earnings with a fixed cap of CAN 435 per week (Crooks and Williams, 2008[92]). Although such leave is generous in terms of weeks off, the halving of salary is likely to represent an issue for informal carers who need to provide care for a prolonged time. In Belgium, there is a palliative care leave for up to 3 months, but employees might also benefit from a time credit (part-time or full-time career break) from one year to up to five years leave full or part-time. In Japan, while employers are not obligated to offer paid leave to informal carers, there is a public system in place that provides financial support equivalent to 67% of the number of usual wages to those who meet certain requirements.

Yet, some other countries have much less generous leave arrangements, such as Luxembourg, where the “congé d’accompagnement de fin de vie” is for five working days at a time and per year. The Netherlands only allows employees to receive care leave, while this is not available for self-employed carers. Care leave has a cap of 240 hours per year and is unpaid. In some cases, financial support can be received based on collective bargaining agreements or working arrangements. In the Czech Republic, relatives of dependent persons are entitled to a right to work part-time, which is de facto rarely granted by employers (Observatory for Sociopolitical Developments in Europe, 2016[91]). Moreover, in many countries there is no specific leave to take care of a relative with terminal illness nor broad care leave (e.g. Croatia, Greece, Hungary, Portugal) or only unpaid broad care leave (e.g. Korea). Even for broad entitlement to leave for care, only about half of countries offer some form of paid leave for caring and it tends to be restricted to a short duration.

Flexible working arrangements can also support informal caregivers balancing personal and professional responsibilities with care needs. A study from the United States found that flexible working hours increased by 50% the likelihood that women caregivers would still be employed after two years of caregiving (Pavalko and Henderson, 2006[93]). Evidence from the United Kingdom also shows similar results, with supportive employers and flexible working arrangements being listed as the most relevant factors to retain employees with caregiving responsibilities (Gardiner et al., 2019[45]). Furthermore, the literature reports that informal caregivers value their job and that their workplace represents a way for them to obtain some respite from the caregiving (Bijnsdorp et al., 2021[40]). Allowing flexible work arrangement would thus benefit caregivers and would likely have a stronger impact on women, who are more likely to quit the labour market due to caregiving responsibilities. Across OECD countries, on average more than half of employees have their working hours set by their employer without possibility for change, with this share ranging from over 30% in Sweden to around 75% in Lithuania (Rocard and Llena-Nozal, 2022[90]). In some countries, together with paid leave, informal caregivers have the possibility of obtaining flexible working arrangements such as part time jobs. In Germany people can reduce their working hours to 15 hours per week for a maximum of two years. During the two years, part of the salary lost can be received in the form of a loan to be repaid without interests after the person returns to work full time, in the form of salary reductions (Maetens et al., 2017[52]). As mentioned above, in Belgium carers can negotiate part-time work arrangements or a break from work from 1 to 5 years. Furthermore, in Norway, people caring for a dying relative can work from home (OECD interviews, 2021). The pandemic has boosted the use of flexible working arrangements. The number of people working from home has increased substantially in OECD countries, by one-third on average, and has been particularly high among women (Rocard and Llena-Nozal, 2022[90]).

5.4. Conclusions

This chapter shows that, despite the concern about high cost at the end of life, very few countries have data which is comparable on the topic and on the drivers of end-of-life care expenditures. Similarly, countries do not tend to have a policy to control end-of-life care budgets, even though needs and expectations are growing. International evidence conveys that end-of-life spending comprises only a modest fraction of aggregate expenditures, because the fraction of the population that dies in any given year is small, but projections on the number of people dying forecast an increase in those numbers and this will have an upward impact on costs (French et al., 2017[7]). Countries will need to make sure that end-of-life care is adequately funded in a sustainable manner to address future needs.

Yet the focus on costs should not overshadow the importance of ensuring that financing of end-of-life care is appropriate and provides high-quality people-centred care in the last days or months of life. Currently, end-of-life care is publicly funded in most OECD countries, but public coverage is often partial and varies across settings of care. Partial public coverage leads to people relying heavily on informal support, with half of people currently receiving informal care before dying. Overreliance on informal care, without adequate public support for informal carers, generates indirect societal costs linked to the reduced employment and financial costs that can affect informal carers. Similarly, many patients do not receive palliative care to manage their pain and other symptoms, and financing should be redesigned in a way that there are more incentives for promoting palliative care and cost-effective interventions outside of hospitals, as well as ensuring better end-of-life planning with a view to reducing unplanned hospital costs.

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Note

[1] This report conceptualises end-of-life care as the care provided to people who are in the last 12 months of life. It refers to the terminal stage of palliative care, as well as including some elements of curative care and help with mobility limitations. Chapter 1 of this report provides a more detailed definition of EOLC.

6

Strengthening governance and evidence-based design for end-of-life care

This chapter focuses on the governance and evidence-based design of end-of-life care (EOLC) systems. The COVID-19 crisis has shed a light on the unpreparedness of EOLC services to emergencies, causing disruption in service provision for people at the end of life. Poor governance can also exacerbate fragmentation in the care that people receive at the end of life. It highlights the weakness of EOLC research and data, which hinders benchmarking and prevents best evidence to inform policy making. Countries have already started to promote community care and technology in EOLC during the pandemic, and further efforts could be undertaken. Information sharing and case management can be useful tools to provide more integrated care to people with complex needs approaching death. EOLC would also benefit from better evidence produced through a scale up in research, improvement of data linkages and design of indicators.

Introduction

The landscape of end-of-life care[1] (EOLC) has changed substantially in the last decade due to changes in demographics, medical technologies and disease patterns, resulting in a large number of people who live with conditions requiring palliative care (Leung and Chan, 2020[1]). Moreover, the recent rapid growth of palliative care services signals a shift towards broader acceptance of EOLC and palliative care within health care systems and the wider public, which has resulted in the greater uptake of these services by patients and their families (Chen et al., 2014[2]).

This chapters finds that more could still be done to strengthen the governance and evidence-based of end-of-life care. The COVID-19 pandemic has also shown the paramount importance of ensuring continuity of services despite wider pressures on the health and care system, including national emergencies. It has also raised the need of delivering end-of-life care in different care settings outside the hospital while also increasingly relying on digital solutions. In addition, EOLC is often fragmented, with individuals having several people involved in different aspects of their care. This can be confusing for the individual as well as their relatives and informal carers. More investment in research for palliative care and EOLC would help to improve symptom control and adequately meet demand (Sleeman, Gomes and Higginson, 2012[3]).

Health and social systems that can withstand pressures during emergencies such as economic downturns and pandemics will benefit individuals by avoiding bottlenecks in care as well as lack of compassionate care for dying patients. Ensuring sound EOLC research and data informs decision-making and offering integrated and adaptable EOLC services are important elements to improve care for those at the end of life and their families and carers. Good care co-ordination of EOLC services means people receive the cohesive care and services, which are joined-up and provide an overall benefit. The availability of sound data is an important driver of effective management of EOLC. EOLC research is essential for policy makers to make informed and sound decisions and can help to improve the quality of EOLC services while sharing knowledge and research among countries. Finally, sufficient data and evidence, together with policy coherence help systems to be more adaptable.

The remainder of the chapter is organised as follows. Section 6.1 highlights the importance of the sub-principles of a well-governed and evidence-based system in EOLC. Section 6.2 illustrates the consequences of system lacking such focus, while Section 6.3 explores policies and best practices to improve information, integration and adaptability.

Key findings

- Few countries issued specific guidelines for health workers to adapt palliative care to the COVID-19 pandemic. Guidelines from only five countries mentioned both palliative care needs and mode of delivery. Because of the surge in demand, frontline workers in primary care and long-term care had to provide end-of-life care with insufficient training and knowledge. Insufficient medication such as morphine and oxygen in those settings made end-of-life care more challenging. A systematic review of evidence across countries suggests that discussions on advance care and end-of-life care declined. Social distancing rules led to isolation at the time of death and lack of support for relatives.
- EOLC is often fragmented, requiring different services in different locations. More could be done to improve co-ordination for users. 60% of countries do not have any programme or strategy to implement an integrated approach across different levels of government or across ministries. Because of uncoordinated care, people experience delayed discharges and many care transitions, with more than half of patients moved to another care setting at least once in the last three months of life. Hospitalisations occurred in two-third of cases for people at home, due to a decision to provide more life-sustaining care.
- Data infrastructure in OECD countries is still weak because end-of-life care data requires strong data linkages which are not yet in place in most countries. Only nine OECD countries collect data integrated into health and social information systems which can be used for end-of-life analysis. Nearly half of the responding countries did not collect EOLC data through specific indicators that were integrated into broader health and social care information systems nor had a system in place to monitor and evaluate palliative care. This hinders evaluation of care progress and international benchmarking.
- Research in EOLC is insufficient and not high-quality due to low funding and ethical and methodological challenges to gather information from the population. Less than 30% of OECD countries have a national research agenda and less than 16% a local research agenda on the topic. This leads to lack of strong evidence about best practices of care and such gaps in high-quality evidence hinder policy prioritisation and the translation into optimal care practices.

Policy options

- In anticipation of future shocks, countries could develop new models of palliative care with an increased emphasis on training frontline health and social care workers, ensuring supplies of medicines and equipment, and promoting advance care planning and the use of technology for palliative care consultations to scale up services in case of surge demand. Luxembourg made efforts during the COVID-19 pandemic to ensure that people in need of EOLC could receive adequate care at home, without being hospitalised, when possible. The United States developed an online platform to provide specialist palliative care remotely and training for generalist palliative care.
- Care co-ordination can help the end-of-life care experience and reduce the extent of hospital care. Sharing information through electronic notes sharing or shared electronic systems – such as those available in Australia and Costa Rica – represents an essential step to support care co-ordination and integration. Care co-ordinators such as the nurse liaison in Ireland or the mobile palliative care teams in Belgium can also support a more integrated system.

- Countries could maximise the use of the wealth of available data by developing links across different datasets. The availability of linked and timely data would facilitate the calculation of meaningful internationally comparable indicators of care quality at the end of life, resulting in international benchmarking and support to the policy making around EOLC. Sweden has the Swedish Register of Palliative Care for that purpose. Other countries such as Ireland and England focus on publishing and monitoring key performance indicators.
- Countries could improve research capacity on end-of-life care by promoting funding and developing institutional capacity to increase research projects on EOLC. Some countries, including Belgium, Ireland, France, and the Netherlands, have developed strong organisations supporting palliative care research. Addressing knowledge gaps in cost-effectiveness and models of care can contribute to putting EOLC higher in the policy agenda and improve training for professionals.

6.1. Why are good governance and evidence-based design in end-of-life care important?

This section outlines why it is critical to ensure that end-of-life care has continuity of services despite wider pressures on the health and care system, is integrated across care settings, and reflects the latest research, data, and evidence. Each component or sub-principle of the well-governed and evidence-based principle (adaptable, integrated, data-driven and research-based) is discussed. The remaining principles are discussed in the different chapters of the report while the overview Chapter 1 presents the overall framework.

The first sub-principle is that care is *adaptable* to withstanding pressures between and during emergencies, such as economic downturns and pandemics. A systems-level approach is necessary to ensure high standards and quality of EOLC for patients and families, as well as the well-being of staff, are maintained despite external pressures (Hanna et al., 2021[4]). Adaptability of EOLC is important to foster resilience in the face of disruptions and shocks, but it also helps with changes in population preferences over time and adapting to socially and culturally diverse groups.

The second sub-principle is that EOLC is *integrated* across the health care system and all care settings, as well as across and within levels of government, regardless of underlying conditions. Ensuring quality EOLC requires collaborative, cohesive, and co-ordinated care across settings. Integrated care models need to be flexible and supported by clear, well-considered protocols and policies, with a well-resourced multidisciplinary approach fundamental to ensuring the provision of integrated care (Evans, Harding and Higginson, 2013[5]). From a patient perspective, the provision of integrated care enables them and their caregivers to navigate between services more easily and empowers them to manage their care needs across different stages of their end-of-life journey (Thomas-Gregory and Richmond, 2015[6]).

The third sub-principle is that EOLC is *data driven*. Data on EOLC needs to be collected, utilised to monitor and manage the immediate care of the individual patient, as well as evaluate and improve standardised care for all patients and families (Davies et al., 2016[7]). Data may include administrative data, clinical data, as well as patient and family reported outcome and experience data, with insights drawn upon to improve care (Bainbridge and Seow, 2016[8]). Missing data, data fragmentation and an insufficient data infrastructure represent challenges to monitor the quality of care and to allow for better integration (Rajaram et al., 2020[9]).

The last sub-principle relates to EOLC being *research-based*. Investment in EOLC and palliative care enables the delivery of high quality, evidence-based palliative care, critical for maintaining a good quality of life. This includes funding research into pain and symptom management, psychosocial support, appropriate medical interventions, and maintenance of quality of life for the patient and their family. Research producing information on preferences of place of death, patients' experiences and outcomes can direct the provision of care towards patients' needs and preferences while also providing crucial information to patients and their families facing difficult care choices. Research can create opportunities for collaborative work, facilitate interdisciplinary approaches, and support decision-making by clinical teams, patients, and carers. International collaboration and knowledge-sharing, as well as sharing successful funding frameworks that support research focused on benefits for patients, their families and those close to them is also critical (Higginson, 2016[10]). Evidence from research needs to be better embedded into national policies, plans and regulations. Research findings can only change outcomes if adopted and implemented by health care systems, organisations and clinicians (Evans, Harding and Higginson, 2013[5]).

6.2. The consequences of a lack of well-governed and evidence-based end-of-life care

This section highlights current shortcomings in the governance of end-of-life care and its consequences. Research and data on the topic are still underdeveloped and thus rarely incorporated into policy making. Care provision is hardly integrated within settings of care and across government departments. The current pandemic has shed light on the lack of preparedness of end-of-life care services for emergencies.

6.2.1. Countries have been unable to scale up care during the pandemic

At the onset of COVID-19 crisis, countries were particularly unprepared for a pandemic, and most countries had not developed specific palliative care guidelines for emergencies. Many countries issued specific guidelines for health systems in the first months of pandemic onset, but palliative care was rarely included. Among 20 countries that issued guidelines on infection control in long-term care, only five mentioned specific provisions for palliative care needs and mode of delivery (Canada, Latvia, Luxembourg, Portugal and the United States); Ireland included the possibility of transferring people at the end of life across settings to ensure they are provided with the palliative care they need; and Slovenia activated a helpline for health care workers to receive counselling on the provision of palliative care services (Rocard, Sillitti and Llena-Nozal, 2021[11]). Additionally, Australia and Denmark recommended relaxing the visitor bans for patients at the end of life (OECD, 2020-2021[12]). In Ireland, guidance provided information on the care for patients with COVID-19, supportive therapies at the end of life, and advance care planning in residential settings (HSE - Ireland, 2020[13]).

Even when specific guidance on palliative care and end-of-life care existed, substantial gaps were identified. In the COVID-19 guidance documents concerning palliative care, key aspects of palliative care, practical guidance, and broader structural and co-ordination considerations were largely absent (Gilissen et al., 2020[14]). In particular, guidance for the health and social care sector did not include holistic symptom assessment and management at the end of life, comprehensive ACP communication, and support for family including bereavement care. Only a few made specific recommendations regarding symptoms at the end of life and nonphysical (ethical, cultural psychological, social, or spiritual) needs were hardly addressed. Moreover, the COVID-19 pandemic hindered discussions surrounding advanced care planning both inside and outside the hospital due to the overwhelming situation (Hirakawa et al., 2021[15]). Recommendations related to end-of-life care were not specific enough with respect to staff training regarding communication and decision-making, referral to specialist palliative care or hospice, support for staff, and deployment of staff, such as moving palliative care staff from acute settings to the community.

As a result of the surge in deaths during the pandemic and the lack of specific provision for such services, the provision of end-of-life care was greatly impacted during the COVID-19 pandemic, leading to increased hardship for those needing such care. The increase in mortality directly and indirectly had an impact on all parts of the health care system (see Box 6.1). Increased demand had also a large impact on palliative care needs, especially in certain settings. For instance, in the United Kingdom, deaths in care homes increased by 220%, while home and hospital deaths increased by 77% and 90%, respectively (Bone et al., 2020[16]). Fear of COVID-19 infections and hospitals being overwhelmed led to a change in behaviour: in the United States there was a decline in emergency department (ED) and inpatient visits across the country by 38% and 46%, between March and May 2020 (Zhang, 2021[17]).

Specialised palliative care teams were not always able to support other workers and the patients in the community (Marie Curie UK, 2021[18]; Santé publique, 2020[19]). Some palliative care wards were transformed into COVID-19 wards, reducing the availability of beds for people in need of end-of-life care. There was an unplanned shift towards home and end-of-life care and towards nursing home end-of-life care during the pandemic. This shift left first-line health and social care professionals in the challenging position of managing end-of-life care, even as they did not have the right knowledge of palliative care nor were proficient in communication on those topics. In the United Kingdom, for instance, community nurses and General Practitioners (GPs) experienced a substantial increase in the need for and complexity of palliative and end-of-life care such as having to provide more symptom management and bereavement support (Mitchell et al., 2021[20]). In Belgium, health care workers in primary care felt unprepared to manage the crisis, probably because of the insufficient use of ACP and the lack of end-of-life care guidelines, elements that make it challenging to make decisions during the crisis (Service public fédéral, 2020[21]). COVID-19 disproportionally affected those residing in care homes, leading to a surge in palliative care needs and creating enormous pressures to deliver high-quality EOLC with the result of an increased emotional toll on staff (Bone et al., 2020[16]). Delivery of quality care was compromised in all settings because of staff shortages. Several studies suggest decreased advance care planning and end-of-life discussions with residents and relatives because of social distancing measures or lack of staff availability, reversing progress achieved in palliative care in previous years (Spacey et al., 2021[22]). Finally, the lack of essential supplies and a medicine shortage, in particular oxygen and sedatives, challenged the provision of quality care (Marie Curie, 2021[23]).

Such challenges together with the impact of lockdowns and restricted visitation rights led to lonely situations at the end-of-care. People in nursing homes and hospitals experienced restrictions in visitation rights. Countries adapted the guidelines progressively in this respect. In Austria, several organisations provided guidelines on end-of-life care and visiting restrictions were lifted for people at the end of their life in nursing homes (Adelina Comas-Herrera, 2020[24]). Australia and Denmark also recommended relaxing measures that banned visitors for people at the end of their life (Rocard, Sillitti and Llena-Nozal, 2021[11]). Similar measures were adopted for people in hospitals or ICU, especially if they tested positive for COVID-19. In many instances, professionals adapted and used remote or telephone consultations. Even so, it was sometimes challenging to include relatives in end-of-life care decisions and even more to provide support. The process of grief and bereavement was also more complex for family members because of visiting restrictions (Fadul, Elsayem and Bruera, 2020[25]).

Box 6.1. The impact of COVID-19 on mortality

COVID-19 has led to an important number of deaths since early 2020. The total world cumulative mortality is 6.55 million as of October 2022. This represents approximately 829 confirmed deaths per million population worldwide. As of mid-2021, the average across the OECD was of 1 285 deaths per million, ranging from 5 deaths per million inhabitants in New Zealand to 3 070 deaths per million in Hungary. COVID-19 contributed to a 16% increase in the expected number of deaths in 2020 and the first half of 2021 across OECD countries (OECD, 2021[26]).

For some countries and some time periods, the number of confirmed deaths is much lower than the true number of deaths due to COVID-19. The comparability of COVID-19 deaths has been hampered by differences in recording, registration, testing and coding the cause of death. Excess mortality provides a measure of mortality that is less affected by these differences but is capturing other causes of death. Excess mortality – the number of deaths over and above what would have been expected at a given time of the year – has been used to measure the impact of the pandemic overall. Across all countries, excess mortality was positive for all but one country (Norway) and was 60% higher that reported deaths in 2020 but was more moderate in 2021. On a global scale the number of excess deaths in 2020 was estimated to be 3 million and the total cumulative death count over the entire period is estimated to be twice or four times the current count of confirmed deaths. The Economist estimates the global COVID-19 deaths to be four times the confirmed deaths, while HIME's estimates them to be less than 3 times higher than the confirmed data (Adam, 2022[27])

There has also been an indirect increase in mortality due to delayed care, which is more difficult to quantify. For instance, cancer screening and referrals were significantly delayed during the pandemic, Data from Health at a Glance 2021 shows that the proportion of women screened for breast cancer within the last two years fell by 5 percentage points in 2020 (OECD, 2021[26]). Such delays have a negative impact on mortality due to associated delays in cancer diagnosis. Evidence shows that delaying surgical treatment for cancer by four weeks was associated with a 7% increase in the risk of death, while a delay of systemic therapy or radiotherapy increases death by 13% (Hanna and al, 2020[28])

Visits for cardiac and cerebrovascular events declined, causing worse outcomes. Hospital admissions for such patients declined, especially at the beginning of the pandemic, and the reduction in hospital visits for minor events appears to be related to more risk of complications and mortality for those finally reaching hospitals. Other disruptions in care pathways such as delays in ambulance time and critical interventions have been associated in higher mortality in some studies (OECD, 2021[26]).

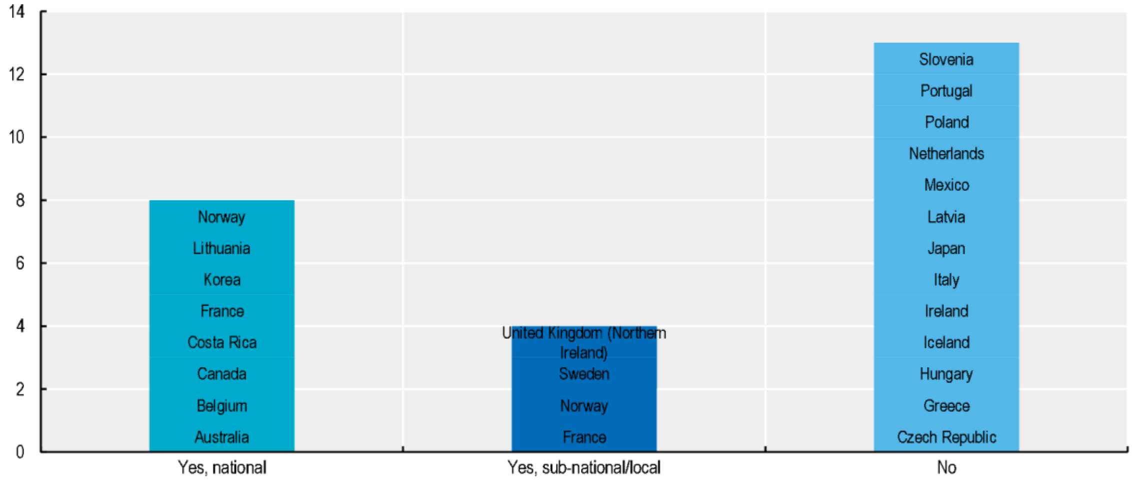
The pandemic has led to a decline in life expectancy in 24 of 30 OECD countries. In the United States, for instance, the decrease in life expectancy was 1.67 years, translating to a reversion of 14 years in life expectancy gains (Chan, Cheng and Martin, 2021[29]). Across several countries, the excess years of life lost due to the pandemic in 2020 were more than five times higher than those associated with the seasonal influenza pandemic of 2015.

6.2.2. Fragmented systems undermine effective end-of-life care delivery

Despite increased awareness of EOLC across countries, policies are not always well co-ordinated. Among 23 OECD countries surveyed, 60% do not have any programme or strategy to implement an integrated approach across different levels of government or across ministries. Among the countries that reported such programmes/strategies, seven countries (Australia, Belgium, Canada, Costa Rica, France, Lithuania, and Norway) issued them at the national level and four (France, Norway, Sweden, and the United Kingdom (Northern Ireland) at the subnational/local level (Figure 6.1).

Figure 6.1. Programmes/strategies for integrated cross-government approaches to EOLC governance

Countries' answer to the question "Do you have any programmes/strategies for developing integrated cross-government approaches?"



Source: (OECD, 2020-2021[12]).

Patients often experience multiple transitions near the end of life. An analysis of European countries highlights that more than half of patients in all countries were moved to another care setting at least once in the last three months of life, between 5% and 12% of patients were transferred three times or more in the same period, and 1 in 10 patients who died non-suddenly experienced a transition in the final three days of life (Van den Block et al., 2015[30]). Such transitions affect the continuity and quality of care. Most often such end-of-life care transitions are late hospitalisations for people residing at home. Furthermore, the VOICES survey for bereaved families shows that more than a third of respondents reported poor co-ordination between inpatient and outpatient services in England (United Kingdom) (ONS, 2016[31]). Similarly, only around one-third of the VOICES survey's respondents in New Zealand reported that co-ordination between hospital and other services worked well (Reid et al., 2020[32]).

Preventable hospital readmissions are frequently a consequence of poorly managed transitions. There is evidence from cross-country studies of admission to hospitals that could be considered unnecessary and/or remaining in acute hospitals for longer than necessary, which can also result in unnecessary high costs (Cardona-Morrell et al., 2017[33]). Such hospital admissions and frequent transitions appear to be related to the need for life-prolonging treatment because of the challenge of managing clinical complications in primary care settings and the lack of availability of palliative care outside hospitals (Van den Block et al., 2015[30]). Repeated hospital admissions at the end of life and intensive care unit (ICU) admission can lead to worse quality of life for the patient including increased emotional and physical suffering, as well as caregiver distress (Bernacki and Block, 2014[34]; Leith et al., 2020[35]; Wang et al., 2016[36]; Zhang et al., 2009[37]). There is also evidence that delayed hospital discharges can occur among palliative care patients, particularly because of the challenges in co-ordinating the discharge planning and finding appropriate services outside hospitals (Catherine Thomas, 2010[38]).

With population ageing and changing family structures an important share of people at the end of life are in nursing homes and there is often a lack of co-ordination among acute care, hospital palliative care and long-term care. According to data collected by the European Association of Palliative Care, in the majority of responding countries collaboration only happens "sometimes" between long-term care workers and palliative care specialists. In only three OECD countries (Austria, Belgium, Lithuania) collaboration happens “always” or “most of the times”, and in three other OECD countries (Czech Republic, Israel, Italy) collaboration happens “very rarely” (Arias-Casais N, 2019[39]). Lack of funding also hinders integration of palliative care into long term care facilities. Only half of the surveyed countries report dedicated funding for the provision of palliative care in long-term care facilities, including nine OECD countries (Austria, Belgium, Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, and the United Kingdom) (Arias-Casais N, 2019[39]).

Uncoordinated care can also lead to overtreatment, particularly with respect to medication. People in later life often have more than one medical condition and take a range of different drugs to treat these. While polypharmacy (taking multiple medicines) is in many cases justified for the management of multiple conditions, inappropriate polypharmacy increases the risk of adverse drug events, medication error and harm – resulting in falls, episodes of confusion and delirium (OECD, 2019[40]). Polypharmacy may also lead to higher hospitalisation and institutionalisation. OECD data shows that polypharmacy rates among older people vary more than 11-fold across countries: it ranges from 22.3% of those 75+ to 68% in primary care and from 7.5% to 87% in long-term care. More targeted studies show that a substantial share of older persons with life-limiting diseases receive drugs of questionable clinical benefit during their last three months of life: 32% of adults continue to take such drugs and 14% receive them for the first time (Morin et al., 2019[41]). This suggest that different policies play a role, such as the establishment of targeted polypharmacy initiatives in some countries, including prescribing policies. Lack of training and guidance of professionals as well as the co-ordination of drug prescribing among professionals might contribute to adverse drug-related events. Research also shows that having an interprofessional health team can co-ordinate polypharmacy and prescribe drugs if necessary (Dahal and Bista, 2022[42]).

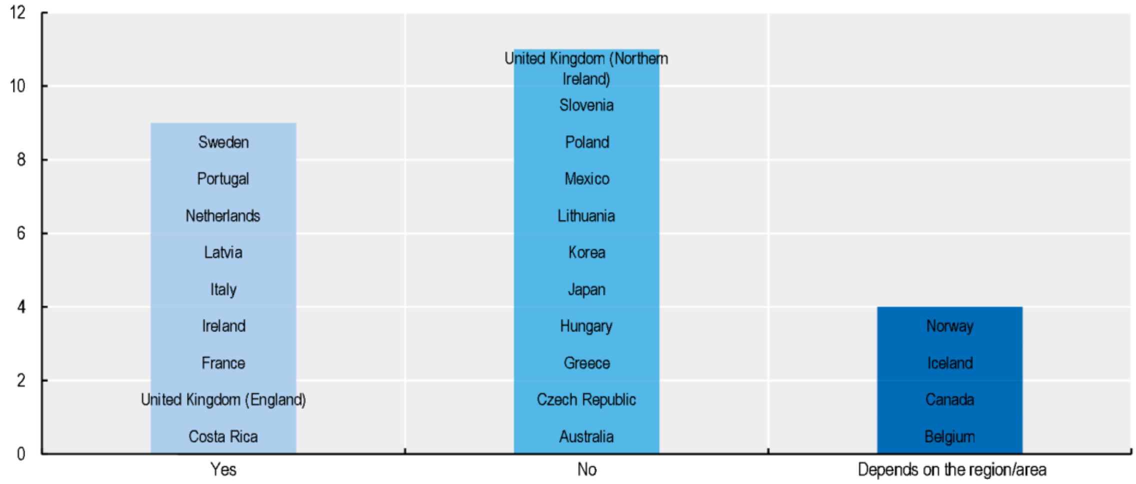
6.2.3. Lack of appropriate data prevents benchmarking

Previous OECD work has shown that health lags far behind other sectors in harnessing the potential of data and digital technology and this is even more so for end-of-life care. Missing data, data fragmentation and an insufficient data infrastructure pose significant barriers to the analysis and integration of data for ongoing quality improvement in palliative care services and precludes the examination of gaps at a system level (Rajaram et al., 2020[9]). Data collection on quality of care and pathways at the end of life linked to cause-specific mortality is limited.

Collecting and sharing timely data is still an underdeveloped practice across OECD countries. Figure 6.2 indicates that an important share of OECD countries surveyed (46%) did not collect EOLC data through specific indicators that were integrated into broader health and social care information systems. Furthermore, four countries (Belgium, Canada, Iceland, and Norway) reported that the collection and integration of data in information systems varied across regions/areas. Only nine countries (Costa Rica, France, Ireland, Italy, Latvia, the Netherlands, Portugal, Sweden, and the United Kingdom (England) reported performing such collection and integration of data.

Figure 6.2. End-of-life care data are not always collected and integrated into health and social care information systems

Countries' answers to the question "Is EOLC data collected through specific indicators and integrated into broader health and social information systems?"

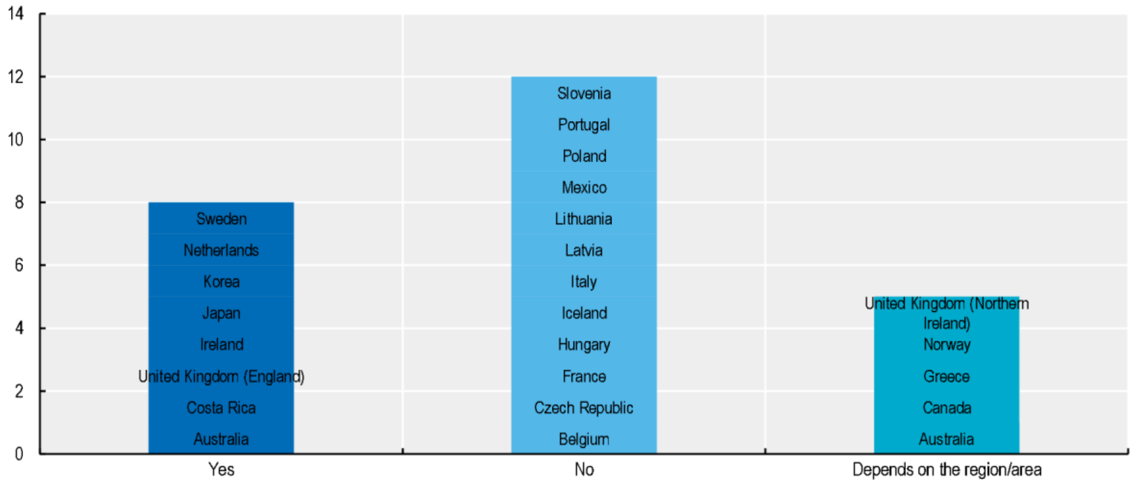


Source: (OECD, 2020-2021[12]).

In a survey of OECD countries, nearly half of the responding countries (12 out of 25) held no system in place to monitor and evaluate palliative care experiences and outcomes such as patient reported outcomes (PROMs) and experiences (PREMs) (Figure 6.3). Eight countries (Australia, Costa Rica, Ireland, Japan, Korea, the Netherlands, Sweden, and the United Kingdom – England) reported having some system in place and five countries (Australia, Canada, Greece, Norway, the United Kingdom – Northern Ireland) reported that the existence of such systems may vary across regions/areas. For instance, in Belgium, only very little information is collected on end-of-life care. The Flemish community only collects indicators on the place of death and the presence of Advance Care Planning (ACP – see Chapter 3 for definition), and only in nursing homes (OECD, 2020-2021[12]). Canada has no national standardised system for collecting indicators on EOLC and when such indicators exist, there is variability about the extent to which they are integrated into broader health and social information systems (OECD, 2020-2021[12]). Nevertheless, the Canadian Institute for Health Information (CIHI) has compiled the available information on access to palliative care in Canada in its latest report on the topic (Canadian Institute for Health Information, 2018[43]). Japan has two surveys which are undertaken every few years and target people who have experienced cancer or bereaved families of people who have died from cancer, but they do not use established evaluation indicators nor validated PROMs or PREMs. Nevertheless, they serve as useful surveys to capture the experience of families at end of life.

Figure 6.3. Nearly half of OECD countries report a lack of systems to monitor and evaluate palliative care experiences and outcomes

Countries' answers to the question "Do you have systems of monitoring and evaluation of palliative care experiences and outcomes?"



Source: (OECD, 2020-2021[12]).

Countries reported severe data constraints when attempting to collect data on hospitalisation at the end of life for the OECD pilot data collection on end-of-life care. The lack of interlinked data hampered the collection of many indicators as it is possible to look at hospital admissions but not necessarily for those who died within a given period. As an example, Belgium is not able to follow up with patients after they leave the hospital, while Germany reported not being able to link databases as needed. Data on medication used at the end of life and on the length of stay in palliative care programs were the least available across countries. The OECD National Health Data Infrastructure and Governance survey conducted in 2020-21 highlights that 12 out of the 23 respondent countries claim to not use data linkage at all or in less than 60% of their databases for the same purpose (Oderkirk, 2021[44]).

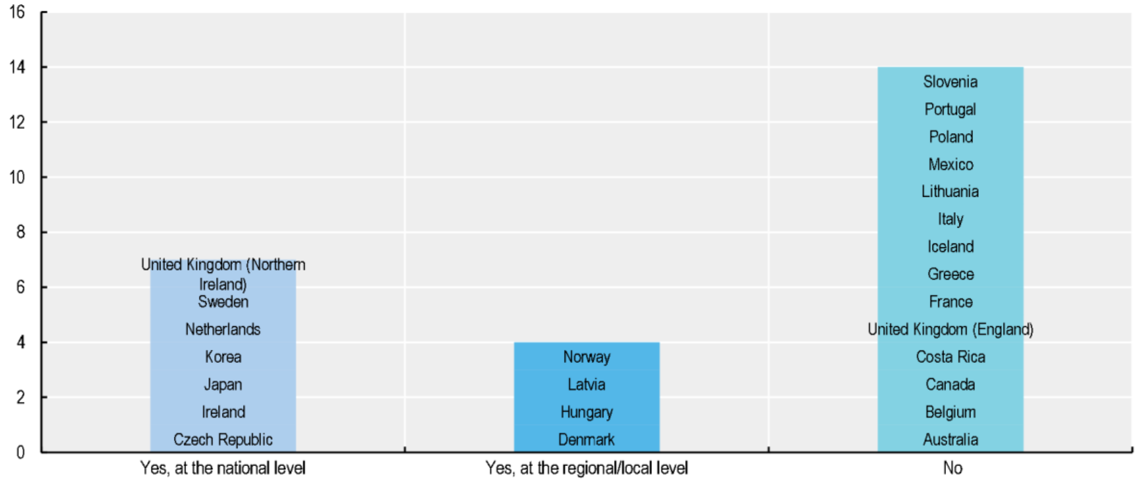
Without reliable indicators and its monitoring, it remains challenging to provide information on the progress of end-of-life care within a country as well as to benchmark countries internationally. Indicators can inform decision-makers about the gaps and challenges in care provision and can be used to decide resource allocation and strengthening activities. With the absence of such indicators, it is challenging for countries to establish baselines, as is currently the case.

6.2.4. Weak research generates information gaps and can hinder adequate policy making

A research agenda in end-of-life care remains rare: most surveyed OECD countries (14 out of 25) do not possess a research agenda for EOLC at the national, regional, or local level. Such agenda would help provide strategic direction on how effort and resources will be focused and provide research priorities. It would encompass research on different areas such as mental health service improvement, pharmaceutical development, biomedical research, or other areas related to EOLC (Figure 6.4). Less than 30% of surveyed countries (Czech Republic, Ireland, Japan, Korea, the Netherlands, Sweden, and the United Kingdom (Northern Ireland) possess a research agenda at the national level, while 16% of countries have developed research agendas (Denmark, Hungary, Latvia, Norway) at the local level. In Canada, despite the Framework on Palliative Care recognising research on this topic as a priority, no national research agenda for EOLC exists. Nevertheless, the Canadian Institutes of Health Research provides funding for palliative care research (OECD, 2020-2021[12]).

Figure 6.4. Most countries report having no end-of-life care research agenda

Countries' answer to the question "Do you have a national research agenda for EOLC?"



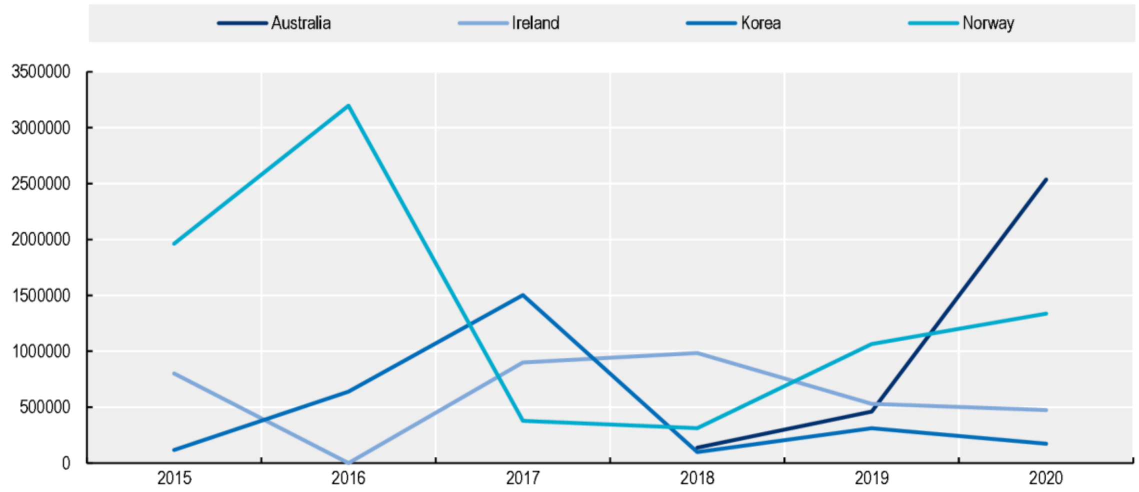
Source: (OECD, 2020-2021[12]).

In several countries, research on end-of-life care is underfunded and remains limited, compared with studies into the prevention and cure of life-limiting conditions. In the United Kingdom, despite the high number of publications compared to other European countries, less than 0.3% of the GBP 500 million spent on cancer research in the United Kingdom is allocated to palliative care. Funding for non-cancer conditions is likely to be even less (Higginson, 2016[10]). Similarly, in the United States, a study reported that from 2011 to 2015, the 461 grants related to palliative care research awarded by the NIH in the United States represented 0.2% of total NIH research awards (Brown, Morrison and Gelfman, 2018[45]). Three NIH institutes – the National Cancer Institute, the National Institute for Nursing Research, and the National Institute on Aging – accounted for 80.2% of all awards distributed for palliative care in the United States (Brown, Morrison and Gelfman, 2018[45]). Aldridge et al. point out that the limited investment in palliative care research may be attributable to there being no federal agency specifically charged with a focus on palliative care and on persons with serious illness, with NIH institutes being largely disease-specific (Aldridge et al., 2016[46]).

Among the OECD countries for which data was available, public funding for EOLC/palliative care research seems to have fluctuated in recent years. The investment increased in the years following the World Health Organization's (WHO) first-ever resolution to integrate palliative care into national health services, policies, budgets, and health care education, in May 2014. In particular, public funding in Norway recorded a peak in 2014 (USD 3.6 million in PPP), in Korea in 2017 (USD 1.5 million in PPP) and in Ireland in 2019 (USD 1 million in PPP). Funding has since then decreased in many countries. One exception is Australia, whose data are only available for 2018-20, and for which public funding for research in EOLC/palliative care grew in those years (Figure 6.5).

Figure 6.5. Public funding for end-of-life/palliative care researched fluctuated in recent years

Public spending to fund end-of-life care/palliative care research projects, in million USD (PPP)

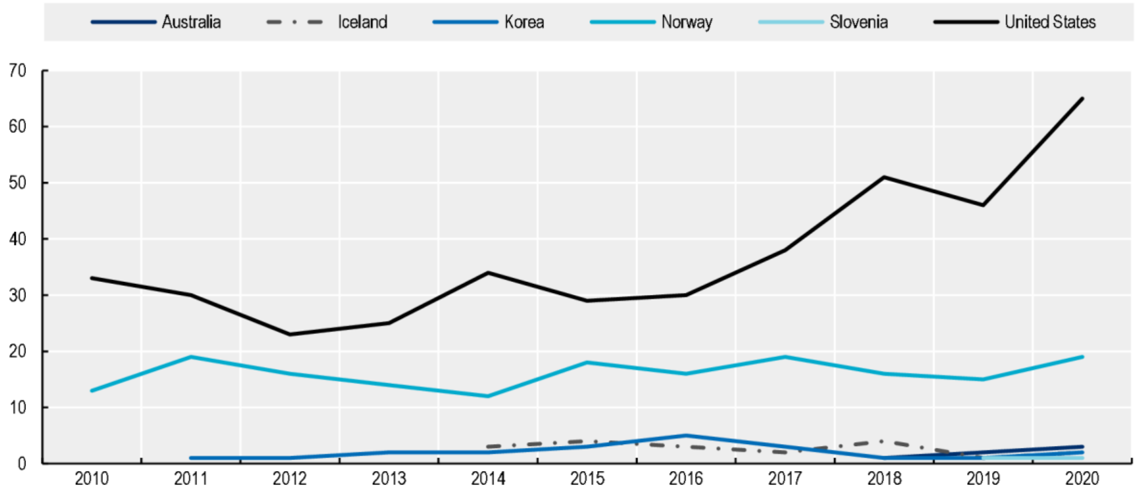


Source: (OECD, 2020-2021[12]).

Together with the magnitude of public funding, the number of publicly funded research projects is also an indication of amount of research dedicated to these topics. Among the OECD countries that provided data, the United States undertook by far the highest number of publicly-funded research projects reaching 65 projects in 2020 – a number that has increased over time. The number of projects as well as the amount of public funding remains small in this area compared with other health research topics. In comparison, there were 630 research grants in the United States as of mid-2021 for cancer (American Cancer Society, 2021[47]). In other OECD countries, the number of projects remains limited and has been stable or it has decreased. In 2020, Norway funded 19 projects, while Australia, Iceland, Korea, and Slovenia had either 1 or 2 public funded research projects on the topic (Figure 6.6). According to an analysis by the European Association for Palliative Care, the number of scientific publications on palliative care between 2015 and 2018 varied widely across European countries. The United Kingdom recorded the highest number (2 448 publications), followed by Germany (1 153), France (814), Italy (698), the Netherlands (650) and Spain (627). Central and Eastern European countries recorded the lowest levels, with fewer than 10 publications across the three years analysed (Arias-Casais N, 2019[39]).

Figure 6.6. The number of publicly funded projects varies widely across OECD countries

Annual number of publicly funded end-of-life care/palliative care research projects



Source: (OECD, 2020-2021[12]).

Experts point to significant research gaps in palliative and end-of-life care and a weak and inconsistent evidence base, as a result of lack of prioritisation and underfunding (Evans, Harding and Higginson, 2013[5]). There are methodological gaps, as studies remain observational instead of based on evaluation and there only a small number of clinical trials have been conducted (Sonja McIlfatrick, 2018[48]). A systematic review of the literature found that gaps in research study design were present in 40% of the papers, with a lack of studies following people over time, pointing to the need to improve recruitment of study participants and use of randomisation (Antonacci et al., 2020[49]). Palliative care has historically faced problems conducting study designs like randomised control trials due to the ethical complications and the quality of studies is often low (Clark, Gardiner and Barnes, 2020[50]). Similarly, because of ethical and medical challenges, studies are more often focused on providers rather than highlighting the views and experiences of patients (Hasson et al., 2020[51]).

Research in end-of-life care is also predominantly disease-specific, while there is a lack of evidence on some socio-demographic groups. Study design includes less often those with chronic conditions and people living with multi-morbidity or the 'oldest-old' (people 80 or above). Research related to experiences and practices of end-of life care in long-term care facilities and hospices is lacking, with much research hospital-based (Antonacci et al., 2020[49]). Interviewed experts also point out to research on cancer, followed by dementia, while research on other diseases at the end of life is rarer. As an example, in 2018 in the United Kingdom, Cancer and Neoplasms were the second most funded area of health research, after the research on generic health relevance. Research on cardiovascular diseases, respiratory, renal, and urogenital diseases, which are also likely to require end-of-life care, was much smaller and represented less than one-third of the expenditure on cancer research (Mikulic, 2020[52]).

Additionally, there is a lack of strong evidence for important topics highlighting the appropriateness and affordability of care. Gaps in research evidence exists in appropriate timing of introduction of palliative care, and innovative models for delivering care such as how services should be delivered, particularly outside hospitals (Philip and Collins, 2020[53]). Further gaps in knowledge can be found in the provision of culturally sensitive care, with a lack of culturally appropriate services meaning those at the end of life from diverse cultural backgrounds may feel uncomfortable with current palliative services or feel dissuaded from using or accessing end-of-life care entirely (Antonacci et al., 2020[49]). Related to that, reasons for inequalities in access and policies to promote equitable access to care depending on the location and socio-economic or cultural group remain poorly documented and understood (Hasson et al., 2020[51]). Understanding grief and bereavement and support and needs of carers is also another area for which more research is needed (Antonacci et al., 2020[49]). Overall, there is a lack of research on cost-effectiveness and evaluation of interventions.

6.3. What policies are being pursued to ensure care is well-governed and evidence-based?

6.3.1. Promotion of end-of-life care expertise in community settings and the use of technology can make end-of-life care systems more adaptable

It is important for end-of-life care services to respond rapidly. This requires ensuring that adapted protocols for symptom management are available, shift more resources into the community (including to non-specialists), and use technology to communicate with patients and carers (Etkind et al., 2020[54])

Integrating end-of-life care into pandemic and crisis planning would be crucial to avoid shortages and poor quality of care. In the future, to ensure better preparedness, it would be paramount to include EOLC experts in task forces and decision-making during emergencies in facilities to allow the prioritisation of the needs of people at the end of life. This strategy, together with establishing palliative care guidelines and protocols on the provision of EOLC during emergencies would ensure more expertise on this topic in different care settings. Several countries have already moved in that direction. Some countries issued specific guidelines on end-of-life care, while others included end of life care and palliative care within broader guidelines or guidelines for long-term care. Luxembourg published specific guidelines on providing EOLC during the pandemic and Ireland published information around the transfer of people at the end of life across settings of care, provided information around the supportive therapies for COVID-19 patients at the end of life and around ACP in residential settings (Rocard, Sillitti and Llena-Nozal, 2021[11]). In the United Kingdom (England) already in April 2020 guidelines highlighted that palliative care support should be made available where appropriate and in collaboration with relevant health and social care providers (Adelina Comas-Herrera, 2020[24]). In the United States, the CDC also developed recommendations and resources for people with serious illness and their relatives, as well as for clinicians to support them in providing the right end-of-life care. Care settings-specific guidance was also available (Adelina Comas-Herrera, 2020[24]). In Canada, general guidelines on COVID-19 included considering the potential increase in demand of EOLC services. Guidelines advised, among other measures, to prioritise community support for people at the end of life, when possible, to reduce exposure to COVID-19 (OECD, 2020-2021[12]). In 2021, Canada also published a report summarising the effects that the pandemic had on end-of-life care, the lessons learnt, and successful measures put in practice to minimise end-of-life care services disruption (Health Canada, Healthcare Excellence, CPAC, CHCA, 2021[55]). Belgium and France included measures to ensure the provision of palliative care within the guidelines on the care and support for older people during the COVID-19 crisis (Government of France, 2020[56]), while Norway included a section on palliative care among general COVID-19 guidelines (Helsedirektoratet, 2020[57]).

Improving the use of advance care planning (ACP) and improving the availability of specific supplies in different care settings would allow carers to be better prepared for such events (Santé publique, 2020[19]). The pandemic heightened the importance of having conversations around preferences recorded in the form of ACP and having a surrogate decision-maker in the event of rapid deterioration of prognosis, bleak prospects for recovery and transfer across care settings. The United Kingdom (England) published specific guidelines for children and young people with end-of-life care needs, who were cared for in a community setting, as well as clinical guidance for supporting compassionate visiting arrangements for those receiving care at the end of life. Guidance on verification of death in times of emergency and ACP were also issued during the pandemic (OECD, 2020-2021[12]). Innovations to promote the use of ACP have also taken place at a small scale during the pandemic, which could be implemented more widely. For instance, in the

United States, a pilot was performed coupling a highly trained palliative care hospice staff with staff from primary care and resulted in a great outreach for the completion of ACP after one single discussion (Gessling et al., 2021[58])

The COVID-19 pandemic has accelerated the recognition that all people working in health services should be competent in supporting those dying and their families. To preserve continuity of care, it is important to conduct rapid training and find better ways of integrating specialist expertise within primary and community settings which can respond swiftly to increased needs and reduce disparities in access. Nursing homes would also need to ensure the availability of palliative care advice. Enhanced palliative care and end-of-life care provided at home or in a home-like setting requires training of primary care professionals and likely a stronger development of hospital at home approaches, as an alternative to hospital admission or as step-down care after a hospital stay with sufficient medical supplies for symptom management and staffing. In this sense, Belgium recommends the implementation of a middle care level of palliative services for those no longer requiring hospitalisation but not yet well enough to stay at home or in a nursing home (Service public fédéral, 2020[21]). In the United States, a project piloted at hospitals in collaboration with the Center to Advance Palliative Care, is developing an online platform to provide specialist palliative care remotely, while simultaneously developing training for generalist palliative care to be given to individuals within a given hospital system (Blinderman et al., 2020[59]). Luxembourg made further efforts to ensure that people in need of EOLC could receive adequate care at home, without being hospitalised, when possible. People dying at home or in nursing homes had emergency access to a medication kit containing morphine and other EOL medication to give comfort at the end of their life. They could also have emergency access to oxygen therapy at home and in nursing homes, even at night and during the weekends. Oxygen extractors were distributed upon request within 3 hours between April 2020 and March 2021, within 12 hours between April 2021 and March 2022 and within one day since then. Canada also developed the use of palliative symptom management kits, which could be kept in community health care providers or at patients' homes (Health Canada, Healthcare Excellence, CPAC, CHCA, 2021[55]). In July 2020 Italy increased investment in home care to improve the availability of palliative care at home. The investment specifically aims at ensuring adequate home care services across all regions to reduce regional disparities in the access to care.

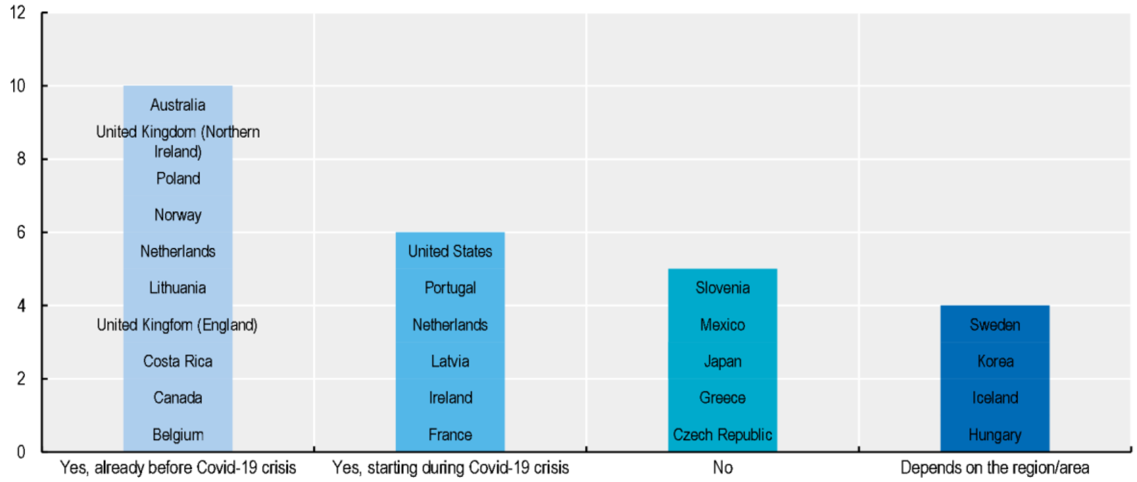
Wider availability of training would help sharing the expertise on EOLC among different care workers. The Swedish Register of Palliative Care (SRPC) developed knowledge support to respond to the pandemic. It produced a checklist of medicines that were widely distributed free of charge to municipalities and regions to minimise the disruption to the provision of EOLC during the crisis. Canada provided training on evaluating respiratory distress to care teams including a set of professionals (physicians, pharmacists, and nurses) (Health Canada, Healthcare Excellence, CPAC, CHCA, 2021[55]). The National Board of Health and Welfare (NBHW) also supported and shared knowledge during the crisis, for instance through the publication of Q&As for health care professionals (OECD interviews, 2021). Slovenia activated a telephone counselling service to provide health care workers with adequate information around the use of palliative care services (Rocard, Sillitti and Llena-Nozal, 2021[11]). The University of Chile provided free access to palliative care training to all health care professionals during the pandemic (Universidad de Chile, 2020[60]). Several countries have started to develop online training. In Canada, Pallium Canada offered learning modules and webinars – the Learning Essential Approaches to Palliative Care – targeting health care practitioners providing EOLC during the pandemic. The training fees were waived for six months, and the training targeted all health care providers, reaching 11 000 registrations (Pallium Canada, 2021[61]). In Norway, in September 2020, the National Competence Service for Aging and Health published a new free e-learning course on palliative care for the older people and seriously ill people with COVID-19. The training is open to all health care workers at the municipal level and touches upon the symptom supporting, clinical observations to identify health deterioration and palliative care (National Competence Service for Aging and Health, 2020[62]). Portugal is planning to make online courses on palliative care available for all health care staff before the end of 2022.

In addition to supporting health care professionals, some countries also developed support for informal caregivers and people living with serious illness and reaching the end of their life. Austria developed telephone hotlines, online support networks, guidance, and resources, while the Austrian Red Cross offered online courses for informal caregivers (LTCCOVID, 2020[63]). Canada provided online resources for grief and bereavement support to caregivers and family members and France provided psychological support to patients and their families (Government of Canada, 2020[64]; Government of France, 2020[56]). The United Kingdom provided tips on mental well-being together with information on where to seek psychological support, while in the United States the CDC published recommendations for people living with serious illnesses and their caregivers (Adelina Comas-Herrera, 2020[24]; Department of Health and Social Care, 2020[65]).

The use of technology at the end of life could be further explored to improve co-ordination of care and care continuity, reduce the movement of patients across settings of care and ensure good communication between patients and their relatives during emergencies. Good use of technology can simplify access to end-of-life care by allowing the sharing of documents across service providers and between patients and clinicians. During the pandemic, technology has led to reducing the movement of people at the end of life across care settings, facilitating the use of care at home or in nursing homes. Finally, the use of technology facilitated contacts between patients and their relatives, who were not always able to access care facilities. Of the 25 OECD countries surveyed (Figure 6.7), 10 (40%) indicated they used digital technology to make EOLC services more accessible prior to COVID-19 pandemic, for instance to receive medical advice in video call, connect patients and family via digital devices, or access documents and medical records online, while 6 countries (24%) made it available during the COVID-19 crisis. 5 (20%) have not made any use of digital technology.

Figure 6.7. Since the COVID-19 pandemic, most OECD countries use technology to improve accessibility of end-of-life care services

Countries' answers to the question "Does your country make use of digital technology to make EOLC services more accessible?"



Source: (OECD, 2020-2021[12]).

Some countries used technology prior the pandemic, but its further development boosted the use of teleconsultations and ensured contacts between patients in care facilities and their relatives. This was the case of Belgium, which used technology to ensure accessible EOLC services already prior to the COVID-19 pandemic, but this use accelerated during the pandemic. Nevertheless, the use of technology is not yet regulated by a legal framework, except for access to medical records (OECD, 2020-2021[12]). In Canada, the Ontario Telemedicine Network is part of a government agency and provides virtual palliative care. It consists of the provision of palliative care services at home to minimise the movement of people at the end of life across settings of care. Among the services provided, people can receive virtual visits with doctors, mental health coaching and short training on symptom monitoring. People are also provided with easy-to-use health kit and will be assigned a nurse to virtually keep in touch with (OTN, 2021[66]). In the United States, prior to the COVID-19 crisis digital technology was used for EOLC, however the COVID-19 pandemic has led to changes in the use of telehealth services. The Centres for Medicare and Medicaid Services has provided Medicare hospices flexibilities in telehealth and telecommunications technology during the public health emergency. Hospice providers can provide services to a Medicare patient receiving routine home care through telecommunications technology, while face-to-face encounters for purposes of patient recertification for the Medicare hospice benefit are conducted via telehealth means (Nakagawa et al., 2020[67]). Moreover, Sweden is currently developing some self-monitoring tools (e.g. monitoring weight and exhalation). The project is still in the experimental stage (OECD interview, 2021). Online bereavement support groups may also assist grieving family members (Fadul, Elsayem and Bruera, 2020[25]).

In recent years, and particularly during the pandemic, there has been increasing interest towards the use of Artificial Intelligence (AI) in health care broadly, including EOLC. The potential of AI to predict clinical outcomes was already explored back in 2018 (Rajkomar et al., 2018[68]), but the COVID-19 crisis has boosted the use of AI as a diagnostic tool and an epidemiological instrument. As an example, the COVID-19 detection neural network (COVNet) is a tool used to diagnose COVID-19, which demonstrated accurate and able to distinguish COVID-19 from other lung conditions and pneumonia (Li et al., 2020[69]) (Kedia, Anjum and Katarya, 2021[70]). To what extent AI can be applied to support diagnoses and health care provision is still under analysis. Nevertheless, examples of the use of AI to support clinicians to predict when a person is reaching the end of life already exist. In fact, recognising when a patient is dying and starting a conversation around death and dying at the right time often represents a challenging task for clinicians. In the United States, the Stanford University hospital, the University of Pennsylvania, and a community oncology practice in Seattle are using AI to scan patients' medical records and notify health care workers when a patient is likely to die within a year. This tool allows clinicians to start conversations around death and care planning while the patient is still able to understand their health status and express care preferences (Robbins, 2020[71]).

6.3.2. Information-sharing and case management can contribute to seamless transitions and more integrated care

People receiving integrated EOLC appear to be more likely to die where they wish, to initiate palliative care earlier on, to receive less acute care and to experience better quality of the dying process (Groenewoud et al., 2021[72]; Vanbutsele et al., 2020[73]). Improving care co-ordination at the end of life involves, in part, policies to enhance information sharing, the use of case management or other innovative models to enhance integration which are detailed below.

Poor communication and information sharing between services is a barrier to achieving high-quality care at home, especially due to out-of-hours professionals not having full-records (Standing et al., 2020[74]). In turn, increased communication and collaboration across service providers can lead to earlier detection of EOLC needs, avoiding unnecessary acute treatments at the end of life (Groenewoud et al., 2021[72]). Part of information sharing starts with guidelines to standardise forms, clinical documentation, and assessment tools. A review of the evidence from the National Institute for Health and Care Excellence established that low-cost methods of information sharing, such as patient held records, would be likely to reduce costs by reducing the duplication of tasks by numerous health care professionals (NICE, 2019[75]). Results from the survey conducted on OECD countries indicate that of the 23 countries which responded, 64% (16) had a system of secure electronic note sharing for EOLC at national, regional, or local level (OECD, 2020-2021[12]).

Shared electronic systems or electronic notes sharing helps can help ensure continuity of information for professionals delivering care. Among the countries where electronic notes sharing is in place, Australia has national data on the activity and characteristics of palliative care services, which is collated in the Australian Institute of Health and Welfare's (AIHW's) *Palliative Care Services in Australia* online web report (Australian Institute of Health and Welfare, 2021[76]). Additionally, Australia has a national digital health record system called "My health record", where information about the patient can be uploaded and shared across the health care system. The system is not specific for EOLC, but some features that can be particularly useful for people reaching the end of their life, such as the possibility to upload ACP and to nominate a person close to the patient who can help manage the digital records. The system is still voluntary, thus there is no full coverage of the population (OECD, 2020-2021[12]). Costa Rica has the Unique Digital Health Record (EDUS), at public health care facilities, where all care services received by the patient can be shown, including the control of pain and symptoms (OECD, 2020-2021[12]). In the United Kingdom, the Electronic Palliative care Co-ordinating Systems (EPaCCSs) provides several different electronic solutions that aim to capture patient wishes and preferred place of death and improve co-ordination of care in real time, through enabling the sharing of information across health and social care services. Other countries are making efforts to develop electronic notes sharing, such us the Netherlands. A current project in the Netherlands is aiming to achieve four main goals: i) strengthening integrated health care delivery across settings and sectors; ii) enabling comprehensive public health monitoring and management; iii) capitalising on recent innovations in health information infrastructure and iv) fostering research and innovation in technologies and treatments that improve health and health care (OECD, 2022[77]). Norway collects data on the use of drugs by prescription, with the National Prescription Drug Registry (NorPD) able to breakdown data by gender, age, and geography (Norwegian Institute of Public Health (NIPH), 2021[78]). There has also been discussion around creating one comprehensive medical record per patient, merging different registries, but no practical change has taken place yet (OECD interview, 2021).

A meta-analysis highlight that the best practice model for palliative care includes case management which requires co-ordination of services beyond the health care sector, including social services and pastoral care. This would involve the integration of specialist palliative care with primary and community care services, and enable transitions across settings, including residential aged care. Such a model was associated with significantly reduced time in hospital and caregiver burden (Luckett et al., 2014[79]). Intermediate palliative care is provided as an alternative to hospital admission or as step-down care after a hospital stay and can be provided at home or in dedicated intermediate care beds in community hospitals or care homes: it is often referred to as hospital at home. Intermediate palliative care at home was associated with increased odds of dying at home and reduced symptom burden (IHUB, 2019[80]).

Many countries also developing innovative solutions such as care networks to promote care integration across care settings. In Belgium, mobile units from hospitals act as a liaison between the hospital and home organising discharges from hospitals and contacting primary and secondary teams for the patient. The country has also introduced an initiative to transfer knowledge on EOLC across professionals. Palliative care physicians and home care physicians meet with four other colleagues without a specialised background on EOLC, to organise peer education sessions and spread professional knowledge around the topic. Since 2010, Italy provides palliative care through networks of palliative care (Reti locali cure palliative and reti regionali cure palliative). They consist of networks of palliative care providers that communicate and co-ordinate to ensure that patients have adequate palliative care that is people centred, integrated and available to everyone who needs it. Professionals are regularly trained and provide care according to an integrated and multiprofessional patient pathway (Ministry of Health - Italy, 2021[81]). In Italy, a model of clinical governance for the development of Palliative Care Local Networks was developed and piloted for the development of integrated pathways for people in need of palliative care (Fondazione

G. Berlucchi & Fondazione Floriani, 2015[82]).In Sweden there is an integrated care programme for people in need of EOLC regardless how close they are to the end of their life. The programme aims to integrate palliative care in the treatment of diseases as early as possible. It is developed in the framework of the co-operation with Regional Cancer Centres (RCC) and the Sweden's Municipalities and Regions (SKR) (Swedish Palliative Care Register, 2020[83]).

OECD countries are also putting in place further efforts to improve the integration of palliative care across different government departments and with primary care. In Australia, several measures are currently in place to improve integration on the provision of end-of-life care. The National Palliative Care Strategy (2018) included a specific goal related to governance, which aims at developing a governance structure under the Australian Health Ministers' Advisory Council, involving all state and territory governments and the national Australian Government working together. Moreover, the Greater Choice for At Home Palliative Care (GCfAHPC) measure provides funding to improve the integration of palliative care provision across Primary Health Networks (PHNs). The initiative aims at improving the co-ordination across health services, developing a system that allows early referrals to palliative care and strengthening the community support for people's relatives. It also aims at providing resources to local communities and work with local providers to ensure the availability of home-based palliative care to meet the communities' needs for palliative care. The pilot was introduced in 2017 across 11 (out of a total of 31) PHNs that were selected to participate. From 1st of July 2021 all PHNs received funding to co-ordinate palliative care activities in their regions (Australian Government, 2021[84]). In Northern Ireland, the Palliative Care in Partnership (PCIP) programme aims to provide a single direction and regional work plan for the continuing improvement of palliative and EOLC across all care settings. PCiP aims to ensure that people who would benefit from a palliative care approach have the same opportunity for support and service regardless of where they live or what life limiting condition they have been diagnosed with, with recent focus on improving EOLC initiatives across the government departments.

A systematic review of the evidence indicates a clinically important benefit of a care co-ordinator in reducing the use of community services, hospital and ICU admissions and visits, visits to accident and emergency and death in hospital (NICE, 2019[75]). For instance, in Ireland, a palliative care nurse liaison to ensure that the discharge plan is in place prior to discharge, establishes links with the primary care team and undertakes a follow up visit, if deemed necessary (Department of Health, Social Services and Public Safety, 2010[85]). Lincolnshire, in England (United Kingdom), established the Palliative Care Co-ordination Centre (PCCC) to co-ordinate the provision of community care for people nearing their end of life. It centralised the co-ordinating the booking of community care for patients nearing the end of their lives. The PCCC improved care co-ordination while also reducing the burden of work of nurses, by taking up administrative tasks (King's Fund, 2011[86]).

6.3.3. Linking data and designing appropriate indicators should enhance monitoring

To ensure high quality EOLC is provided to those in need, it is paramount to improve data-quality and availability. EOLC indicators require linkages across mortality data registries and data on care provision (e.g. settings of care, enrolment in palliative care programs, pharmaceuticals). Several institutional barriers including poor institutional arrangements and governance models currently undermine the linkage and the sharing of data among public authorities. Only 16 countries have mortality data containing an identification number which could be used to link datasets and 10 countries (Australia, Austria, Czech Republic, Finland, Israel, Korea, Latvia, the Netherlands, Slovenia, the United States) regularly link health care data to mortality data (Oderkirk, 2021[44]).Comprehensive health data governance with legislation and policies that allow health data to be linked and accessed can help harness the potential of data in end-of-life care. Experts also highlighted the need to build expertise in the field of safe data linkage techniques and looking at opportunities to gather other data sets (Davies et al., 2016[7]).

Certain countries have moved forward in linking data or undertaking surveys on this topic. Scandinavian countries, in particular, make widespread use of shared unique identifiers, strong collaboration between data holding bodies, an established legal basis for the collection and use of data, and broad public approval for the use of linked administrative data (Davies et al., 2016[7]). Australia developed the Australian Palliative Care Outcomes Collaborative (PCOC), which comprises data on specialist palliative care. Australia has further focused on data development and created a Palliative Care and End of Life Care Data Development working group to improve EOLC data collection and development. Experts from Korea reported the existence of a web-based system to monitor basic information on terminally ill patients and the provision of EOLC. Germany has launched the Palli-MONITOR project, which allows people receiving palliative care and their relatives to communicate their physical, psychological, social, and spiritual symptoms to the teams through their smartphone, tablet, or computer, on a weekly basis. As of 2022 the initiative is ongoing and an observational study is planned to evaluate its success (Gemeinsamer Bundesausschuss, 2022[87]). In Japan, surveys on patient experience and surveys reported by bereaved families conducted by National Cancer Centre include questions on palliative care, while in Estonia, it is a legislative requirement to carry out patient experience surveys for every health provider. In the United States, while Government-wide national systems are not in place, the CAHPS® Hospice Survey samples the primary caregivers of deceased hospice patients and covers topics including treatment of symptoms, hospice team communication, caregivers' own experience, and rating of hospice care (Centers for Medicare & Medicaid Services, 2020[88]).

Experts in several countries have highlighted that data on EOLC could be produced using routine data or through information provided via primary care. In Belgium and the Netherlands, to collect a population-based level end-of-life care data across patient groups and care settings, a collaboration was set up with the nationwide Sentinel Network of General Practitioners in both countries, which was followed by Spain and Italy. All participating Sentinel GPs were asked to fill in a short registration form on the care the deceased received in the last phase of life (Van den Block et al., 2013[89]). A similar data collection via a questionnaire sent through GPs was piloted in Australia coupled with data extraction from electronic medical records on medication and investigations and highlighted the feasibility of collecting such data but the need to address the challenge of non-response rate (Ding et al., 2019[90]). Other countries are still underutilising the potential of data. Safe and ethical secondary use of data is often cited as a barrier preventing access to routine data for research.

Monitoring and evaluating end-of-life care using indicators can help to understand effectiveness, performance and determine priorities for improvement (NSQHS, 2021[91]). High data quality and availability require the use of standardised data collection tools and registries but also a discussion on the right indicators to measure good quality outcomes, and a broader range of population-based metrics, such as including the number of hospital admissions towards the end of life. Some countries are still currently working on the development of performance indicators. This is the case of Costa Rica, where the National Center for Pain Control and Palliative Care recently developed indicators and quality standards that are under analysis to be implemented in the future (OECD, 2020-2021[12]). Luxembourg is also planning on reducing avoidable admissions at the end of life for people living in nursing homes since the pandemic and will be monitoring this indicator.

Some countries have already well-established datasets for end-of-life care or indicators. In Sweden, the Swedish Register of Palliative Care is a central source of information with an extensive data collection used by governmental bodies, caregivers, and researchers (OECD interview, 2021). The register was created in 2005 and builds upon a questionnaire on end of life (ELQ) composed by 30 questions. The questionnaire is answered by health care staff after the deaths of the patient and focuses on the care provided in the patient's last week of life (The Swedish Register of Palliative Care, 2021[92]). In Ireland, National Key Performance Indicators (KPIs) are included in the Health Safety and Executive (HSE) Annual Service Plan, while monthly Management Data Reports include accessibility measures (access to specialist inpatient bed and triage in inpatient care or specialist palliative care services within the community or treatment within their home), care standards (multidisciplinary care planning), as well as specialised measures for children's palliative care. In the United Kingdom, since 2013 a team at the Cicely Saunders Institute, King's College London, leads the Atlases of Variation, which helps identify unwarranted variation and assess patient populations and outcomes, as well as service provided, to support improvement (National End of Life Care Intelligence Network (NEoLCIN), 2018[93]). A separate indicator reporting the percentage of deaths with three or more emergency admissions in the last three months of life is used to measure the quality of EOLC services, and how well people are supported in the community (Healthcare Quality Improvement Partnership, 2020[94]). At the local level in England the use of dashboards is promoted to monitor outcomes and inequality.

6.3.4. Making end-of-life care a research priority is critical to address knowledge gaps

Investment in palliative care research is critical to building the evidence base for palliative care integration and securing funding for the expansion of palliative care services across settings (Aldridge et al., 2016[46]). Investment in EOLC research can support informed decision-making, facilitate quality improvement of EOLC services, and foster knowledge-sharing, informing national and international policy making. For instance, patient-reported improvement in breathlessness using an integrated support service has shown the potential to improve patient quality of life and symptom control with no additional health care costs (Higginson et al., 2014[95]), and has attracted interest internationally (Higginson, 2016[10]). A meta-review has demonstrated that some palliative care models may contribute to improvements in quality of care via lower rates of aggressive medicalisation in the last phase of life, accompanied by a reduction in costs (Luta et al., 2021[96]).

There is a need to continue to build capacity in many countries and address barriers to research. Such barriers include in part cultural barriers to discuss death and suffering among study populations. Greater awareness and reducing stigma around death through public campaigns will help to shift attitudes of researchers and the general public on this topic. More importantly, public efforts should also target addressing broader systemic barriers, especially the limited number of funding sources for palliative care, lack of well-trained investigators, as well as institutional capacity (Chen et al., 2014[2]). Moving forward, governments could encourage more research to overcome knowledge gaps which are particularly salient and prioritise funding for research with respect to timeliness of access, models of care and cost-effectiveness.

High quality EOLC research must include an approach that is methodologically sound to advance evidence on what works or not. Unfortunately, conducting the 'gold standard' randomised controlled trials (RCTs) is not always feasible because of the complex multi-morbidity in end-of-life care, difficulties in achieving adequate sample sizes, and high attrition rates. Visser et al. suggests nonetheless that high quality research can be achieved with non-RCT methodologies, but which have equivalent validity and size. This is possible through a pooling of resources and using multiple research tools in combination with a "mixed method" approach (Visser, Hadley and Wee, 2015[97]). Another possibility is the integration of routine assessments into clinical practice and the using clinical administrative databases. Similarly, researchers have suggested strategies to address sampling concerns with the development of a taxonomy to guide clinical trial recruitment but also supplementing this through statistical approaches to deal with missing data and attrition (Aoun and Nekolaichuk, 2014[98]).

Several OECD countries are promoting research in this area through funding and the development of specific research centres.

- In Belgium the government finances one research group from the Free University of Brussels, which focuses on EOLC research. Moreover, in 2009 the Belgian Healthcare Knowledge Centre (KCE research institute) received public funding for research on EOLC (OECD interviews, 2021).
- In Norway, the government does not have a specific fund for EOLC research, but when research funding is obtained from the EU, the Norwegian Government adds one-third of the value to the

grant, to incentivise research. Moreover, the Norwegian Cancer Society plays an important role in research, for instance by supporting the European Research Centre for palliative care (located in Oslo). The Norwegian Government also revises guidelines and national action plans on palliative care every 2 years, to incorporate the latest research results. (OECD interview, 2021).

- The National Institute for Health and Care Research (NIHR), in the United Kingdom, invested 22 million pounds over the past 5 years into EOLC research. The NIHR funded 16 partnerships in 2022 to establish networks and collaborations across the whole country. Furthermore, the Department of Health and Social Care commissioned research, due for publication in late 2022, on assuring quality and reducing inequalities in end-of-life care for people who die at home.

Similarly, the United Kingdom (Northern Ireland), France and the Netherlands have organisations supporting palliative care research.

- The Northern Ireland Palliative Care Research Forum encourages collaboration among palliative care researchers and practitioners to improve research capacity and promote research initiatives and ideas that are relevant, important to service users and stakeholders, and improve practice and service delivery. Ireland has the All Ireland Institute of Hospice & Palliative Care, a collaborative of hospices, health and social care organisations and universities on the island of Ireland. The institute also has a Palliative Care Research Network including leading researchers from partner organisations that focus on palliative care research that has high impact, builds research capacity, and drives collaboration.
- France created the national platform on end-of-life care in 2018, with the aim of improving the quality of research and to foster collaboration and networking among researchers. Since the establishment of the platform, research projects and thesis on end-of-life care have increased in France, with 10 additional projects in the time span of one years, between 2020 and 2021 (Plateforme nationale pour la recherche sur la fin de vie, 2021[99]). France has also included the improvement of EOLC research and the dissemination of resulting evidence in the national plan 2021-24. The plan states the willingness of the ministry to further develop the national platform on end-of-life care and provide it with additional funding (French Ministry of Health, 2022[100]).
- In the Netherlands, ZonMw, supported by the Ministry of Health, Welfare and Sports and the Netherlands Organisation for Scientific Research, designs programmes and funds research and innovation projects. In relation to palliative care, ZonMw supports research on specific themes such as spiritual care; as well as specific communities including the homeless, children, those with a migrant background, people with dementia, as well as those with chronic illnesses, intellectual disabilities, or mental illnesses (ZonMw, 2021[101]).

More importantly, current research remains narrow, not part of broader global health issues and non-transferable to other areas of health. Making it broader could increase its potential for raising policy attention and attracting further funding. Publications remain often confined to specific palliative care journals and outside major publications related to ageing or health systems. In a systematic review of studies, only 11 studies were identified which explicitly took a public health perspective (Clark, Gardiner and Barnes, 2020[50]). While there are some developments of cross-country and international research, no outputs were published in journals which focus specifically on international issues relating to health or ageing more broadly, which fails to give more prominence to the topic. In contrast, in countries where palliative care has been included as part of the Universal Health Care Coverage discourse, such as Costa Rica and Australia, have seen a development in research on this topic (Clark, Gardiner and Barnes, 2020[50]).

More effort is needed to translate scientific results into clinical practice as evidence is not always incorporated into routine care. For instance, anticholinergic medications have been used for the treatment of excessive respiratory secretions or “the death rattle” at the end of life, despite a lack of available evidence of their efficacy (van Esch et al., 2018[102]). Information gaps influence both treatment choices and policy making because of lack of awareness about the benefits of palliative care in general and of specific interventions. There is thus a need for better sharing research findings with key stakeholders and practitioners. Evidence from stakeholder engagement and knowledge exchange process in Scotland, for instance, suggest that it can lead to promote ownership of research and increased use of research-based evidence in professional settings (Finucane et al., 2021[103]). Another interesting approach from the United States is the use of research-to-practice consensus workshops to generate collaborative research agenda between providers and researchers (Pillemer et al., 2015[104]).

6.4. Conclusions

The governance of end-of-life care shows room for improvement in many countries. Highly fragmented systems hinder people's end-of-life experience, and the COVID-19 crisis has shed a light on the poor adaptability of end-of-life care services to shocks. Considering the experience with the COVID-19 crisis, countries have the opportunity to take action today to strengthen the governance of end-of-life care and make it more evidence-based. Improving the governance of end-of-life care increasing care integration, promoting EOLC in community settings and improving the use of technology for the provision of EOLC services can be the first steps that countries can undertake to move towards EOLC services that are more adaptable to shocks.

Sound policies in EOLC would require a strong evidence base, yet research on end-of-life care is poor and data is fragmented, generating information gaps. In view of future emergencies that are expected to affect the health care systems directly or indirectly, countries should strengthen the evidence base of end-of-life care by making end-of-life care a priority in the research agenda and improving the availability and linkages of data.

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Note

[1] This report conceptualises end-of-life care as the care provided to people who are in the last 12 months of life. It refers to the terminal stage of palliative care, as well as including some elements of curative care and help with mobility limitations. Chapter 1 of this report provides a more detailed definition of EOLC.

OECD Health Policy Studies

Time for Better Care at the End of Life

With more chronic conditions and an ageing population, a growing share of the population will need end-of-life care, reaching close to 10 million people by 2050. While end-of-life care services help improve quality of life through relieving pain and other symptoms, currently, there are substantial gaps in the provision of services. More than half of deaths still occur in hospital across OECD countries, despite home generally being the preferred place of death, because of lack of appropriate services and poor care co-ordination. There are marked inequalities in access with people from higher education twice as likely to receive end-of-life care services than those with low education. Planning, recording of wishes and shared decision-making fall short of what is desirable, with only one-quarter of wishes being recorded in the form of advance directives. People at the end of life do not always receive appropriate symptom relief, while others suffer from overtreatment. This report suggests avenues to improve care for the dying by enhancing measurement and monitoring of quality and rethinking funding and governance models of care. End-of-life care could also be improved by increasing knowledge among health care staff across different care settings, and making communication around the topic more person-centred.

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