# Barriers and facilitators in providing palliative and end of life care in prison settings: A qualitative study of professional stakeholders' views and experiences in six Western countries

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*On behalf of the EAPC Task Force on Palliative Care for People in Prison*

## Abstract

**Background**

Increasing numbers of people require PEOLC within prison settings, mainly because of ageing populations and increasingly long sentences. There is limited research in this area, but evidence suggests that prisons possess limited resources to provide adequate care for ageing and frail people at the end of life.

**Aim**

The study aimed to explore how palliative and end of life care (PEOLC) is provided in prisons in different countries, and identify factors that facilitate or impede its provision.

**Methods**

A cross-sectional qualitative study using semi-structured interviews was utilised to interview prison and health care staff involved in the organisation and/or delivery of PEOLC to incarcerated adults in six countries. Sampling was purposive and adopted a snowball technique. Data were analysed using framework analysis.

**Findings**

The study provides evidence that numerous barriers exist that can impede the organisation and delivery of PEOLC to people in prison, including barriers at individual, staff, organisation, and regulatory level. Facilitators co-existed alongside the barriers. Similar barriers and facilitators were identified in each country.

**Conclusions**

Despite some good practice, multiple challenges remain in providing the same quality of PEOLC that is available outside prison, and thus those dying in prison continue to be disadvantaged.


## Background

The World Health Organisation (WHO) regards palliative care as a crucial part of health service provision and a "global ethical responsibility," placing emphasis on the need for countries to improve equitable access to palliative care services (WHO, 2024); this means providing palliative care to all who need it, including those in prison.

Prison populations are continuing to rise across the world (McParland et al., 2023), in part because of ageing populations, but also because more people are being imprisoned and given longer sentences than in the past (Handtke et al, 2017), therefore increasing the number of people who live in prison with complex health care needs, chronic illness and those requiring palliative end of life care (PEOLC) in custody (Schaefer et al., 2023; Ashpole, 2023). Approximately 11.5 million people are held in prison or correctional institutions worldwide (Fair & Warmsley, 2024), and there is no indication that the increase in numbers will change in the foreseeable future. Within the United Kingdom (UK) for example, the prison population has risen by 80% in the last 30 years and is currently projected to rise from the current total of 88,000 (April 2025) to over 100,000 by 2029 (Ministry of Justice, 2024). This issue has been exacerbated by higher numbers of older men being committed to prison following historical sexual abuse investigations (Crookes et al., 2022), a trend that has been replicated worldwide (Fair & Warmsley, 2024). The risk of developing a health condition is associated with age, and older people in prison may already have existing chronic and co-

morbid health problems such as COPD, Parkinson's Disease, dementia, and cancer at the time of committal. Prisons therefore face manifold challenges in providing PEOLC (Webb & Smith, 2023).

How people who are incarcerated experience PEOLC and dying in prison has received little research attention despite some increases in empirical literature (Ashpole, 2023). Anecdotal evidence suggests that there are insufficient resources in many prison settings to provide adequate care for those who are ageing and ill, and prison personnel may be struggling to meet the basic care needs of those approaching the end of life. McParland et al (2023) contend that international patterns in custodial care differ, existing on a nexus where clinical guidance, criminal justice and cultural practices inhabit the same space. The arrangements for delivering PEOLC for people in prison usually takes the form of individuals remaining in custody whilst receiving health care from within the prison setting or from specialist community sources or by allowing early release or parole on compassionate grounds (Kaushik & Currin-McCullouch, 2023). However, in terms of compassionate release there are legal and policy variances between and within countries which are often restrictive and underpinned by rigid eligibility criteria (Holland et al., 2021; Kanbergs et al., 2019; Kaushik & Currin-McCullouch, 2023; Turner et al., 2021) with people who are incarcerated often incurring significant legal and practical obstacles in this process (Mulgrew, 2023). Moreover, Maschi et al. (2014) advise that prisons often opt in favour of programmes of care that focus on providing symptom control using a multidisciplinary approach rather than using compassionate release as viable option for the provision of PEOLC.

There is no single strategy or definitive framework to address the challenges associated for arranging and delivering PEOLC for those who are seriously ill and dying in the prison context. The health care afforded to people in prison is expected to be equivalent to that which an individual would receive in a community setting (Johns et al., 2021; Maschi & Richter, 2017). However, there are many additional barriers that people in prison experience in accessing high-quality person-centred care (Ashpole, 2023; Schaefer et al., 2022) that may be considered human rights issues (Johns et al., 2021; Maschi & Richter, 2017). Barriers that have been identified include: social environmental barriers associated with the set-up of prisons and risk averse palliative care provision (Loeb et al., 2014; Saunders, 2022; Peacock et al., 2017); staff training needs; absence of family members (McParland et al., 2023); relationship constraints and conflicting priorities in the setting; inequality; reduced agency of individuals who are incarcerated; negative attitudes and lack of grief support (Correia-Garcia et al., 2024); and the punitive nature of the prison regime itself (Hudson et al., 2019).

Gaps in relevant knowledge about the current situation in prisons still exist in terms of access to and provision of PEOLC in these settings. Several studies have been conducted in individual European countries (Pazart et al., 2018; Turner et al., 2018; Chassagne at al., 2017; Richter & Hostettler, 2017), but a recent scoping review (Gilbert et al., 2024) interrogating models of palliative care delivery for people in prison in high-income countries concluded that further research was required to elicit and address the psychosocial needs of people with life-limiting illnesses in prison. Quality PEOLC within the prison setting has therefore become a wider public health issue (Ashpole, 2023).

A Task Force on palliative care for people in prison in Europe was established in 2017, under the auspices of the European Association for Palliative Care (EAPC), to begin to address gaps in knowledge by undertaking the first international research in this area and share learning between countries. The first part of the Task Force's work was to map the provision of palliative care in seven European countries and Australia (Turner et al, 2021). This paper reports the second part of this work, a qualitative interview study with key professional stakeholders either employed by or providing services to prisons, and explores barriers and facilitators in providing PEOLC to people in custody.

## Methods

**Study design**
A cross-sectional qualitative interview study was designed to elicit the views and experiences of key professional stakeholders active in prisons, including medical and nursing staff, social workers, psychologists, chaplains, prison officers, prison governors and managers, and health care managers. Participants with experience of providing care for people in prison with serious or life-limiting illness were sought.

**Recruitment**
The study was carried out in Australia, Belgium, England, Northern Ireland, Portugal, and Scotland; these countries joined the Task Force and so were self-selecting. Each country aimed to recruit 20 participants, to take part in either individual or group interviews. Participants were sought from purposively selected prisons that were known to house older people and people with serious, life-limiting disease, and those known to have had people die within the institution after protracted illness trajectories. In the participating prisons, permission was sought from management to distribute information about the study to key professional stakeholders external to the prison, who were or had recently been active in their prison. In addition, an existing network of professionals interested in PEOLC in prison, which was established as part of the EAPC Task Force, was used to distribute information about the study, and an invitation to participate was sent to those who met the study inclusion criteria. These were:

- Involvement in the organisation and/or provision of care for people in prison;
- Experience with health care, PEOLC provision or organisation for at least one person in prison;
- Experience no longer than three years prior to interview.

**Data collection**
All participants gave written informed consent to take part in the study. Interviews were planned to last 45-90 minutes and were conducted either individually or in small groups, depending on the preference of the participants. An interview topic guide was used (Appendix 1), and a short demographic questionnaire was completed by each participant. Interviews were conducted either face-to-face, by telephone, or by video call, depending on participant preference, practicalities, and the specific permissions in each country. Interviews were fully transcribed in the local language, in some countries by a professional transcription agency and in others using transcription software such as Sonix.

**Data analysis**

Data analysis was undertaken using a framework method (Gale et al, 2013). The framework for analysis was devised by the research team, based on the study aims and objectives, and consisted of four main frames of analysis with several sub-frames in each (see Appendix 1); this initial framework was developed as the analysis progressed. Qualitative analysis software (NVivo12) was used to organise the data, and all the coding and analysis were done in English by the local research team in each country. Regular international data analysis meetings were held online to discuss the analysis and ensure consistency in coding and interpreting concepts.

**Ethical considerations**

The main ethical issues inherent in the study were around informed consent, anonymity and confidentiality, and the welfare of participants; overall the study was considered to be low risk because it only involved interviews with professional staff, not people in prison themselves or their families. Nevertheless, complex ethical and governance procedures were undertaken in each country to obtain the required permissions from prison and health authorities and organisations; in total, it took 18 months to gain all the necessary approvals, so the interviews began at different time points in the six participating countries.

## Findings

**Characteristics of the sample**

A total of 113 participants took part in 89 individual and group interviews across the six participating countries. The most prevalent age group was 45-54, and most participants (71.7%) were female. Almost three quarters of interviewees (73.5%) worked in the prison; the remaining quarter (26.5%) worked in external organisations, and provided in-reach services to the prison. Table 1 provides further details about the demographic characteristics of the sample.

**Table 1: Participant demographic information**

| | **Australia** | **Belgium** | **England** | **Northern Ireland** | **Portugal** | **Scotland** | **All** |
|---|---|---|---|---|---|---|---|
| **No. of participants** | 18 | 27 | 21 | 16 | 17 | 14 | **113** |
| **Individual interviews** | 18 | 5 | 19 | 12 | 17 | 10 | **81** |
| **Group interviews** | 0 | 4 | 1 | 2 | 0 | 1 | **8** |
| **Most prevalent age group** | 45-54 | 35-44 | 45-54 | 45-54 | 55-64 | 45-54 | **45-54** |
| **Male/Female** | 4/14 | 6/21 | 7/14 | 5/11 | 4/13 | 6/8 | **32/81** |
| **Internal/external to prison** | 18/0 | 25/2 | 9/12 | 6/10 | 17/0 | 8/6 | **83/30** |
| **Medical professional** | 2 | 2 | 4 | 1 | 3 | 2 | **14** |

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|---|---|---|---|---|---|---|---|
| **Nursing professional** | 8 | 21 | 5 | 5 | 5 | 3 | **47** |
| **Allied health/ Social care professional** | 2 | 3 | 0 | 0 | 4 | 0 | **9** |
| **Prison/security staff** | 3 | 1 | 7 | 5 | 2 | 6 | **24** |
| **Prison Director/ Governor** | 1 | 0 | 2 | 1 | 1 | 1 | **6** |
| **Chaplain** | 0 | 0 | 1 | 0 | 0 | 1 | **2** |
| **Other** | 2 | 0 | 2 | 4 | 2 | 1 | **11** |

**Barriers and facilitators**

The study findings centre on barriers to and facilitators in providing PEOLC care in prison settings. These barriers and facilitators operate at multiple levels, in relation to individuals in prison, staff, the prison environment, and at both internal and external regulatory levels. The study findings are presented at these different levels in Table 2, and are illustrated by anonymised extracts of data from across the six countries.

**Table 2: Findings: Barriers and facilitators**

| THEME 1: BARRIERS AND FACILITATORS FOR INCARCERATED INDIVIDUALS | | |
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| **Theme** | **Subtheme** | **Example data extract** |
| Individual barriers | Ageing prison populations bring greater need for care | "There's been a one hundred and fifty percent increase over the last ten years in patients who would be regarded as geriatric, so that in itself brings a need for [palliative care]." (NI09*) |
| | Increase in historical sexual offences | "The majority of our [incarcerated individuals] who have been receiving palliative care are sex offenders and older gentlemen" (SC04). |
| | Behaviour of people in prison | "It can be very, very difficult [to be] compassionate and empathetic, but not fall into being manipulated and used, because [incarcerated individuals] are very good at doing that as well." (SC02) |
| | Separation from family | "If those [incarcerated individuals] are taken to Bruges while their family lives in Ghent, yes, that causes serious problems. Detainees are far away from their families to receive the best care." (BE01) |
| | Family rejection of person in prison | "There is the other side; the family doesn't want them." (PO14) |
| Individual facilitators | Good communication between staff and person in prison | "The relationship with patients for sure is important. And to be honest, our relationship is pretty good with patients. |

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| | | People can usually appreciate that we're there for a good reason and we're not there to enable them to be locked in a cell, you know, we're there to look after them." (NI06) |
| | Informal support from peers | "In the regular cells, most of them also receive help from their fellow residents; there are two or three in a cell and so someone who has difficulty walking, for example, is supported by the others." (BE02) |
| | Formal support from peers | "We have [incarcerated individuals] who are employed as carers for other [incarcerated individuals] and they push wheelchairs and go and collect meals and all that. And that seems a reasonable thing to do. But they can't do intimate and personal care, so they can't toilet." (EN10) |
| THEME 2: STAFF BARRIERS AND FACILITATORS | | |
| Staff barriers | Personal challenges faced by health care staff | "It's a really hard thing mentally for us, I think, because, instinctively, as human beings, someone's dying, you want to provide compassion and comfort. But here there are lines, there's things that are appropriate and things that are not appropriate, and that can be quite hard to navigate sometimes." (AU01) |
| | Cultural barriers | "It sounds crazy I know, but there are prisons […] where staff will not push a wheelchair, you know, a man who is in a wheelchair, for any reason, because 'It's not my job'." (EN11) |
| | Concerns and questions about practice | "Is this going to come back and bite me? [What if] I didn't do the right thing, or if I made the wrong decision?" (AU02) |
| | Lack of knowledge and skills | "We talked about starting a syringe driver and the health care staff said, first ever syringe driver, never done it before; no idea how they would do it." (NI01) |
| | Need for specialists in palliative care | "We have nurses who are specialised in diabetes and wound care; it would be interesting to start a team that focuses on palliative care. They could then be a point of contact if we are confronted with [incarcerated individuals] who have palliative care needs." (BE03) |
| | Lack of staff | "We are not medically trained, so if someone says to us 'I'm having chest pains', we have to rely on trying to get a nurse. And sometimes there's very few nurses within the prison and they finish at eight o'clock at night." (SC02) |

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| Staff facilitators | Access to members of multidisciplinary team | "We have medical assistants, nurses, doctors, psychologists, nutritionists, occupational therapists, physiotherapists, and a series of professional groups that work with these patients." (PO01). |
| | Good working relationships | "Relationships with the local hospital are really good. So they know us. They've, you know, worked with us for a long time and us them." (EN10) |
| | Training for prison staff | "They've had palliative care information now and education, which I think was extremely beneficial for them to understand why they're going [into the cell] again – why they need to unlock the door again. And then that allowed them to also advocate for us to have that door open, to have an extra officer because a door was open, and things like that we needed." (AU03) |
| | Attitudes to people in prison | "I don't judge people; they have already been judged" (EN02) |
| | Compassion amongst staff | "I think that there is a tremendous will on behalf of the staff to deliver something that is appropriate and right for the individual. I think [this is] the biggest enabling factor because the desire is there to make things as good as they can be for that individual in that circumstance" (NI07) |
| | Support of prison leaders | "I actually feel quite supported. In my role, I have my boss and then the Governor, who manages the prison; my boss is the Deputy Governor and I get lots of great support from them." (SC04) |
| THEME 3: ENVIRONMENTAL BARRIERS AND FACILITATORS | | |
| Environmental barriers | Locked doors | "We depend on the security personnel. If, on the advice of a doctor, we have to monitor someone every half hour, we need a guard for that […] to open the door. It is an extra burden to get all this organised." (BE04) |
| | Restricted space in prison cells | "When you have to start putting additional equipment and resources in there, even for nurses to sit with them for a couple of hours, it's not the best place really." (EN05). |
| | Intimidating environment | "[Prison is] a whole different environment. Yeah. I don't know how to put that into words, it's just different […]You have to be a strong individual, I think, to be working in that environment, because you're dealing |

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| | | with people that have got mixed crimes, mixed personalities." (SC06) |
| Environmental facilitators | Flexibility of prison management regarding locked doors | "We eventually did get the permission to leave the door open, so that was reassuring to him. I felt like that was a really nice thing for us to achieve, not just from a health care point of view. It obviously helped us keep [observation] on him, and make sure he had his respirator, and all those sorts of things were under control, but also, it gave him a sense that we were there to support him." (AU01) |
| | Improvements in access to palliative care | "We've now got different procedures in place around drug use and some drugs that certainly four years ago when I started, you wouldn't have had them in the prison without non standard operating procedures, [now] with separate lock boxes and facilities we can get oramorph and things that we wouldn't have had previously" (SC03) |
| | New prison buildings | "I think the new build is slightly less oppressive and you're in your own cell and you've got a nice shower and your own toilet, which has a door on it, you know, so that side of things in the newer built environment maybe helps with that slightly" (NI06) |
| THEME 4: REGULATORY BARRIERS AND FACILITATORS | | |
| Regulatory barriers | Inflexible regulations around locked doors | "If we've got somebody who's palliative, we're not allowed to open the [cell] door until they're actually bedbound and can't move. So that's difficult. So, if you've got somebody who's palliative on a syringe driver, not exactly dying but they're palliative and they're getting close, you know they're getting close, but they're still walking around, that door gets locked 23 hours a day. So why can't that be relaxed?" (AU06) |
| | Rules about prison visiting | "Also of course the accessibility of prisons to visitors outside normal hours, that is a huge problem, isn't it, if someone is dying at eight o'clock in the evening, no one from the family will be able to be there." (BE05) |
| | Regulations around medications | "We've been trying to get a medicine safe on the hall so that we can sign controlled drugs out of the health care unit and into the hall for the day. So that should somebody need it, it's there and accessible to save the nurse running back |

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| | | and forth. But the red tape was having to go through the prison service, having to go through pharmacy. And it's just proved almost virtually impossible." (SC08) |
| | Lack of access to IT systems | "When the patient leaves […] we do not have access to the electronic health record, we cannot find out where he is followed up or who the family doctor is, we cannot make the referral." (PO02) |
| | Use of restraints | "[A fellow incarcerated individual] came to me, and he was like, 'That's just disgusting that they would shackle a man, [when] he can't even move by himself'. And even if they're on a stretcher and they're not walking, they still have to be shackled on the stretcher. And he was like, 'I just think that's disgusting.' And in that moment, I was like, 'You're not wrong.'" (AU02) |
| | Early release on compassionate grounds | "It is possible, yes, [but it] does not happen in two days, it has to go to Brussels, it has to go to court, it all takes a very long time." (BE06) |
| | Regulations following a death | "I just know how I've always done it in the hospital, so it was very hard to come here and just not even having the access to the patient like you do in the hospital. I was always used to, when somebody's died, you'd go and give them a wash and we used to always place a bunch of flowers or something on their chest for them, make them look nice for the family. And it's very, very hard here that as soon as they die, it's like get away, doors closed off, you're not allowed near them again." (AU07) |
| Regulatory facilitators | Flexibility around family visits at the end of life | "When you get to this stage [end of life], family members are allowed to come into the prison health care unit and visit with them here." (AU07) |
| | Strong leadership from the top | "I think the biggest enabling factor is having someone who feels it's important at the top. I think being a lone voice within the system or organisation is quite challenging." (EN08) |
| | Consideration of health care needs in design of new prisons | "I'm aware that there's a new prison going to be built in [location] inside the next ten years. I can't go into any detail, but I think that the design of that prison will be looking at providing some kind of provision for [incarcerated individuals] who require more a hospital environment than a prison environment, but it would |

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| | | be within the prison. So that would be an enabler" (SC05) |
| | Recognition of needs of older people in prison | "That is an excellent wing because it is set up very much like an outside care home […] I think they get an excellent standard of care" (EN15). |
| | Independent investigations following deaths in custody | "Whenever you go to [the investigator's] interviews and you know, the feedback that is coming from families, and families are actually saying thank you for everything you've done, I know my job is done." (NI10) |
| | Legal mandates for equivalent care | "[incarcerated individuals] have the right to health, just like any citizen. They cannot be deprived of health by law." (PO02) |

*Anonymised participant identification is by country (AU=Australia, BE=Belgium, EN=England, NI=Northern Ireland, PO=Portugal, SC=Scotland) and participant number (e.g. AU01).

## Discussion

This study used a qualitative approach to explore the experiences of professional stakeholders who organise and deliver PEOLC to people in prison. Importantly, this is the first study to explore these issues from an international perspective. Its findings include evidence from the UK (England, Scotland, and Northern Ireland), Belgium, Portugal, and Australia which, despite some jurisdictional differences, demonstrate a general consensus about the barriers and facilitators in the organisation, implementation, and delivery of PEOLC in prison settings. These findings also broadly concur with other research in this context, which highlights some of the challenges already faced by prison and health care staff (Stephenson & Bell, 2018; Roulston et al, 2021), with a particular emphasis on the increasing numbers of people requiring PEOLC in custodial settings (Fair & Walmsley, 2024). Key findings emanating from the data provide insight and knowledge of the measures and approaches undertaken at different levels to facilitate the provision of high quality PEOLC within the prison setting.

As the first study to focus on palliative care for people in prison across multiple countries, the findings of this study highlight that there are many barriers within the prison setting that impede the organisation and delivery of PEOLC. Barriers identified operate at four levels: at the level of the individual in prison, staff working in prisons, the prison environment, and the regulations in place within local and national prison organisations. At the first of these levels, barriers include the increasing age of people in prison, the behaviour of those in prison, and the nature of the offence; in some countries, increasing numbers of people convicted of sexual offences present additional challenges, both because they have to be separated from other people in prison at all times for their own protection, and because some staff are unwilling to work with them because they regard sexual offences as the worst of crimes. Barriers at this level also include the behaviour of family members, and both the lack of family support and poor access for family members to visit. Some of these issues have been

identified in previous research (e.g. Turner et al, 2018; Chassagne et al, 2017), but the current study shows that the same challenges exist in different parts of the world, and provides further evidence of their impact. Similarly, the issues identified by Turner & Peacock (2017) in relation to challenges faced by prison staff in the UK were evident in other countries in this study. Staff barriers include the challenging nature of the work, the staff culture, a lack of knowledge and skills, high staff turnover, and the increased need for specialist palliative care provision. At the environmental level, there were significant concerns about the nature of the prison setting in terms of restricted space in cells to allow the use of additional equipment; locked doors that prevent swift access to unwell individuals and issues around access and monitoring of very ill patients; and the intimidating nature of the prison setting for health care staff. Finally, at the regulatory level, barriers were identified in relation to the inflexibility around locked doors and the difficulties this raises in providing PEOLC; access to certain medications and IT systems; and restrictions on family visiting. Legal investigations and independent scrutiny following a death in custody also acted as a barrier in some instances, as staff were fearful of the consequences if there were any shortfalls in care provision.

This study also shows that, because of both internal and external regulations governing the use of restraints, people approaching the end of life are often handcuffed or shackled when they are escorted out of prison to hospital or hospice, even when they present little or no risk of escape nor any risk of reoffending because of their frailty or poor health. There is very little research that focuses specifically on the use of restraints at the end of life; however, the example given in Table 2 from an interview with an Australian nurse regarding the use of restraints provides a stark illustration of how the prison regime and regulations can at times appear to ignore basic humanity. Prison authorities of course have a duty to assess and manage risk when transporting people who are incarcerated outside of the prison, to keep the public safe. However, the risk assessment is frequently based on the offence committed (sometimes many years previously), rather than the actual risk presented by the person at the time. This is evidenced in the UK, where prisons are frequently criticised by the independent Prisons and Probation Ombudsman (who investigates every death in custody) for the inappropriate use of restraints at the end of life (PPO, 2025).

However, it is important to note that the findings also provide insight and knowledge of the facilitators that co-exist at each of these levels. These include continued communication between people in prison and health care and prison staff, and the support from other people in prison as buddies to provide peer support. This is demonstrated in Table 2, where an interview with a prison officer highlights the role of peers in formally undertaking a caring role to support a person with poor mobility by for example pushing them in a wheelchair and collecting their meals. Various forms of ‘buddy’ models are used in different countries (Loeb et al, 2013), and there is scope for expanding such roles across more prisons, although appropriate safeguards need to be in place; as the example from our study shows, usually it is not permitted for buddies to provide personal care (such as bathing and toileting). There was a sense from our data that staff were determined, had good multi-disciplinary relationships, were compassionate, and had support from managers to be effective in their approach to delivering palliative care. At the environmental level, facilitators included a flexible approach to security where appropriate, to improve access for staff to administer PEOLC, and new prison buildings to improve space and allow personal care needs to be met.

At the regulatory level, there was evidence of an increased awareness of the needs of older people in prison, and more emphasis on the importance of equivalence of care.

There is broad international consensus that the organisation and delivery of health care for people in prison should be equivalent to that which a person could expect to receive outside of prison (Eichelberger et al., 2023). This is enshrined in the Nelson Mandela Rules, which state the right of a person who lives in prison 'to enjoy the same standards of health care that are available in the community' and 'have access to necessary health care services free of charge' (United Nations General Assembly, 2015). This is also stipulated in national policies and constitutions such as the Dying Well in Custody Charter in England (NHS England, 2025). However, significant tensions remain between care and custody, as articulated by Turner et al., (2011), and the findings from this research highlight these tensions in terms of regulation, the prison regime, the prison environment and infrastructure, and the processes involved in applying for compassionate release for those who are actively dying. In general, the data gave an overall sense that although there have been some improvements, the barriers remain pervasive and there is still a long way to go to address them all.

A significant barrier noted in the study findings was the issue of compassionate release, or early release on compassionate grounds (ERCG) and the difficulty in obtaining it for those who are at the end of life. Findings demonstrate that ERCG is an area of much debate; this is consistent with findings from a scoping review by Schaefer et al (2023), who contend that it should be the first consideration for people who are dying in prison, to address their specific care needs adequately. However, there are concerns within prison authorities about releasing people who purportedly have a very limited prognosis, only for them to outlive all expectations. A notable example of this was Abdelbaset al-Megrahi, the 'Lockerbie Bomber' who was released from a Scottish prison in 2009 with terminal prostate cancer and a prognosis of less than three months, but then lived for another three years. Our study found that in some countries (such as England, Scotland, and Australia) there are significant challenges in applying for and securing compassionate release for people who are dying, where for most people it is not a viable option because it is so difficult to meet the criteria for consideration. This results in most cases being rejected or the application being made very late and not considered before the applicant dies. The findings of this study support those of other studies that have found that barriers to compassionate release result in the need for palliative care to be provided in prison settings (Handtke et al., 2017; Kaushik & Currin-McCullouch, 2023; Mitchell & Williams, 2017).

This study provides an analysis of the participant accounts of the barriers and facilitators to the organisation and delivery of palliative and end of life care to people in prison, taking account of a range of professional stakeholders' experiences, including health care and prison staff from six different countries. These perspectives enhance knowledge and understanding of the experiences of staff from both within and external to the prison setting.

**Strengths and limitations of the study**

This study has generated new insights and understanding in an important but under-researched area. As the first international study of palliative care in prisons, it has identified common barriers and facilitators to the delivery of palliative care across the participating countries, and allowed comparisons to be made between different prison regimes and systems. This has resulted in the potential to share learning from the different approaches, which other countries can use to improve their own practices. There were some limitations to this research. To begin with, only staff were interviewed, not people in prison or their families; the ethics and governance procedures required just to interview staff were extremely time-consuming and onerous, and it was beyond the scope of the study to recruit individuals in prison, particularly because at the time most prisons were locked down due to the COVID-19 pandemic and access to people who live in prison was simply not possible. The lack of their perspectives and those of their families remains a gap in the research knowledge. In addition, most of the study participants worked in male prisons, so the study has not necessarily captured the experiences of those working with female or non-binary people in prison. It is important to note that women make up only 5% of the worldwide prison population (Fair & Walmsley, 2024), and the number of non-binary people in prison is even smaller, so future research is needed to explore the specific needs of these groups.

**Conclusion**

Numerous barriers still exist in relation to assessing and managing risk, the ageing profile of people in prison, staff boundaries and training, prison environments, and the bureaucratic management of compassionate release or parole for those approaching the end of life in prison. The study makes the following recommendations:

- In response to ageing populations in prisons, it is important that prisons learn from one another about how best to improve their existing facilities, or build new wings to accommodate specialist equipment that mirror hospital wards.

- Given the rising need for specialist palliative care within prisons, in-reach staff need timely access to people in prison and systems to store and administer controlled drugs, and prison healthcare staff need basic training in palliative care.

- When people are diagnosed with life-limiting disease, protocols should be implemented that prompt advance care planning, referrals to specialist palliative care, consideration for early release on compassionate grounds, more flexible visiting, and a review of restraints. Doing so will promote dignity, human rights, and access to equivalent care.

- Buddy systems and peer support are valuable informal resources, but there is limited access to personal care. Consideration should be given to employing and training buddies to deliver personal care in teams, that do not compromise safety and dignity.

This study has identified ways in which the delivery of palliative care can be facilitated so that people in prison receive the same standards of care at the end of life as people in the outside community. It is imperative that these and other facilitators are put in place to prevent people in prison continuing to be disadvantaged at the end of life when compared with people dying outside of prison.

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**Appendix 1: Framework for analysis**

**FRAME 1: THE MEANING OF PC & EOLC IN PRISON SETTINGS (CULTURE)**

Suggest: open subframes (iterative construction via inductive coding)

**FRAME 2: ORGANISATION OF PC & EOLC IN PRISONS (STRUCTURE)**

a) ACTORS & ROLES: who is involved (profiles; in-house vs external)? What are the roles of each actor involved?
b) TYPE: what type of care is provided (medical, psychosocial, existential)?
c) SPACE/CONTEXT: where is PC & EOLC provided? What facilities are available?
d) TIME: when is it initiated? What is a prisoner's typical profile & trajectory?
e) REGULATION: are there (written) rules & protocols? What do they stipulate?

**FRAME 3: EVALUATION OF CURRENT PC & EOLC PROVISION IN PRISONS**

| | Barriers | Facilitators |
|---|---|---|
| Prisoners level | | |
| Staff level | | |
| Prison environment level (internal + external) | | |
| Regulatory level (in-house) | | |
| Regulatory level (broader policy) | | |

**FRAME 4: NEEDS & RECOMMENDATIONS TO IMPROVE PC & EOLC IN PRISONS**

a) CULTURE/AWARENESS
b) TRAINING/SUPPORT
c) ENVIRONMENT/FACILITIES
d) REGULATION/POLICY
    - Compassionate release
    - …