Unlocking Disparities for People in Prison with Palliative Care Needs

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Introduction

UK citizens have a fundamental right to compassionate healthcare, including palliative care, irrespective of their circumstances. Palliative Care focuses on relief of suffering, provision of comfort, and preservation of dignity for those living with life-limiting illness. Within correctional facilities, achieving this is fraught with challenges. The prison population is marked by an overrepresentation of individuals facing socioeconomic, health, and life history disparities.

We aimed to explore disparities in palliative care provision for people in prison in the UK, through a mixed methods approach.

A secondary aim was to develop our understanding of healthcare inequalities and to explore and reflect upon our own attitudes to potentially minoritised populations and what this means for our future work as doctors.

Methods

We undertook a literature review examining palliative care for people in prisons in the UK, including the barriers and challenges associated with provision. This informed interviews with professionals working in prison palliative in Edinburgh to explore their experiences and perspectives, and a focus group with University of Edinburgh students (non-medical), to explore their views on the provision of prison palliative care.

We interviewed 3 healthcare professionals who regularly provide palliative care in a prison settings (two in-person, one by video call). No recording took place as this was out-with University permissions, but responses were written down by the study group.

Our peer focus group consisted of 7 non-medical students attending the University of Edinburgh, who were known to the study team. Participants were given two minutes to discuss their thoughts for each question in small groups before sharing their ideas with the rest of the focus group.

Results: informed by literature review, interviews and focus group

Prison Environment

Prisoners are typically biologically 10 years older than their societal counterparts. Many prisons have 19th century infrastructure preventing lifts being installed or widening of cell doors for wheelchair access. Prison cell size is very small with little room for equipment for those with additional needs. Prison regimes are restrictive, with guards always present and without 24hr access to healthcare but also limited support overnight for frail people needing assistance with basic needs such as toileting (leading to people lying soiled all night) and pain control. Compassionate release criteria are very stringent making it impossible for many prisoners to die outside with family and friends.

Lack of Resources

There is a lack of palliative care training for prison healthcare staff. Hospice staff may have little to no experience working in a prison. High turnover of prison staff means new staff are often unfamiliar with the prison environment and the patients. We have an ageing population with growing palliative care needs. Training is dependent on resources and budget.
There are usually no resources in place for 24-hour healthcare, and staff may be prevented from seeing patients without security, or during prison lockdowns. Prisoners are unable to receive care at night and can only access healthcare by dialling 999. The palliative care specialists we spoke to echoed this. Inequality exists between prisoners and patients receiving palliative care at home, in hospitals, or in hospices where equipment is readily available.

Medications

In their final days, palliative prisoners (like those not in prison) usually require 24-hour monitoring and administration of medications - a service unfeasible in prison. This results in prolonged periods of pain and uncontrolled symptoms, particularly overnight. Healthcare staff are anxious about medication requests, fearing misuse, and vulnerable inmates can face violence due to medication demand. Those with a history of substance abuse may be unfairly viewed as drug-seekers despite being in genuine pain. Staff and prison guards often lack training and knowledge to facilitate proper care. Prescription management is often delayed, necessitating days of planning and longer wait times than for people not in prison.

Emotional Challenges

Ensuring dignity in palliative care is crucial for a humane end of life, with autonomy, respect, and empowerment as key components. However, prisons often hinder dignified deaths. Some argue that dignity compromises are inherent in palliative care within prisons due to their punitive nature. Autonomy is rarely considered, as the focus is on confinement and punishment. Gender disparities in healthcare are evident among female prisoners who face health problems, anxiety, and depression. Additionally, female inmates particularly report valuing human connections to the outside world, which diminish over time, leading to loneliness. Prisoners experience heightened death anxiety, attributed to their lack of control, age, social support, and mistrust in the healthcare system.

Our Reflections as future doctors:

"We learnt about both the physical barriers and moral debates that continue to exist surrounding prisoner care. It is something you just don't think about on a day-to-day basis, but when you sit down and find out more about it, it really opens your eyes and puts things into perspective."

"It is important to understand patients' socioeconomic and social history, and how this can influence their health. Healthcare decisions should be made with empathy and independent of one's personal beliefs, a vital skill to have as a future doctor."

"Exploring ethical topics prepares us to consider diverse patient perspectives. Revisiting palliative care in prisons allows us to apply this mindset to evolving social contexts. Understanding patients' beliefs and social influences is vital for patient-centered care."

"Speaking with non-medical peers revealed diverse healthcare opinions, challenging our views. This experience prepares us to collaborate with diverse colleagues and care for patients with varying perspectives. Engaging with palliative care professionals and reading research papers deepened our knowledge."

Conclusion

Many inequalities and a clear lack of dignity were key findings from our review, interviews and focus group. Views on prisoners from lay interviewees sometimes conflicted with professionals, with professionals exhibiting full support of prisoners receiving the same standard of care. Some non-medical students felt unsure that prisoners deserved this.

Suggestions for improvements from our literature review, interviews and focus group were: having a specialist healthcare wing with 24 hour resources, better educating healthcare and prison staff and increasing space and equipment. However, a lack of policy and funding are major barriers.

Our scope was limited to Edinburgh prisons. Exploring inequalities in other regions would be interesting. Also considering whether any measures of access to palliative care may be feasible.

In summary, there are clear inequalities in palliative care provision for people in prison and this needs attention. Further research is needed to inform changes to policy and practice.

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