Palliative and end of life care in Scotland's prisons: a mixed-methods evaluation

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Abstract

In a mixed-methods study of palliative care provision in Scotland's prisons, we found that prison clinical and custodial staff had variable confidence in their abilities to provide palliative care. People in prison provided a rich description of living in prison with palliative conditions, including the novel role played by peer carers and prison officers in supporting them. The prison environment, structural and organisational factors present significant barriers to care.

Related publications:

McParland, C. Johnston, B. (2019) 'Palliative and end of life care in prisons: a mixed-methods rapid review of the literature from 2014–2018'. *BMJ Open.* doi: 10.1136/bmjopen-2019-033905 McParland, C. and Johnston, B. (2021) 'Caring, sharing, preparing and declaring: how do hospices support prisons to provide palliative and end of life care? A qualitative descriptive study using telephone interviews', *Palliative Medicine*. doi: 10.1177/0269216320979194.



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Background

- The prison population is getting older. Many age during long custodial sentences, others are already old when imprisoned for the first time for historic offences.
- The health of those in prison is characterised by complex comorbid chronic illness.
- Compassionate release is relatively rare. Many will die during their sentence.

Methods & Aim

- This 12-month mixed-methods study aimed to evaluate palliative care provision in Scotland's prison, in order to inform future practice.
- We conducted a rapid review of the literature on palliative care in prisons
- We interviewed representatives from all 17 adult hospices in Scotland about their involvement with prisons
- We surveyed 81 prison healthcare and custodial staff about their levels of confidence and experience providing palliative care
- We conducted qualitative case studies of people in prison and their support networks to understand the experience of living in prison with palliative care needs



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Results

The **rapid review** noted growing international interest in palliative care in prisons; themes included the value of family relationships and prison environment as a barrier to care.

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The **case studies** involved people in prison, their family, prison officers, clinical staff, support staff and inmate peer caregivers (n=24 participants). Six descriptive themes were generated.

Incompatibility with prison life

We have young offenders' units, we have women's units... So, nowadays there's going to be a lot more of an ageing population. People laugh about it, but it might become that you might have, similar to a young offenders' [unit], you'll have an old people's unit.

[Eric, prison officer]

Prison officers: carer and custodian

Some staff see [providing care] as this is something that ethically is the right thing to do, and also it's going to make my job easier, and some staff are like, this isn't my job, I'm not interested, and are very kind of standoffish and don't want any kind of information

[Paula, healthcare staff]

Descriptions of care delivery ...what I have noticed is, about half eight at night, they get the nurses coming in, and we'll leave the cell, and they'll go and make sure he's alright, if he needs anything, et cetera, and all that. And I think that's brilliant [Sean, patient]

The role of peer carers

You're always on call. You're there when needed, if needed. [Martin, peer carer]

Conclusion

The effect of conflict on the provision and uptake of care

Some of them that have refused to go hospital over the time and say, they judge me. I have to sit out there with handcuffs on in hospital, I don't want to go there with handcuffs on where people don't want to come near you. [Rachel, healthcare staff]

Death, dying and declining health

I don't think you're sentenced to die in prison, you know. It's a kind of strange expression: you're sentenced to do a sentence, and then leave. [Martin, peer carer]

Increasing attention has been directed towards improving care for people with palliative care needs in Scotland's prisons recently, from both inside and outside the prison walls. Yet significant barriers to equitable care still exist. These will require continuing collaboration between prisons, hospices and other community organisations to overcome.

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