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Background

- The End of Life Care Strategy (2008) states: ‘high quality services should be available in all locations, including prisons’
- Prisons and prisoners have characteristics which potentially create inequalities in the delivery of care
- A paucity of research means that the need for palliative and end of life care in prisons has not yet been established
Aims and Methods

- To quantify palliative and end of life care need, in adult prisons in England and Wales and identify strategies for enhancing care

- A semi-structured survey was developed

- Completed by healthcare managers (or nominated deputy) in prisons in England and Wales

- To assess current palliative care needs; strategies for developing services; the use of end of life care tools; access to specialist palliative care services when needed and education

- All necessary approvals and consents were obtained
Results

- 124 adult prisons in England and Wales approached and data obtained from 39 prisons (31.5% response rate)
- Between 2010 and 2012
  - 113 prisoners died from natural causes
  - 68 prisoners required palliative care
  - 45 were considered for release to receive care in alternative locations, of which 20 were released
Implementation of end of life care tools

- Gold Standard Framework/palliative care register: 12 Implemented, 11 Planning to implement, 16 Not planning to implement
- Macmillan Adopted Prison Standards: 6 Implemented, 21 Planning to implement, 33 Not planning to implement
- Liverpool care pathway or alternative: 9 Implemented, 14 Planning to implement, 16 Not planning to implement
- Advance care planning: 10 Implemented, 12 Planning to implement, 17 Not planning to implement
- Preferred place for care: 11 Implemented, 13 Planning to implement, 16 Not planning to implement
Access to specialist palliative care services

![Bar chart showing access to palliative care clinical nurse specialists and access to palliative medicine physicians. The number of prisons is on the y-axis, and the access types are on the x-axis. The chart compares telephone advice and face-to-face review.]
31/39 have access to palliative care education

‘education can be arranged as needed but nil formally arranged currently’

‘2 x Clinical Leads have passed their Palliative Care Diploma’

‘Would be able to access education needed through Macmillan nurses where there are excellent links’

‘We access as required due to staff shortages’
Holistic and multidisciplinary care

‘Palliative care lead (RGN) – oncology diploma and palliative care certificate; associate lead (RGN) - experience of working with end of life patients; RMN – provide psychosocial support; GP – linked with local hospice; Macmillan nurse available to visit patient within prison and support nursing staff; district nurses can also be utilised if required; patient has designated family liaison officer to establish contact with families and ensure that the patient has the support of their families; access to chaplaincy to meet religious and spiritual needs; regular multidisciplinary team meetings with patient as part of care planning process; involvement of offender manager unit in multidisciplinary meeting; if we are unable to provide effective symptom control or are unable to manage a patient we have an understanding that the local hospice will admit them until they can return to us or until alternative arrangement can be arranged (e.g. 24 hour healthcare, release on temporary licence)’
Environment/equipment

‘Disability room with en suite facilities located at the end of the prison with easy access for community care staff’

‘There is very little scope or opportunity to develop a palliative care service within this prison. The design and geography of the establishment (it is an old Victorian jail) make having a suitable environment in which to deliver palliative end of life care almost impossible’
Access to medication

‘Patient had a single dose of oramorph kept in a locked box in her room and only patient and staff had key. Patient could then take overnight if needed’

‘Starting to use fentanyl patched for strong opioid but clearly need to check present on a regular basis’
How things have changed

‘Palliative care provision has come a long way in the last 6 years in terms of the vast improvement in terms of care provision. I have worked within 2 different establishments and have seen a change in the way that the prison as a service views palliative care patients, and the fact that patients have better access to specialist resources. I feel that we are finally offering service which is comparable to what the patient would receive within the community and feel that things are going to get better in the future’
The challenges

‘Since the training was undertaken by staff at the prison we have been looking at ways in which we can improve delivery of palliative care within the prison setting. We have and will continue to be bound by budgetary constraints but will still continue to ensure that all of the palliative care needs of any future patients will be met in as comprehensive a way as possible. The staff are looking to promote end of life care in a positive and proactive way and there are various events, in the planning stage, which will be used to highlight this important area of Healthcare’
Limitations

- 31.5% response rate therefore difficult to extrapolate results or form conclusions on a national level
- Prisons who participated may reflect those with a greater interest or more developed services
Conclusions

- The number of prisoners requiring palliative care is probably larger than expected.
- Although there is evidence of palliative care support and principles available, work is still required to ensure equity in end of life care provision for prisoners.
- Range of strategies have been adopted for delivering care but need to establish impact on patients and families and the experiences of staff.
- This study forms part of preliminary scoping work for a Marie Curie Cancer Care funded project titled “Both sides of the fence: Using action research to improve end of life care for prisoners” which aims to “devise a collaborative programme of organisational practice development, involving prison staff, primary care staff and SPC practitioners, that enhances the delivery of high quality care for prisoners with palliative care needs”
References

7. Stone K, Papadopoulos I & Kelly D. Establishing hospice care for prison populations: An integrative review assessing the UK and USA perspective. Pall Med; 26(8), 969-978