Dying behind bars: an evaluation of end of life care in prisons in Cumbria and Lancashire

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World context

- 10 million people worldwide in prison
- Considerable variation between countries
- US has highest prison population rate in the world, with 756 prisoners per 100,000 population
- Two thirds of countries have rates above 150 per 100,000 population
UK context

- UK has 151 prisoners per 100,000 population
- UK has 60% more prisoners than Belgium, France, Germany, Ireland or Italy
- 139 prisons in England and Wales housing 83,500 prisoners
- Projected to increase to up to 93,900 by 2015
Local context

- 6 adult male prisons in Cumbria and Lancashire housing total of over 4,000 prisoners (range 240 – 1,150)
- Rural and urban locations
- All have outpatients departments; two also have in-patient beds
- Young Offenders Institutions not included
The study

• Aim:
  To evaluate current end of life care provision in prisons in Cumbria and Lancashire as reported by prison healthcare staff and specialist palliative care providers

• 9 month study from April – December 2009
Objectives

• Map the number of prisoners in Cumbria and Lancashire with end of life care needs
• Describe the availability of general palliative care in six prisons
• Describe the links and barriers to access to specialist palliative care services for the prison population
• Measure the current skills, knowledge and confidence of prison-based healthcare staff in relation to palliative care and identify training needs
• Explore the perceptions of healthcare staff working in prisons about palliative care
• Scope the literature around end of life care in prisons
Setting

• All six adult male prisons in Cumbria and Lancashire

• Four independent hospices
  – Selected for geographical proximity to prisons
  – Range from small 9-bedded rural hospice to large 28-bedded urban hospice
  – One has three prisons in its catchment area, the other three each have one prison in their area
Study design

• Strand 1: scoping and reviewing literature – research literature and policy documents
• Strand 2: interviews with prison healthcare staff and specialist palliative care staff
• Strand 3: questionnaires for prison healthcare staff to assess knowledge, skills and confidence in end of life care
Ethical and governance procedures

• Service evaluation, not research
• Approval from DHR, Lancaster University
• R&D approval from each of 3 PCTs
• CEO approval for each of 4 hospices
• Prisons approval:
  – NW Regional Psychologist for HM Prison Service
  – Governors at each of 6 prisons
Strand 1: Literature

• Aim: to carry out a scoping of the existing literature and policy documents
• Database search for articles relating to end of life care and to prisons
• Papers on suicide excluded
Findings of literature search

- 147 items identified
- Classified according to country of origin and date of publication
- Categorised by type
## Country of origin

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of items (%)</th>
</tr>
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<tbody>
<tr>
<td>United States</td>
<td>91 (62)</td>
</tr>
<tr>
<td>England and Wales</td>
<td>42 (28)</td>
</tr>
<tr>
<td>More than one country</td>
<td>7 (5)</td>
</tr>
<tr>
<td>New Zealand</td>
<td>3 (2)</td>
</tr>
<tr>
<td>Australia</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Canada</td>
<td>1 (1)</td>
</tr>
<tr>
<td>South Africa</td>
<td>1 (1)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>147 (100)</strong></td>
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</tbody>
</table>
Dates of publication

Number of publications

## Type of paper

<table>
<thead>
<tr>
<th>Type of paper</th>
<th>Number of items (%)</th>
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</thead>
<tbody>
<tr>
<td>Discursive, commentary or opinion pieces</td>
<td>45 (31)</td>
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<tr>
<td>Description of cases (prisoners, hospice programmes etc)</td>
<td>40 (27)</td>
</tr>
<tr>
<td>Empirical research or evaluations</td>
<td>27 (18)</td>
</tr>
<tr>
<td>Law, ethics and policy</td>
<td>18 (12)</td>
</tr>
<tr>
<td>Statistics on end of life in prison</td>
<td>4 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (9)</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>147 (100)</strong></td>
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Research papers

• 27 papers (18%)
• Texts obtained and read
• Reduced to 11 papers: 8 research papers and 3 literature reviews
Key findings from literature

• Lack of published evidence
• Prevailing view that prison experience should be ‘punishing’ – ‘institutional thoughtlessness’
• Few concessions for older or less mobile prisoners
• Barriers include concerns about drug misuse and lack of continuity of care
Policy review

• Two key policy initiatives:
  – Phased transition of responsibility for prison healthcare to NHS from 2004
  – National End of Life Care Strategy 2008

• Prison Service Orders (PSOs) on range of subjects including clinical governance, continuity of healthcare, older prisoners, deaths in prison and compassionate release
Strand 2: Interviews

• 26 interviews:
  – 17 prison healthcare staff
  – 9 specialist palliative care staff in hospices local to the prisons

• All audio recorded and transcribed
## Interview participants

<table>
<thead>
<tr>
<th></th>
<th>Doctors</th>
<th>Nurses</th>
<th>Healthcare Assistants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prisons</td>
<td>0</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Hospices</td>
<td>4</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>4</strong></td>
<td><strong>19</strong></td>
<td><strong>3</strong></td>
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Data analysis

• Framework analysis undertaken
  – Each transcript analysed for any content relating to the aims of the project
  – Researchers also looked for other themes not encompassed in the project aims
## Analytical framework

<table>
<thead>
<tr>
<th>Frames of analysis</th>
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<tr>
<td>Current or recent prisoners with end of life care needs</td>
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<tr>
<td>Context</td>
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<tr>
<td>Prison healthcare staff’s experience of end of life care</td>
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<tr>
<td>Specialist palliative care staff’s experiences in prisons</td>
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<tr>
<td>Links between prison healthcare and specialist palliative care services</td>
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<tr>
<td>Barriers to accessing end of life care in prisons</td>
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<td>End of life care tools</td>
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<tr>
<td>Recent developments</td>
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Identifying end of life care needs

- Difficult to assess – different staff perceptions
- Identified 3 prisoners who were dying at time of study or who had died in recent months (case studies)
- Compared to wider population the number of prisoners with end of life care needs was small
Context

• Quantity and quality of end of life care provision in prisons is related to local context:
  – Geographical location of prison (remoteness from services)
  – Grouping of prisons, local hospices and palliative care services
Local groupings

<table>
<thead>
<tr>
<th>Area</th>
<th>Prison / hospice</th>
<th>Geographical context</th>
</tr>
</thead>
</table>
| A    | 1 prison
     1 hospice          | Town and surrounding area                 |
| B    | 1 prison
     1 hospice          | Rural and remote from services            |
| C    | 1 prison
     1 hospice          | Town and surrounding area                 |
| D    | 3 prisons
     1 hospice          | Town and surrounding area                 |
Prison staff experiences

- Prison healthcare staff had limited experience of end of life care:
  - Five had some experience mostly from previous posts in the community
  - Six had minimal experience
  - Six had no experience of end of life care
SPC staff experiences

• Specialist palliative care staff had limited experience of working in prisons:
  – One had connections with prisons over a number of years
  – Two had limited prior involvement
  – Four had no experience prior to their current involvement
  – Two had no experience of prisons at all
Case Study 1: John

- 65 year old man with lung cancer
- Nursed in prison healthcare unit
- Chose to stay in prison; input from hospice
- 24-hour nursing access allowed
- Liverpool Care Pathway
- Died in prison healthcare unit
- Inquest required as death in custody
Impact on prison healthcare staff

“Initially some staff thought ‘We can’t manage this patient here’. But a lot of people got a lot out of it – they remembered why they became a nurse.”  
[Healthcare Manager]

“It was draining and emotional for staff, and yet those we didn’t think would cope well became stars.”  
[Nurse]
Barriers

- Language and practices
- Nowhere to die
- Mobility and access
- Prison systems and cultures
- Drugs and pharmacy issues
- Emotional and personal support
- Compassionate release
Case Study 2: Paul

- 39 year old man with lung cancer
- Chemotherapy and radiotherapy unsuccessful
- No in-patient facility in this prison
- Application for compassionate release denied
- Macmillan Nurse and GP involvement
- Open visits, dietary needs, drug issues
Language and practices

“What was also the issue, and I didn’t understand the terminology, he said ‘I’m not getting my canteen sorted out’, and he explained that he fills in a form for stuff that he wants to buy from his money for food on a Friday. Because all of his appointments were on a Friday he was missing his canteen form, and he was being told ‘well tough, you weren’t here’. Initially I couldn’t believe I was having to do this for someone who was terminally ill with cancer.”

[Macmillan Nurse]
Nowhere to die

• “If someone needed constant watch and constant pain relief and support, then they wouldn’t stay here, it wouldn’t be possible.”

[Healthcare Assistant]

• Transfers between prisons
Mobility and access

• Physical environment
• Old buildings, lack of disabled access
• Cells too small for specialist equipment
• Adaptation restricted in listed building
Type of prison

- Holding prisons
- High security prisons
- Elderly and disabled unit in one prison
Prison systems and culture

• Expectations of ability to self-care
• ‘Institutional thoughtlessness’ – prison system not coping well with caring for dying prisoner
• Underlying attitudes of prison officers – should be no preferential treatment
• Fear of death in custody and need for all deaths to be investigated
No special treatment

“When I tried to go to hospital with [prisoner] on his first appointment, I knew that he was going to be told he had terminal cancer, he didn’t know this [...] I was asked why do I need to go, there will be plenty of other nurses with him. I felt I had to defend my position [...] I felt I was fighting for him.”  

[Nurse]
Fear of death

“I think the Prison Service may have felt a bit frightened by what they had to deal with, especially the officers, not knowing what was going to happen with a terminally ill patient.”

[Nurse]
Drugs and pharmacy issues

- Drug abuse common amongst prisoners
- Anxiety about legitimate need for drugs
- Provision of drugs ‘on the wing’ – security issues
- Delays in prescribing and providing drugs – limited times when doctor and pharmacist in prison
“Normally when we start with an opiate we would go with 12-hourly dosings – so 8am and 8pm – but in order to do that we had to get special permission for him to take the drug on to the wing, and initially that caused a lot of angst.”

[Macmillan Nurse]
Emotional and personal support

- Difficulties in providing individual personal support
- Difficulties for staff in having conversations with prisoners about dying
- Limited access to counselling and psychological support
Compassionate release

• Issue of compassionate early release is complex
• High profile cases of Ronnie Biggs and Abdelbaset Ali al-Megrahi
• Two contrasting cases in this study
Case Study 3: George

- Older prisoner with lung cancer
- In open prison, at the end of long sentence
- SPC assessment, attended hospice day care
- Released but wanted to stay in prison: “He wishes he had never been released”.
- Social isolation
Questionnaire

- Completed by 16 members of prison healthcare staff
- Focus on skills, knowledge and confidence in relation to palliative care
- Based on questionnaire used in previous study in community hospitals
Skill self-rating

• Respondents were asked to rate their skills in relation to nine aspects of end of life care:
  – Complete beginner = 1
  – Novice = 2
  – Quite skilled = 3
  – Competent = 4
  – Expert = 5
Skill self-rating scores

Degree of self-rated expertise

- Communication with patients
- Communication with relatives
- Communication with colleagues
- Psychological support
- Bereavement support
- Spiritual support
- Use of equipment
- Pain relief
- Other symptom control
Staff training

![Bar chart showing number of staff trained in various categories.]

- Communication with patients: 8 Yes, 6 No
- Communication with relatives: 6 Yes, 4 No
- Psychological support: 7 Yes, 3 No
- Bereavement support: 8 Yes, 4 No
- Spiritual support: 10 Yes, 5 No
- Use of equipment: 8 Yes, 4 No
- Pain relief: 7 Yes, 3 No
- Other symptom relief: 9 Yes, 3 No
Good end of life care

Facilitated by:
- Internal and external relationships
- Communication
- Staff attitudes
- Environment/resources
- Training/education
- Co-ordination of care
- Holistic approach
- Use of EOLC tools
- Symptom control

Barriers:
- Environment/resources
- Prison security
- Staff knowledge/experience
- Fear
- Procedures/protocols
- Lack of support
Limitations of the study

• One geographical area
• Self-report data
• No prisoners or families included in the study
• No high security prisons (Category A) in this area
Conclusions and recommendations

• Practice: education, training and support; ‘champions’; clusters; internal relationships; awareness raising; changing attitudes to death

• Policy: PSO for end of life care

• Research: prisoners/families; accurate mapping of need; effectiveness and cost-effectiveness of initiatives; longitudinal studies
Further information

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Thank you for your attention