Caring for ‘end of lifers’: findings from the ‘Both sides of the fence’ study

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"Now I’m a lifer…. I may never get out, I may be one of your end-of-lifers at some stage" (Prisoner)
Prison context

• Increasing prison population despite falling crime rates; currently around 86,000 prisoners (148 per 100,000 population)
• Prison population has doubled in last 20 years
• Longer sentences and more stringent licensing conditions (ROTL)
• Funding cuts – “benchmarking” – staff shortages, loss of experienced officers
• Increasing numbers of older, frail prisoners
In England and Wales:

- 12,000 prisoners (14%) over 50; 4,000 over 60; 100 over 80
- Over 60s are the fastest growing age group – 164% rise since 2002
- 42% of over 50s are sex offenders
- Deaths from natural causes in custody are rising each year (141 in 2014)
- Compassionate release is rare

*Prison Reform Trust: Bromley Briefings*
The ‘Both sides of the fence’ study

- **Timescale:** 36 months from June 2013 – May 2016
- **Methodology:** Participatory Action Research in 3 phases
- **Aim:** To develop a transferable model of integrated palliative and end of life care for prisoners
- Funded by Marie Curie
- Approved by NHS Ethics and NOMS
Participatory Action Research

Phase 1
- Situational analysis
- Interviews and focus groups inside and outside prison

Phase 2
- Cycles of action
- Working with staff and prisoners to make changes

Phase 3
- Deliberation with stakeholders
- Workshops and consensus exercise
Phase 1: Situational analysis

Data collection (62 participants)

Focus groups:
• 30 participants in 5 focus groups – prison officers, nurses and prisoners

Individual interviews:
• Inside the prison – 27 interviews with senior prison officers, governors, chaplains, probation, prison healthcare and others
• Outside the prison – 5 interviews with specialist palliative care staff and coroner

Case study:
• Prisoner approaching the end of his life and three people involved in his care and support
## Global and organising themes

<table>
<thead>
<tr>
<th>Current healthcare and end of life practices</th>
<th>The effects of current prison healthcare practices</th>
<th>Negotiating current prison healthcare practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staffing in the prison</td>
<td>Proximity to illness and death</td>
<td>Prisoner care and prisoners</td>
</tr>
<tr>
<td>Prison facilities and resources</td>
<td>Fear of loneliness and dying</td>
<td>Defences and coping strategies</td>
</tr>
<tr>
<td>Prisoners’ access to healthcare services and resources</td>
<td>Changing roles</td>
<td></td>
</tr>
<tr>
<td>Healthcare emergencies</td>
<td>Healthcare as punishment and reward</td>
<td></td>
</tr>
<tr>
<td>Current healthcare and end of life practices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current medication practices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prisoner care and members of staff</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
“There’s a misconception, and we had it in the military as well, when you pull a uniform on, you’re a robot and you’re completely free of emotion. And that couldn’t be further from the truth..... you put this uniform on, that’s it, you know, you are a robot. People forget the impact factors of your home life, what sort of day you’re having as well...it all affects how you go about your job”
“You are getting people... in their late 60s, 70s – even into the 80s – which is... quite a different level of care. Their needs are different, it’s more around medical, health issues; not really any control problems as you get with the younger population, no real control problems at all, but a different set of issues; ...health... they’ve got family problems because of the offence if it was committed in the family... some of the men haven’t got anybody. But it is a marked difference.”

(Governor, VP Wing)
“The other thing is, is that for me the resources aren’t there for us to deal with [end of life care] as we would. So more for instance if we had an endless pot of money, purpose built wings or units, plenty of staff, plenty of support. [...] And you can see it because when prisoners go to the hospice you know, the environment is totally different and they do buck up.”

(Prison Officer)

“Mr H, for example, [was] doubly incontinent in the middle of the night. There was no provision to put him in the shower and give him a shower. We offered; ‘You can’t’, you know, ‘Everybody’s asleep, it’s not happening.’ So we had to wash him down, three of us trying to hold him up in a cell that wide... to wash him, change him. Nobody had clean kit; we were borrowing off the rest of the landing at 3 o’clock in the morning.”

(Nurse)
Prison systems

“I don’t think that the staff don’t care because, to be honest with you, I think the staff do care, a lot of them do care about you, but I think it’s just there’s... no system in place for anybody who is in real bad pain.”

(Prisoner)
Proximity to illness and death

“It’s bad enough being aged, losing friends and family all around you, forcing you to look at your mortality, and that’s what it does. And here that is exaggerated again because, not only are you looking at that, you haven’t got your family and friends around you...”

(Prisoner)

“I don’t think we’re trained to deal with [end of life]. I mean the nine weeks I spent [training] in 1987, I certainly don’t remember anybody sort of talking anything about that at all. I think we probably had a chat off the chaplaincy for half an hour or so, but I certainly do not remember anybody touching on sort of end of life stuff or preparing people for, you know, for finding people who have taken their lives or they’ve passed over.”

(Prison Officer)
“I think in the community ... people would be put on the syringe drivers for like three days to get them symptom-controlled and then taken off it, whereas the options of that aren’t really available when they’re on the wings...because they’re just not allowed them. So that’s the difference that I see. I think one of the other things was that... which I wouldn’t have even considered, was like for this man, he was so thin but he couldn’t have a mattress because his bed... his bed’s not wide enough... they’re in a three-quarter bed, aren’t they, instead of a full-size single, so you can’t get a pressure mattress to fit. And, you know, things like that that you wouldn’t even blink an eyelid out in the community about, getting pressure equipment.”

(Nurse)
Phase 2: Cycles of action

Strand 1: Prisoners
- Older prisoners group
- Leaflet on approaching the end of life
- Survey of older prisoners
- Creation of Older Prisoners’ Unit

Strand 2: Staff
- Awareness sessions for discipline staff about palliative care
- Palliative care training for healthcare staff

Strand 3: Palliative care audit
- Macmillan Adopted Prison Standards (MAPS)
Survey of older prisoners

- Survey questionnaire designed by research team in collaboration with prison staff
- 20 questions in 6 groups:
  - Basic demographic information
  - Health status
  - Daily life and mobility
  - Healthcare in the prison
  - Social and psychological needs
  - Future developments
- Combination of tick-boxes and free text responses
- Distributed in named envelopes to every prisoner aged 55 or over on all wings across whole prison (202 prisoners)
The sample

- 127 (of 202) completed and returned (62.9% response rate)
- Age: mean 64.97; median 64; range 55 – 91; 25% over 70
- Mean time in prison on current sentence is 65 months; 33% are serving less than 2 years but 27% serving more than 5 years
- 25% had served a previous sentence; 58% had not but an additional 17% left this question blank, indicating no previous sentence
55.9% reported 3 or more concurrent health conditions

Most common conditions:
- Arthritis/joint problems (42.5%)
- Hypertension (39.4%)
- Chest/lung problems (29.1%)
- Anxiety (26.8%)
- Depression (25.2%)

50% take five or more medications and almost 90% take at least one
Frailty and mobility

- Two thirds of respondents (60.6%) have difficulty with at least one aspect of daily living, and 38.6% have difficulty with two or more
- 11.8% are either not able to walk at all or have very poor mobility (<10m); a further 14.2% can walk less than 100m
- 18.9% unable to manage stairs unaided
- 43.3% use one or more medical or health aids
- 30.7% had experienced a fall during the previous two years
Phase 3: Deliberation with stakeholders

- Two workshops with staff and one with prisoners in HMP Wymott in October 2015
- Deliberative Panel in London
- Consensus exercise
Key recommendations (1)

1. Policy and strategy
   • Palliative and end of life care should be a prominent part of the prison healthcare agenda (1)
   • There should be a national strategy for older prisoners that focusses on the healthcare, social care and palliative care of offenders aged 50 and over (2)
   • More work is needed on measuring the quality of palliative and end of life care in prisons, and what constitutes a ‘good death’ (8)

2. Organisation and funding of services
   • Prison funding should reflect the multiple and complex needs of older prisoners and the extra resources they require (3)
   • Continuing Healthcare Funding should be available for prisoners as it is for any other NHS patient who meets the criteria (5)
   • Local and regional groups and networks should be established to focus on older prisoners and end of life care, in order to share best practice (6)
Key recommendations (2)

- A ‘whole organisation’ approach towards palliative care should be fostered and supported in every prison to embed it at all levels of the organisation (9)

3. Sentencing
- A national debate is required to address to most appropriate place and facilities for older prisoners (4)

4. Staff training
- More training opportunities (in addition to mandatory training) should be available to prison staff, focusing on older people, palliative care and anticipated deaths in custody (7)

5. Palliative and end of life practices
- Each prison should foster a multidisciplinary approach to palliative and end of life care, ensuring the use of individualised care plans for each prisoner (10)
Study team & acknowledgements

- **Co-investigators:** Mary Turner (PI), Katherine Froggatt, Sheila Payne, Gill Scott, Bob Gibson, Andrew Fletcher
- **Researchers:** Marian Peacock, Sandra Varey
- Governor John Illingsworth, Mick Butler, Gareth Cheetham, staff and prisoners at HMP Wymott
- **Project Advisory Group:** Dr Heather Richardson, Adrienne Betteley, Katrina Forsyth, Sarah Colover, Azrini Wahadin
- **Stakeholder Group:** Anita Dockley (Howard League), Francesca Cooney (Prison Reform Trust), Lesley Dixon (Action for Prisoners’ Families), Tracy Eadie (Recoop)

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