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

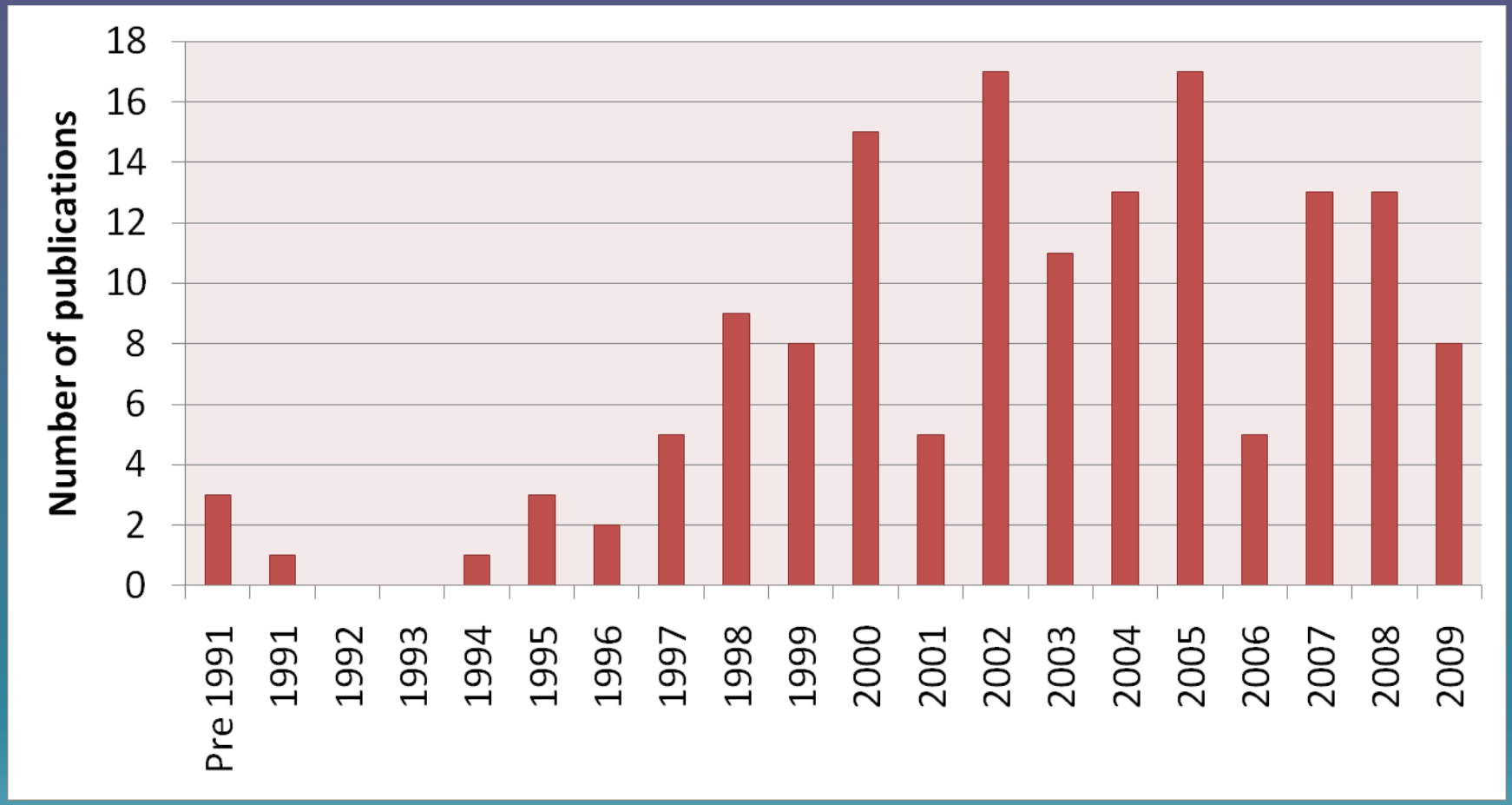
Findings of literature search

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

Country of origin

Country	Number of items (%)
United States	91 (62)
England and Wales	42 (28)
More than one country	7 (5)
New Zealand	3 (2)
Australia	2 (1)
Canada	1 (1)
South Africa	1 (1)
TOTAL	**147 (100)**

Dates of publication



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Type of paper

Type of paper	Number of items (%)
Discursive, commentary or opinion pieces	45 (31)
Description of cases (prisoners, hospice programmes etc)	40 (27)
Empirical research or evaluations	27 (18)
Law, ethics and policy	18 (12)
Statistics on end of life in prison	4 (3)
Other	13 (9)
TOTAL	**147 (100)**

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

	Doctors	Nurses	Healthcare Assistants
Prisons	0	14	3
Hospices	4	5	0
TOTAL	**4**	**19**	**3**

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

Frames of analysis
Current or recent prisoners with end of life care needs
Context
Prison healthcare staff's experience of end of life care
Specialist palliative care staff's experiences in prisons
Links between prison healthcare and specialist palliative care services
Barriers to accessing end of life care in prisons
End of life care tools
Recent developments

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

Area	Prison / hospice	Geographical context
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

Drug issues

"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

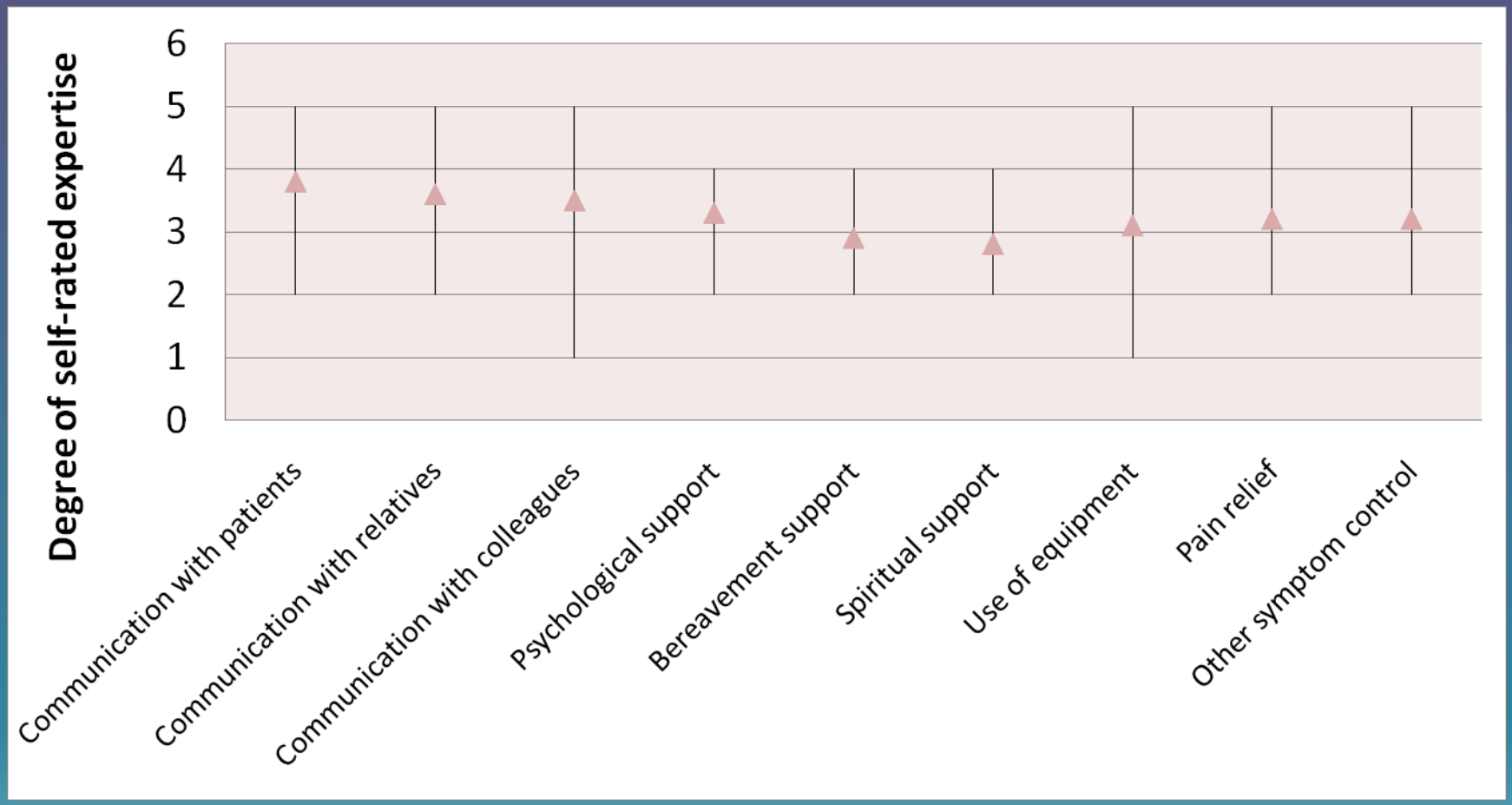
Questionnaire

- 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



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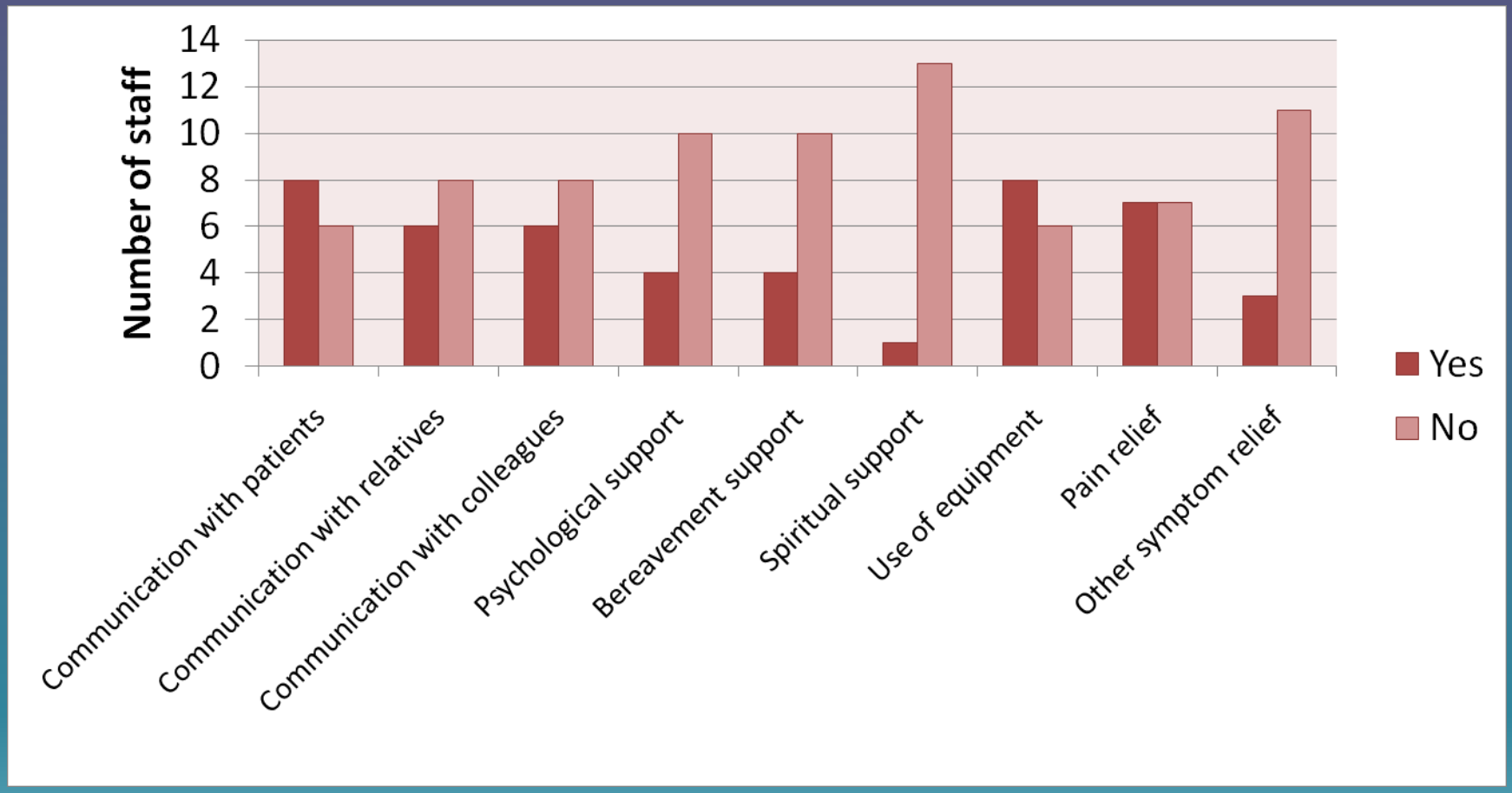
Staff training



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