

Improving palliative care for prisoners: the 'Both sides of the fence' study.

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Introduction

Since 2013, research has been underway in one prison in North West England with the aim of improving palliative and end of life care for prisoners. This paper draws on early findings from the research to explore some of the emerging issues – both challenges and examples of good practice – inherent in this difficult area. To begin with however, some background will be provided to contextualise the research.

Whilst accurate measures of crime rates are notoriously difficult to obtain, there is a consensus that in the United Kingdom crime rates have fallen or remained flat in recent decades. However, over the same time period the prison population in England and Wales has doubled and now stands at around 86,000¹, the highest prison population in Western Europe. There are a number of reasons for this shift, including longer sentences, tougher licence conditions, and a rise in the number of older prisoners convicted of historic sexual offences. In England and Wales there are now 148 prisoners per 100,000 of the population; this compares with 98 in France and 79 in Germany². The prison population, like the general population, is ageing; latest available figures indicate that there are approaching 12,000 people aged 50 and over in prison in England and Wales, and that a third of them are aged 60 and over³. This group constitutes the fastest growing section of the prison population, and has risen by 164% between 2002 and 2015⁴. Many of these 4,000 prisoners have multiple and complex healthcare needs, and live in an environment neither built nor equipped to manage them. There has also been a corresponding increase in what can be described as 'anticipated deaths' in prison – deaths from natural causes that can be foreseen and prepared for, often through the provision of palliative care. The number of natural cause deaths (anticipated or not) in 2014 was 141, the highest on record⁵.

Contrary to what many assume, compassionate release for prisoners with a life-limiting diagnosis is extremely rare; between 2009 and 2013 in England and Wales only 45 prisoners were granted early release on compassionate grounds⁶, although no figures are available for the number of applications that were rejected. Some prisoners do not wish to apply for compassionate release; the length of their sentences and the nature of their offences may mean that they have no supportive network outside prison, and consequently their significant relationships are inside prison with other prisoners and to some extent staff. Thus there is a need to understand what is happening with this older prisoner population, and in particular to begin to overcome the practical, ethical and emotional challenges that dying in prison presents.

A wide range of social and health characteristics of the prison population support the contention that prisoners are a disadvantaged group in our society. Around half of male prisoners were excluded from school, and 47% have no formal qualifications (compared with 15% of the general population of working age. Fifteen percent of newly sentenced prisoners reported being homeless before custody and in 2013-14 only a quarter of newly

released prisoners entered employment on release. Around one third of prisoners (36%) are estimated to have a physical or mental disability, and up to 30% have learning disabilities or difficulties that impact on their ability to cope with prison⁷. Thus prisoners come into prison with considerable disadvantages, and whilst the health of some may improve in prison, for the majority, and particularly older prisoners, this is not the case.

Older prisoners and the increasing need for palliative care

It is widely acknowledged that premature ageing is linked to incarceration, with prisoners' health status generally considered to be equivalent to that of people 10 years older in the general population; it is therefore argued that the age at which prisoners should be counted as 'old' is 50 rather than 60⁸. A significant factor among this population however is that more than 40% are convicted of sexual offences, and the rise in those convicted of 'historic abuse' means that increasing numbers of older people are now going into prison for the first time in their lives. Britain's oldest prisoner was jailed in April 2015 at the age of 96, for offences committed more than 50 years ago, having never been in prison before⁹. This type of prisoner presents a very different set of challenges to the prison service.

Inevitably, as the number of older prisoners increases, the number dying in custody will increase correspondingly, and 2014 saw the highest number of deaths in custody on record¹⁰. As commented above, compassionate release is rarely granted, and even release on temporary licence (ROTL), where a prisoner may be transferred to a hospital or a hospice, raises questions about the balance between dignity and security, with reports from the Prisons and Probation Ombudsman frequently criticising the use of cuffing and restraints on frail and dying prisoners¹¹. Some prisons now provide palliative care facilities, but these are unevenly distributed across the prison estate and little is known about the palliative care needs of prisoners and to what extent these are or can be currently met.

Researching end of life care in prisons

A national End of Life Care Programme was initiated across England and Wales in 2004, and the first national strategy was produced in 2008¹². The central purpose of both the Programme and the Strategy was to improve end of life care for everyone who needed it:

The aim of this strategy is to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. (p.33)

In response to this policy imperative, researchers at Lancaster University were asked to undertake an evaluation of end of life care in prisons across Cumbria and Lancashire¹³. Six prisons were included in the evaluation, which consisted of interviews with prison healthcare staff and with palliative care staff from hospices local to the prisons. Prison healthcare staff also completed a questionnaire which was designed to ascertain their levels of knowledge, skills and confidence in relation to palliative and end of life care, and two illustrative case studies of dying prisoners were constructed to capture some of the many challenges in providing palliative care in a custodial setting. The study highlighted tensions

between the philosophies of care and custody, and revealed low levels of staff confidence in some areas of end of life care such as bereavement support and spiritual support. In particular the study identified that for some prisoners their most salient relationships were with other prisoners, and that this was particularly the case for those whose offences were against their families. In addition to safety and security concerns that might hinder compassionate release or release on temporary licence, this demonstrated a need for care, albeit for a minority, for whom dying in prison was considered to be the most appropriate, humane and decent death. But, as our subsequent work has highlighted, the provision of prison palliative care has an inherent tension and raises ethical questions. There may be a case for high quality palliative care in prisons, but its provision may result in greater reluctance to grant compassionate release if there are appropriate services available. This first evaluation therefore provided the foundation for the current study.

The 'Both sides of the fence' study

The research study, 'Both sides of the fence: using action research to improve end of life care for prisoners' began in June 2013 and will be completed by the end of May 2016. It is taking place in HMP Wymott, a Category C prison with a high number of older prisoners, and is funded by the charity Marie Curie. The overall aim of the study is to develop a model of palliative and end of life care for prisoners that can be shared with other prisons to improve practice. The study uses action research methodology¹⁴, in which the research participants (in this case, prison staff and prisoners) and the research team work together to make changes to practice. The research is designed in two main phases, with a short third phase for consolidating the findings and sharing them with other prisons.

Phase 1: Situational analysis

In Phase 1, we conducted a series of individual and group interviews with a wide range of people both inside and outside the prison. This enabled us to gain a detailed understanding of palliative and end of life care in the prison. It also helped us to identify good practice and some of the challenges of providing palliative care in the complex environment of prison. A total of 62 people were interviewed in Phase 1, including prison officers, governors, chaplains, probation officers, family liaison officers, nurses and other healthcare staff, and older prisoners, as well as specialist palliative care staff from outside the prison and a coroner. At the start of the research we anticipated that ethical concerns would mean that it would not be possible to work directly with prisoners, so this had not been included in the original study design. The prison, however, already had prisoner involvement in healthcare and other forums, and were keen that prisoners should be included in the research. We therefore successfully applied for an amendment to our ethical approval, which allowed us to run focus groups with prisoners and specifically with older prisoners from a unit designated for older and disabled prisoners. The prisoner perspective has been therefore been an integral part of the study throughout.

The interviews both inside and outside the prison encompassed a broad range of people who were involved in providing end of life care in HMP Wymott. They included two chaplains who had established and run a day centre for older prisoners. This was universally viewed as an invaluable resource, and it figured highly in the prisoners' world; it was seen as setting a tone or ethos which many in the prison valued highly, and which shaped the ways in which older prisoners were perceived throughout the prison.

In addition to the interviews and focus groups, we also undertook a case study in which we interviewed a prisoner who was approaching the end of his life. We asked him to nominate up to five people involved in providing care and support for him, whom we also interviewed. This enabled us to capture different perspectives on the same case.

The study site, HMP Wymott, has a high number of older prisoners and had already experienced the challenges of managing anticipated deaths with decency; there were already a number of staff who were interested and engaged with work in these areas. However, like the pattern across most of the country, this work was very dependent on the good will and interest of individuals, rather than being embedded within prison practice. There had been considerable work invested in trying to develop a palliative care facility within the prison that would allow both prisoner families (external) and friends from within the prison to visit and provide support for any prisoner using the service. However, despite the best attempts of staff, they had never been able to progress beyond the planning stage due to the lack of access to funds or the withdrawal of monies anticipated.

There were numerous examples of good practice but within a physical environment that was manifestly unsuitable for a significant proportion of prisoners. There were also negative examples and procedures which made it close to impossible for the prison to adequately meet needs. But from early on in the study there was a very good engagement between research and prison staff and with prisoners and this has formed a key part of how the study has unfolded. Around 18 months into the study, a lead governor for end of life care and older prisoners more broadly was appointed; this individual and other staff who moved into this area of work have been crucial in taking the work forwards.

Having undertaken many interviews and focus groups, all the data were then analysed using an approach called 'thematic networks'¹⁵. The main themes identified through this analysis, which are outlined below, were the environment; healthcare provision; equipment; the implications for staff; and the impact on other prisoners.

The prison environment was not suitable for many of the older, disabled and chronically ill men. In parts of the prison, considerable attempts had been made by staff to try to overcome environmental challenges but physical and procedural constraints made it impossible to address them all. One nurse gave a graphic account of how environmental constraints impacted on one prisoner:

Mr X [was] doubly incontinent in the middle of the night. There was no provision to give him a shower. 'You can't. Everybody's asleep. It's not happening.' So we had to, you know, wash him down, three of us trying to hold him up in a cell like that wide... to wash him, change him. Nobody had clean kit: we were borrowing off the rest of the landing at three o'clock in the morning. (Nurse)

The complex nature of many older prisoners' health meant that they required greater healthcare provision, both in the prison and in external hospital appointments. This increasing demand was problematic at a time of cuts and reductions. Many older prisoners were taking many types of medication, and wing staff were often managing prisoners with dementia and other challenging conditions.

As with the prison environment more broadly, cells and fittings were not designed with old or disabled prisoners in mind. Beds could not take a hospital mattress and most cells were not wheelchair accessible.

Caring for frail and dying prisoners is challenging work, and whilst there were staff who felt suited to it, others were much less comfortable. Even for those who did want to work with this population, there was a need for further training and recognition of the demands inherent in the job:

I think people probably do come into the Prison Service and don't expect to face end of life situations... particularly with older people. I don't think they've got any idea that we have such an elderly community in prison. (Governor)

For all staff, such work has an emotional cost attached to it. Many prison staff were familiar with "bed watching", where ill or dying prisoners are hospital inpatients but accompanied at all times by operational staff. This is usually two officers in the case of the likely risk presented by prisoners at our study site, but may be more, and prisoners may be cuffed to officers. Whilst officers described situations where they had struggled with aspects of bed watching, such as appraising risk and interactions with medical staff, they described the challenges of being around terminally ill prisoners day to day on the wings as being of a different order. Being faced daily and often for weeks or months by prisoners with chronic or terminal illnesses demanded skills and raised issues that officers did not feel that they were trained to meet. Simply being around those who were facing the end of life raised issues about mortality for staff, in a climate where the emphasis was almost always on being tough and where talking about feelings could be experienced as weakness.

Similarly for prisoners there are practical and emotional challenges. It is hard to be around others who are dying, and many identified fears about what the future might hold. Despite aspiring to provide the equivalent of mainstream NHS care, prison healthcare cannot always meet these standards, and this raised further anxieties amongst prisoners who feared becoming sicker. As one older prisoner reflected:

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... there's no system in place for anybody who is in real bad pain. (Prisoner)

Phase 2: Cycles of action

Phase 2 consisted of 'cycles of action' which were identified following analysis of Phase 1 data. This is the central component of action research, in which participants are guided and supported by the researchers to identify, discuss and plan improvements, with researchers facilitating this process. A key element of action research is engagement with the research participants¹⁶, and the willingness of staff at HMP Wymott to collaborate with the research team has been critical to the success of the project.

At the start of Phase 2, discussions with staff led to the identification of three main strands of work around prisoners, prison staff and palliative care practices. Work in all three strands is still ongoing, but perhaps the most successful to date has been the work with and for older prisoners. A key first step was the establishment of an older prisoners group, which meets every two months with prison staff and members of the research team. This group has generated numerous ideas for improving end of life care, and a number of changes have already been implemented. For example, one suggestion was for written information specifically for older prisoners approaching the end of life. The researchers and prison staff have worked closely with a group of older prisoners and a leaflet is now in the final stages of development.

Prison staff also asked the research team to undertake a survey of older prisoners, and together a survey questionnaire was developed and distributed to more than 200 prisoners over the age of 55. Detailed analysis of the results is still underway, but preliminary findings show high levels of frailty and poor health amongst this population, as well as many concerns and anxieties around safety, medication, healthcare, social care, and the future. Staff were surprised and concerned by the number of older prisoners who described not feeling safe, and began to rapidly address this key issue. A major part of responding to these concerns was to establish an older prisoners' unit, a cloistered environment within a main wing for men aged 50 and over. Relatively small changes, such as the installation of medication lockers in each room, have made a significant difference to the lives of older prisoners, as the following feedback from prisoners on this wing demonstrates: *"I feel much safer knowing I'm not going to be hassled by other prisoners"*, and *"This unit encourages respect both ways"*. The involvement of older prisoners in this work is particularly highly valued, as this comment from a member of the older prisoners' group shows: *"One of the most important aspects of the work being done here is that prisoners are very much involved. The fact that our views are actively encouraged and taken seriously is invaluable to our sense of self-esteem. It means such a lot."*

Phase 3: Stakeholder deliberation

Involvement of key stakeholders in deliberating the project's findings is a valuable way of ensuring that appropriate and meaningful recommendations are developed at the end of the study. In Phase 3 therefore, the research team engaged with as many stakeholders as possible, through a series of workshops and a 'deliberative panel' meeting.

Three workshops took place in HMP Wymott (two with prison staff and a third with older prisoners), where key findings were discussed and debated in small groups facilitated by members of the research team. At the end of each workshop, participants were asked to identify the single most important element that needs to change in order to provide high quality palliative care in prisons. Several issues were identified by both staff and prisoners, including the need for a national strategy for older prisoners; better communication at all levels (between and within organisations); improved (and purpose-built) environments for older prisoners; an integrated, individualised approach to care; and the need for a national debate about the sentencing of older prisoners. Participants were then asked to identify the one element of palliative care at HMP Wymott of which they are most proud and would most like to share with other prisons. The groups identified supportive and dedicated staff; a willingness to talk about end of life care; the importance of having genuine interest and

support from the Governor; co-operation and a sense of community between older prisoners themselves; and exemplary support provided in HMP Wymott by the 'Cameo' day care centre for older prisoners.

These and other issues arising from the research were considered at the final deliberative panel meeting. Participants at this meeting included representatives from the prison service, prison advocacy organisations, health services, palliative care organisations and academia. Again, facilitated group work was undertaken to discuss the findings and start to develop recommendations for policy and practice. The recommendations are currently being developed further through a consensus exercise, and will be finalised before the end of the study.

Conclusions

Analysis of data is ongoing and the final results will be published at the end of the study. However, it is already clear that the number of prisoners requiring palliative and end of life care is likely to continue to increase in the foreseeable future. This is in part because the prison population, like the wider population, is ageing, and with increasing age comes increasing ill-health and frailty. This change in the prison population presents significant practical, ethical and emotional challenges for prison staff and prisoners, but the prison service needs to respond to these challenges in order to ensure high quality palliative care for the growing numbers of prisoners who need it.

The study also highlights the need for a national, public debate about the rising numbers of older prisoners. The increase in those dying in prison is largely unplanned, and is the result of changes in sentence length, licence conditions and other factors. This has turned sentences that were not meant to be life sentences effectively into sentences from which the person will never be released. There needs to be a more open debate around these complex issues to determine if this is indeed what is intended, and a frank acknowledgement of the consequences. Compared to the debates and legal challenges to "whole life tariffs", there has been little public or political discussion of what it means in practice to sentence someone in their eighties to a sentence that will almost inevitably mean that they will die in prison, compared to the same sentence imposed on a person in their forties.

There are also questions about whether prison is an appropriate place for a person with multiple, complex health conditions which may include illnesses such as dementia. There is limited but accepted provision for diversion schemes to keep those with complex mental health problems away from prison and into more appropriate facilities, but nothing comparable for those with physical health problems and no suitable alternative provision to divert to. There is also a need to determine what types of palliative or end of life care provision are needed and where, and to begin to grapple with the ethical and practical dilemmas raised in providing facilities that will then be used and which could arguably increase the numbers of older, chronically ill and dying prisoners.

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