

Palliative care in UK prisons: practical and emotional challenges for staff and fellow prisoners

Abstract

Despite falling crime rates in England and Wales over the past 20 years, the number of prisoners has doubled. People over the age of 50 constitute the fastest growing section of the prison population, and increasing numbers of older prisoners are dying in custody.

This paper discusses some of the issues raised by these changing demographics, and draws on preliminary findings from a study currently underway in North West England. It describes the context behind the rise in the numbers of older prisoners, explores the particular needs of this growing population, and discusses some of the practical and emotional challenges for prison officers, healthcare staff and fellow prisoners who are involved in caring for dying prisoners in a custodial environment.

Key words

End-of-life care

Palliative care

Prison

Frail older adults

Background and context

Introduction

In the United Kingdom (UK), the number of older prisoners has rapidly increased in recent years (Prison Reform Trust 2015) and the need for palliative and end-of-life care has grown correspondingly. This paper will draw on early evidence from a current research study to discuss how British prisons are addressing the needs of older and dying prisoners, and will explore some of the complex challenges they face. To begin with, however, some key issues relating to prisons and prisoners in the UK will be described.

Political, philosophical and legislative context

It is important to situate the contemporary penal system in the UK in both a global context and in the context of recent social and political change, in order to make sense of the institutional practices described. Prison systems and regimes vary considerably across the globe, and range from very harsh and punitive systems (some of which have the death penalty as the ultimate sanction) to more liberal and humane systems where a key focus is on the rehabilitation of offenders. The UK steers something of a middle course between these two philosophies; the death penalty was abolished in 1965 but, as will be discussed below, sentences have become more punitive in recent years. However, Her Majesty's Prison Service (HMPS) emphasises humanity and rehabilitation in its mission statement:

Her Majesty's Prison Service serves the public by keeping in custody those committed by the courts. Our duty is to look after them with humanity and help them lead law-abiding and useful lives in custody and after release. (HMPS 2015)

HMPS is run by a department of the Government, so is influenced by the ideology and attitudes of the political party in power towards crime and criminals; it is therefore subject to change as successive political parties take charge of the country.

Neoliberalism

One way of viewing and interpreting the UK prison system is through the lens of neoliberalism. Hall and Lamont (2013) describe neoliberalism as:

A wide ranging shift in prevalent ideas and social relationships privileging more intense market competition, less state intervention, and an entrepreneurial orientation to action. (p.3)

Over the last three decades, prison regimes have undergone significant changes and the number of prisoners in England and Wales has doubled to almost 86,000 (Ministry of Justice 2015); it is a fundamental contention of this paper (drawing on the work of Wacquant and others) that it is the growth of neoliberal discourses and practices that has been the major driving force behind these changes and has shaped prison dying in the UK. What Wacquant, Eick and Winkler (2011) describe as a 'penal surge' (p.10) has resulted in a significant expansion of the prison population; one major ramification of this is a considerable increase in the number of older prisoners, many of whom will die in custody. Wacquant argues that this increased incarceration is not merely a consequence (possibly unintended) of neoliberal policies, but rather is essential to the 'crafting of the neoliberal state' (Wacquant 2012 p.40).

Neoliberalism has been shown to have an impact on a wide range of indicators of health and wellbeing (De Vogli 2011; Coburn 2004); the focus of this paper, however, is how the

changes resulting from neoliberalism impact on the healthcare, and specifically end-of-life care, that can be delivered to older prisoners. Prisons have not been designed with older or disabled prisoners in mind, and recent changes have exacerbated the constraints to care resulting from the prison regime and the lack of resources. However, it is also argued that neoliberalism has a negative impact on both the discursive resources that people draw upon for self-protection, and on collective identities (in this case identities as prisoners and as staff), as Hall and Lamont (2013) explain:

Groups do not simply call passively on existing sets of resources. Social resilience is the product of much more creative processes in which people assemble a variety of tools, including collective resources and new images of themselves, to sustain their well-being in the face of social change. (p.14)

Neoliberalism promotes individualism and erodes collectivism (Rose and Miller 2008), and in the case of prisons undermines the identities of 'screw' (officer) and 'con' (prisoner), which embody aspects of a positive collective identity and well as pejorative qualities. For officers, this encompasses a sense of employment stability and investment in forms of solidarity which can be vital in risky situations (and can be problematic in officers' unwillingness to 'grass' on any other officer's inappropriate behaviour). For prisoners, this is partially achieved by forms of moral boundary drawing concerning who is and is not an 'ordinary decent criminal' and by the maintenance of an acceptable distance from officers. Neoliberal governance regimes in prisons as described by Crewe, Liebling and Hulley (2014) erode these distinctions and protections, leaving both staff and prisoners more vulnerable when faced with an older, frail and dying prison population.

Organisation of prison services in the UK

The prison population in the UK (as in other Western countries) has been rising steadily in recent years, despite falling crime rates. England and Wales has the highest prison population rate in Western Europe at 148 per 100,000 of the population; this compares with 79 per 100,000 in Germany and 82 per 100,000 in Switzerland (Walmsley 2014). More than 95% of UK prisoners are male, and a disproportionate number are from minority ethnic backgrounds (26% compared with 10% of the general population) (Prison Reform Trust 2015).

The different nations of the United Kingdom have separate prison services; this paper will focus on prisons in England and Wales, as this is where we have undertaken our research. In England and Wales, the Ministry of Justice is responsible for Her Majesty's Prison Service (HMPS), and services are commissioned and managed by the National Offender Management Service (NOMS), which is an executive agency of the Ministry of Justice.

There are 117 prisons in England and Wales (Prison Reform Trust 2015), which provide services for male, female and youth offenders. Each prison is managed on a day-to-day basis by a team of senior management staff (usually called 'Governors'). Prisoners are assigned one of four security categories, depending on how likely they are to attempt escape and their risk of harming others. Category A prisoners are housed in the most secure prisons; prisoners can be moved to lower security establishments if their risk factors are considered to have diminished. Some prisoners are classed as vulnerable prisoners or 'VPs'. These are prisoners who because of the nature of their offence, physical or mental health status, age or other issues, are assessed as being vulnerable to attack or manipulation by other

prisoners and are therefore not considered suitable to be housed in 'normal location' with younger, fitter prisoners. VPs are housed in completely separate areas of the prison, and rarely if ever come into contact with ordinary prisoners.

The impact of 'Benchmarking'

In 2013-4, an exercise called 'Benchmarking' took place in English and Welsh prisons. All aspects of the prison service from operational management to staff pay structures were scrutinised, with the aim of ensuring best value for money from public resources. According to the NOMS Business Plan for 2013 – 2014, the 'vision' for NOMS and the Ministry of Justice was:

To deliver a transformed justice system and a transformed department, which is more effective, less costly and more responsive to the public. (NOMS 2013, p.6)

The UK has the most privatised prison system in Europe (Prison Reform Trust 2015), and the Benchmarking process explicitly draws on neoliberal policies and practices to introduce further competition and market forces into a service that was previously located in the public sector:

We are determined to further reduce the cost of prisons. We will do this by applying the innovative delivery models and benchmarked efficiency savings achieved through competition to the whole prison estate. Core custodial services will continue to be delivered by the public sector, but at much lower cost. (NOMS 2013, p.10)

Perhaps unsurprisingly, prison officers were extremely critical of the benchmarking process, which they perceived as damaging and even dangerous, and many of them, particularly experienced officers, have taken early retirement or found other jobs. The combined effect of rising numbers of prisoners with falling numbers of prison officers means that the ratio of prison officers to prisoners dropped from 1 to 2.9 in 2000 to 1 to 4.8 by the end of September 2013 (Prison Reform Trust 2014).

The 'Both sides of the fence' study

Having provided some background and context, this paper will now consider the group of prisoners most likely to require palliative and end-of-life care in a custodial setting. The following discussion will draw on early findings from a current research study called: 'Both sides of the fence: using action research to improve end of life care for prisoners'. In the first phase of this research, focus group and individual interviews were undertaken with a wide range of prison staff (healthcare staff, prison officers and others) and prisoners. Extracts of data from the study will be used to illustrate some of the issues discussed in this paper.

Older prisoners and their needs

The growing older prisoner population

The fastest growing section of the prison population is made up of older men, and at the end of March 2015 there were 11,720 people over the age of 50 held in prisons in England and Wales (14% of the total prison population). This number included 3,984 prisoners aged 60 and over, and 102 aged 80 and over (Prison Reform Trust 2015).

There are three key reasons for the increase in older prisoners. First, sentencing has become tougher and more people are imprisoned for longer; there are now mandatory life sentences for a wider range of offences and courts are more inclined to imprison much older people. Second, licence conditions that allow people to be released towards the end of their sentence have become more stringent, so more people are recalled back to prison while out on licence. Third, there has been an increase in the number of people successfully prosecuted for historic sexual offences; 42% of prisoners over the age of 50 have been convicted of sexual offences (Prison Reform Trust 2015). These three changes, particularly the latter, have contributed to a shift in the prison population, away from young men from fractured social backgrounds, poor educational attainment, drug or alcohol problems and a history of offending, towards older men, many of whom are in prison for the first time in their lives. This raises a number of challenges for the prison service, as one governor who was interviewed as part of our research identified:

You are getting people in their late 60s, 70s – even into the 80s – which is [pause] 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. (Governor)

This interviewee highlights a key issue inherent in this population: that the need for control is less but the need for care is much greater. This requires a major shift in the role of prison officers and, as will be further discussed below, presents significant challenges for staff.

Healthcare for prisoners

The interview extract above also clearly identifies medical and health issues as a particular need of this older prisoner population. The UK has the world's largest publicly funded health service, and since 1948 the National Health Service (NHS) has provided free access to healthcare to all who need it; this includes prisoners and, according to the Ministry of Justice (2014), prisoners receive the same healthcare and treatment as anyone outside of prison. Healthcare in prison is provided free of charge, but it has to be approved by a prison doctor or a member of the healthcare team, who are employed by the NHS to work in prisons (Turner and Payne 2011). Some prisons have in-patient facilities but most only have out-patient clinic services. If prisoners need investigations or treatment that cannot be provided in the prison, they will be transferred either to another prison with in-patient facilities or to a hospital or other NHS facility outside prison. However, transferring prisoners out of the prison is resource-intensive, as it usually requires two prison officers to escort and guard the prisoner throughout the visit.

The increasing number of older prisoners has created a new and growing problem for HMPS. Research suggests that the physiological age of older prisoners is approximately ten years older than their chronological age (Prison Reform Trust 2014). With ageing comes increasing ill-health, and there is now a growing population of frail, older prisoners who have multiple co-morbidities, disabilities or life-limiting conditions. Many have limited mobility, some use wheelchairs and a few are unable to get out of bed. Their healthcare needs are frequently complex and include assessment and monitoring, medication and other treatments, and specialist intervention from clinicians outside the prison; many require assistance on a daily basis with personal care such as bathing, toileting, eating and

drinking. One prisoner in our study also highlighted the stress experienced by older prisoners:

Prison is a very stressful thing and, for an elderly person to come into prison, it is very stressful, very worrying. [...] Their health does deteriorate in an environment like this.

(Prisoner)

A small but growing number of these prisoners also require palliative care, and some of the complex issues around dying in prison will now be explored.

Dying in prison

In England and Wales in 2014 there were 243 deaths in custody, the highest number on record; of these, 141 were due to natural causes (Prison Reform Trust 2015). One prisoner in our study voiced his concerns about dying in prison:

I mean I'm in my 50s now but if anything was serious [pause] well, the prison system scares me anyhow because if you are seriously ill, there is a lack of care [pause] people coming to the end of their lives and people who can hardly [pause] so I've seen people die. It's a joke how they treat people, you know. (Prisoner)

All deaths in custody have to be investigated by the Prisons and Probation Ombudsman (PPO), an independent review body. The Ombudsman has repeatedly raised concerns about the way in which very ill and dying prisoners are sometimes treated (PPO 2013a, 2013b, 2014, 2015), and in particular has highlighted the inappropriate use of restraints (PPO

2013b). It is not always easy to achieve a good balance between security and humanity, however, and staff can often find themselves in a very difficult position when dealing with dying prisoners.

Palliative care in prison

The PPO (2013a) acknowledges that, given the increasingly ageing prison population, caring for those approaching the end of life is 'a growing responsibility for the Prison Service' (p.17). Some prisons have started to explore how palliative care provision might be improved, and a small number have already developed facilities and services. In our current study, the prisoners themselves were very much in favour of developing good prison palliative care, which was seen as valuable for both prisoners and their families:

But then at least, if that was there, if that was here and you get that care, then a lot of the families will think, 'Well, hold on, he's not getting out but at least he's got something comfortable [pause] decent and comfortable. And at least we can come and see him and it not be like a prison cell. (Prisoner)

However, findings from an earlier study (Turner, Payne and Barbarachild 2011) revealed significant challenges in delivering palliative care, including constraints within the prison regime that make giving appropriate and timely medication for pain and other symptoms very difficult. One of the nurses in the current study also highlighted this challenge:

And what I think is probably the most challenging sometimes is getting on top of symptoms because symptom control is difficult by the fact that [pause] some of the

medications need two nurses to administer. You've got to be days ahead to be able to order things to have them in place. (Nurse)

Prisoners too were aware of this difficulty, and understood that despite the best intentions of staff the system might not be flexible enough to deliver adequate palliative care:

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

Systemic issues such as this call into serious question the Ministry of Justice's (2014) contention that prisoners receive the same healthcare as the rest of the population.

Compassionate release

It might reasonably be assumed that old, frail prisoners would be released at the very end of life and allowed to die outside prison. However, although compassionate release is possible, stringent criteria have to be met before it can be granted. Not only does the prisoner usually have to be considered to be less than three months away from death (which can be very difficult to predict) but also the nature of his offence is taken into consideration; thus release on compassionate grounds is not considered appropriate for most offenders.

The complexity of compassionate release has been further compounded in recent years by several high profile cases in which prisoners were expected to die and were released, but then went on to live for several years (Turner, Barbarachild, Kidd and Payne 2009). In the wake of the controversy surrounding these cases, the House of Commons Justice

Committee (2013) has acknowledged that 'Release on compassionate grounds remains a difficult decision for Governors and in some cases the Minister [for Justice]' (Paragraph 99). Instead it advocates that more palliative care suites should be developed in prisons. This recommendation indicates a shift in policy away from compassionate release towards the development of palliative care facilities and services within prisons, which, as shall be seen, present a different set of practical and emotional challenges for prison staff.

Practical and emotional challenges

This paper has described some of the constraints and complexities inherent in prisons and prison systems in the UK that impact significantly on the delivery of palliative and end-of-life care for prisoners. The remaining discussion will focus primarily on prison staff (both discipline and healthcare staff) who are involved in trying to meet the particular needs of this group of prisoners; however, some specific challenges faced by prisoners who provide care and support for dying prisoners will also be considered.

Prison environment

Environmental issues, including the design, layout and facilities of the buildings in the prison estate, frequently present challenges for both staff and prisoners. Many buildings are old and were designed for younger, fitter prisoners than those housed in them now. For example, one prison that took part in an earlier study (Turner et al 2011) was housed within a medieval castle that was also a historic 'listed building', which meant that alterations such as installing lifts or widening cell doors to allow for wheelchair access simply could not be made. Even newer prisons are not necessarily suitable for older people. In our current

study, one Governor described the prison (which was built in 1979) as 'not fit for purpose', but acknowledged that there is no money to upgrade the facilities.

A typical cell is around 2 x 2.5m in size (too small for a hospital-type bed) and prisoners' access to showers, clean bedding and clothing is restricted, as one nurse graphically describes:

Mr H, for example, [was] incontinent, 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, you know, wash him down, three of us trying to hold him up in a cell like that wide [pause] 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)

For security reasons, prison officers have to be present when nurses go into cells to assess or treat sick patients, but it can take a long time to bring in sufficient numbers of officers, particularly at night, and if a patient has an acute need (e.g. heart attack, epileptic seizure or diabetic crisis) the healthcare team might not be able to respond quickly enough. Security issues can also impact on family members wanting to visit very sick and dying prisoners.

Staffing and resources

This paper has already highlighted how the 'benchmarking' process is having an impact on staff numbers and workload. Experienced prison officers in our study report that the best way to keep the prison running smoothly is to maintain good communication with prisoners;

this of course requires that staff have time to talk and listen to prisoners. The study also shows the need for staff to communicate differently with older prisoners, as illustrated in the following interview extract:

I think some of the staff probably find it difficult – or did find it difficult initially – because it was [pause with the younger population it's more you front it out and shouting and the older guys you don't, [pause] they don't need that. (Governor)

As noted above, the 'benchmarking' process has resulted in the loss of substantial numbers of experienced officers; this means that amongst younger officers there may be a lack of skills and experience to approach different prisoners in the best way.

Personal and emotional consequences

One of the most significant challenges lies in the emotional responses that staff might experience when confronted with old and dying prisoners. Most prison officers do not expect to be working in close proximity to illness and death when they take up the job; one senior officer in our study described the environment as 'more like a care home than a prison wing', and reflected on how shocked and surprised staff are when first confronted by it. This has resonance with the seminal work of Isobel Menzies Lyth, who in the late 1950s observed large numbers of student nurses and theorised how institutions develop protective mechanisms to enable staff to cope with the anxiety inherent in close involvement with illness and death (Menzies Lyth 1960, 1988). Although her work was with student nurses, there are some obvious parallels with prison staff, particularly discipline staff who have had little or no training or preparation to work with frail, sick people.

Menzies Lyth described these protective mechanisms as ‘social defences’, embedded in the culture and routines of the organisation. Such defences included the interchangeability of staff (they all look the same in uniform and can be moved around the organisation as required); the breaking down of the work into tasks; and strict hierarchical structures that prevent the individual from making decisions or using their initiative. However, Menzies Lyth (1960) argued that these defences were ineffective, because the staff were still subject to the difficult emotional demands of the work but were disengaged from the patients, and were thus not able to engage effectively with the root of the anxiety in order to work through the feelings it evoked. Over half a century after Menzies Lyth’s original work, this tendency to disengage in order to cope is illustrated in the following interview extract from our current study:

I don’t know, it’s hard to sort of think about how you feel because you just [pause] you just go into like robot mode [pause] it’s just a job. [...] I don’t know, prison nursing makes you very hard-faced. (Nurse)

Prison officers too have to find ways to cope with the emotions engendered by their work; one Family Liaison Officer spoke about attending the funeral of a prisoner, describing it as ‘pretty grim really’. Some prison officers undertaking this ‘grim’, difficult work have never previously had to deal with older people in custody, and indeed many do not expect to have to take on the role of care worker when they apply for a job as a discipline officer. However, healthcare staff also experience emotional challenges when providing care in a custodial environment:

*It's difficult and especially when you're used to your patient, attachment is there [...]
But my relation with them is just like a normal patient; I never see them as a prisoner
[...] And when you get attached, you know... we just had a recent death of Mr A and he
died of heart failure. He had a history of heart failure, and he suddenly collapsed two
weeks ago [...] He used to come here and we used to chat, used to talk. So when they
die, you feel [pause] you feel hurt[pause] But you just have to carry on. (Prison Doctor)*

This doctor's desire to view the person as a patient rather than a prisoner illustrates the moral conflict that can be engendered by the current practice of imprisoning increasing numbers of older, frail people, and how important it is for staff to maintain their humanity. One nurse described how she has to deal with attitudes of people outside prison that are not necessarily in tune with her own views:

*And I know that a lot of people are very [pause] if you sort of talk to people out in the
community that don't have an understanding of prisons or anything like that, they're
very judgemental towards, 'Well, you know, how could you do anything to help
prisoners? They're not very nice people.' They're people at the end of the day so you
[pause] it is amazing how you put aside any thoughts or feelings you have for who they
are or what they are, as to care for them for being a person. (Nurse 3)*

Prisoners, particularly sex offenders, are frequently vilified in the British media, and many people do not believe that they should be allowed a dignified and pain-free death. This adds an additional layer of challenges for those trying to improve end-of-life care for older prisoners, many of whom are sex offenders. Staff often feel unable to talk about their work

or share models of good practice outside their workplace for fear of criticism by family, friends and even sections of the media. Prison officers too can feel very conflicted and have to rely on their own humanity:

I think everybody no matter what their background is deserves a level of care [at the end of life], a level of dignity, and their families, they also should be receiving that support. (Prison Officer)

Fellow prisoners

For some dying prisoners, particularly those who perhaps because of the nature of their offence no longer have links with family and friends outside prison, the most salient relationships they have are with other prisoners. Many prisons employ more able-bodied prisoners as ‘buddies’ to assist with duties such as collecting meals or making hot drinks for prisoners who are not physically able to do it for themselves. Because many of the old and ill prisoners are sex offenders, it is not deemed safe or appropriate for fellow prisoners to provide personal care. However, regime constraints mean that other prisoners may have to step in to provide personal care, even though this may not be officially sanctioned or acknowledged by prison management; this is exemplified in the following extract from our current study:

Well, in the past three or four months we’ve had two people on here [who] were dying of cancer [...] Night-time there was no care at all for them and it was left to us to look after them, like lift them up, take them to the toilet, etc, etc. And as for this pain relief

– what pain relief? That’s a joke. You know, but it was basically left to our own devices because at night-time, as you know, we’re locked up. (Prisoner)

Nevertheless, some prison officers appear sensitive to the needs of fellow prisoners and acknowledge that when a prisoner dies his friends in prison need to be supported:

So we said a prayer with [chaplain] and everybody sat quietly and we stayed with them and then, when he’d gone, I said, ‘Well, he’s gone now lads, let’s go back to the landing and thank you very much.’ And, you know, some of them had a bit of a cry, but we need to give them [pause] you see we give them support as well when somebody dies because it’s their comrade, their[pause]family. (Prison Officer)

Conclusions

HMPS has begun to respond to the challenges presented by dying prisoners, and some good examples are emerging of palliative care services being initiated and strengthened. In line with the recommendations of the House of Commons Justice Committee (2013), some prisons have developed palliative care suites by converting cells to make room for hospital beds, hoists and other equipment; these suites usually include en suite bathroom facilities, as well as a family room, which can greatly help to improve the experience for prisoners, family members and staff. However, there are wide variations between prisons, and the Ministry of Justice has yet to produce policy guidance in relation to palliative care provision across the whole service.

There is a clear need for both training and support if prison officers and healthcare workers are to be expected to cope with the emotional challenges of caring for dying prisoners. In an innovative project currently underway in the North East of England, the Prison Service, the NHS and Macmillan Cancer Support (a national cancer charity) have to date trained over 90 healthcare and prison staff in palliative care (House of Commons Justice Committee 2013), and this project has reaped numerous benefits for both staff and prisoners. Preliminary findings from our current study also point to the importance of providing appropriate support to all concerned after a death in prison.

The increase in the number of older prisoners shows no sign of slowing down in the foreseeable future, and prisons will continue to face the challenges of balancing security with humanity to find ways of improving palliative and end-of-life care for those dying in custody.

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