Blog of the Month

APMJ Blog of the Month: November 2021 Edition

Dr Clare Greenwood is an Internal Medicine Trainee. For this month's APMJ blog post, Clare describes a case report illustrating some of the challenges in providing palliative care to members of the prison population. Thank you, Dr Greenwood!

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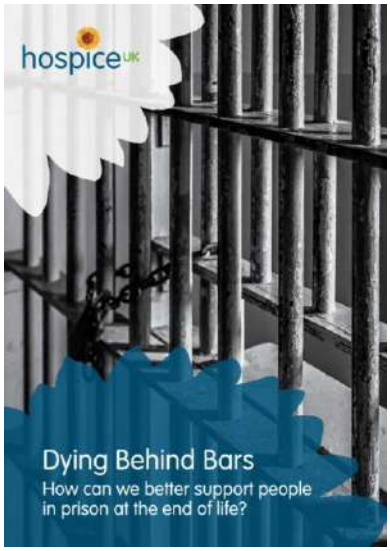
Challenges to providing palliative care in the prison population



Prison healthcare has been under the remit of the NHS since 2006, yet a recent Hospice UK report "Dying Behind Bars" published in April 2021 found a significant disparity in the quality of end of life and palliative care provision for offenders compared with the general population.

During COVID, while working on a respiratory ward, I became acutely aware of some of these challenges. In this blog I am going to explore the challenges on an individual level and an institution wide level.

Case Study

Two prison officers sat outside a side room with the door closed. Inside, a cachexic man was handcuffed to a hospital bed on high flow humidified oxygen. He had been admitted with worsening breathlessness and found to have lymphangitis carcinomatosis from his advanced lung cancer. For the past week of ward rounds, he has been on increasing amounts of oxygen, including a failed trial of ward based NIV. He is currently at his ceiling of care and his prognosis is very poor. With any other patient, I would have called the family to break the bad news that he was unlikely to survive this admission, and may be approaching the end of his life. However, as this patient is in custody and deemed a high security risk, all communication has to be passed through the prison governor and prison nurse, who will in turn contact the family. We telephone them daily, emphasising the poor prognosis. If he had deteriorated suddenly, it is doubtful

whether this system of relaying messages would have summoned the family in time, that is, even if it was felt it was worth the risk of a potential escape attempt allowing them to know his whereabouts.

Communication with the patient himself was hampered by the heavy custodial presence. To have frank discussions about his refusal of further NIV was complicated by the constant presence of the prison officers. It was impossible to tell whether the decisions were truly being taken without undue influence.

The handcuffs made physical care and treatment difficult. He needed unlocking to be allowed to engage with mobility physiotherapy and to allow arterial blood gases. If he had needed cardiopulmonary resuscitation, he would have needed the handcuffs removed before we could defibrillate to avoid the electricity jumping.

For the medical team, I found at times it was a challenge to keep our approach free from bias given these constant reminders that the person in front of us was considered by the courts to be dangerous.

Moreover, the circumstances presented new and unfamiliar challenges of how to ensure patient-centred care was delivered despite the challenges presented in this case- what options were possible when discussing preferred place of death? How easy is it to organise palliative long-term oxygen therapy?

With this case in mind, I have explored the recent publications on this subject and have summarised some of the key themes on the topic.

<u>The scale of the problem</u>

Challenges in providing palliative care in the prison population are a topic of significant interest in recent years, with a major publication "Dying Behind Bars" from Hospice UK in 2021 and a national guidance framework from Macmillan Community of practice in 2018 titled "Dying Well in Custody". Dying Well in Custody has been endorsed by the NHS England Ambitions for Palliative & End of Life Care Partnership and supported by Her Majesty's Prisons and Probation Service and the Prisons and Probation Ombudsman.

It is likely to become an increasingly relevant conversation, as the UK is faced with an ageing prison population. Adults over the age of 50 make 16% of the UK population, but due to trends in sentencing (with an increasing number of historic sex offences being prosecuted) this is predicted to rise to over 25% in the next few years based on Ministry of Justice figures[1], with an associated rise in medical co-morbidity and frailty including terminal conditions requiring palliative care. The number of deaths in prisons due to natural causes has tripled over the last 20 years[1].

The prison population is also over-represented for risk factors of malignancy and chronic health conditions, related to higher rates of smoking, alcohol use, substance abuse and blood borne viruses including hepatitis and compounded by poor engagement with healthcare and health promotion services[1].

<u>Why is it difficult to implement a prison palliative care strategy?</u>

Numerous barriers have been identified to good palliative care provision in the prison environment. These include rigid medication schedules, limited adaptability of the physical environment (beds being too narrow for pressure relieving mattresses, areas not being accessible by wheelchair), lack of personalised care (such as soft diet or thickened fluids) and a lack of specialist training or awareness by prison staff[2,3].

Less than a third of prisons have an established link with a nearby hospice[1]. Bereavement support for staff and fellow inmates of a terminally ill patient is only reported to be offered 22% of the time[1]. The majority

of inmate palliative care is delivered by peer volunteers, with a small number of prisons having established palliative care provision.

What services exist?

At present there is no national standard of procedure for providing palliative care within prisons, and the levels of training, understanding and adaptations are varied between institutions. The charter "Dying Well in Custody" highlights that prisoners should have fair access to coordinated care, and that prison staff should be adequately trained in managing the terminally ill[2].

An increasing number of prisons are building designated palliative care cells or wings, although existing structures are often outdated and difficult to adapt.

Specialist input has been established via local hospice partnerships, such as the well-established link between HMP Dartmoor and St Luke's Hospice in Plymouth, which is also linked to the local Macmillan Living With and Beyond Cancer service.

Recoop is a charity organisation which has designed and implemented a 'wing-based Buddy system', where prisoners are provided with health and social care training to become carers for inmates with terminal conditions. It also provides training for kitchen staff on how to prepare food for those on a textured or softer diet, and for medical staff on setting up and monitoring syringe drivers.

What are the options for preferred place of care/ preferred place of death?

Prisoners are able to apply for compassionate release if they have a prognosis of less than 3 months. Data presented in the Royal College of Nursing report, "Avoidable natural deaths in prison custody: putting things right" showed only 23% of these were granted between 2016-2019, and 43% of cases were still 'under consideration' at the time of death[3]. It is therefore important that this process is initiated in a timely manner and support given with completing the application where needed. Given the often complex social backgrounds of prisoners including high rates of homelessness and institutionalisation, many do not feel able to, or choose not to apply for compassionate release.

Examples of good practice described include offering prisoners the opportunity to transfer to prisons with specialist palliative care units. Alternatives include creating personalised care plans with the support of the local community palliative care nurses, allowing rapid response Macmillan nurses to administer anticipatory medications and involving social workers to review care provision.

As more prisons adopt the framework laid out in the Dying in Custody charter, it is hoped that they will be able to deliver high quality individualised, person centred end of life care, in line with national palliative care ambitions.

This patient was one of many with palliative care needs that I encountered during my time on respiratory in the first wave. The principles of palliative care emphasise treating patients as individuals and understanding their priorities and wishes. The criminal justice setting is not designed to accommodate this approach. Caring for someone with these conflicting approaches can be challenging, and on reflecting on this case, I wonder whether we always had the right balance. Ultimately he made some recovery from his acute illness and was able to be transferred back to the prison medical wing with LTOT with support from the Lung cancer CNS as per his request.

Further reading/ References

Dying Behind Bars, Rini Jones et al (2021) www.hospiceuk.org/dying-behind-bars-report

Dying Well in Custody, Prof Bee Wee et al (2018) www.england.nhs.uk/eolc/resources/

Avoiding Natural Deaths in Custody, Prof Jenny Shaw et al (2020) www.rcn.org.uk/-/media/royal-college-of-nursing/documents/clinical-topics/nursing-in-justice-and-forensic-healthcare/prevention-of-natural-deaths-in-custody-final-nov-2020.pdf?la=en&hash=0992599A705070ED06C9821DDE97B505