Encountering offenders in community palliative care settings: Challenges for effective care provision.

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Introduction

The end of life care strategy (Department of Health 2008) promoted high quality end of life care for all, irrespective of the care setting. It explicitly acknowledged the need for a high standard of care in prisons leading to an increased focus on care provision for the dying within the criminal justice system (Turner et al 2011, Richter and Hostettler 2017). There is a small but growing literature on how specialist palliative care services are being developed for patients who are in prison (Richter and Hostettler 2017) but very little systematic study of the challenges that community based services encounter when they provide care to those who have been sentenced to custody by the courts, and therefore, are under the supervision of the prison or probation services.

To ensure that this group of patients receive care on an equitable basis with other members of the public, it is important to understand how (and whether) being in custody affects care provision for prisoners or those under custodial supervision in the community. There is an increasing focus on the inequality on health outcomes within this group (Wilkinson and Pickett 2009: page?), who are linked with greater levels of morbidity and trauma, often compounded by reduced access to (Fox et al 2014). Furthermore, incidences of and histories of substance addiction, physical abuse or neglect, serious illness or injury and mental health problems are far higher among prisoners and probationers than among the general population (Maschi et al 2011). In addition, comparatively little research has been conducted into the knowledge, attitudes and practices of clinical professionals, particularly in palliative care, who work with offenders in prison or in a community based custody environment. Importantly, there is a dearth of data on whether requirements to comply with security or offender management strategies might impact on the practices and decision making of palliative care personnel. This paper reports on the experiences of healthcare professionals working in specialist community palliative care services of caring for patients and close relatives who come under the scope of criminal justice supervision. Understanding of the challenges and restrictions that arise in these circumstances is required to appropriately direct palliative care services for this patient group and ensure that they receive an equitable level of end of life care.

Methods and Procedures

This paper discusses one part of a larger multidisciplinary qualitative pilot study on bereavement, loss and grief in the criminal justice system. It was conducted by academics from the disciplines of Palliative Care, Nursing, Ethics, Law, and Criminology. It was funded by Keele University, U.K. Ethical permission was obtained prior to commencing the qualitative research. This paper reports on the findings from a focus group with ten health care professionals (nurses and doctors) working in the West Midlands, UK, for specialist palliative service providing inpatient and community services. This is a non-random strategy, based on the assumption that certain groups have an important and meaningful perspective of an issue (Ellis 2016). Sampling was purposive and the research conducted in an area where incidences of both poverty and crime rates were above the national average. The focus group data were recorded and transcribed verbatim. Thematic analysis was completed using Miles and Huberman's (1994) schema where data is displayed, reduced and conclusion drawn. Key quotes are used to illustrate important issues.

Findings

Participants tended to identify patients as offenders in the following ways:

- Patients who were referred to their service by a criminal justice agency or a dying patient being released to a hospice from prison
- Patients who were under community supervision by the probation or police.
- Close relatives who were known by participants to have a criminal record which prevented them from supporting or even maintaining contact with the dying patient.
- Other individuals whose lawbreaking behaviours had not yet come to the attention of police or probation officers, but whose behaviour disrupted care.

Three distinct themes arose from the data. Each theme highlights a particular challenge to the provision of equitable care. These were: 1) Having patients under prison, probation or police supervision altered the dynamics of care provision; 2) Prisoners were restricted from supporting or contacting their dying relatives in the community; 3) Participants (professionals) were obstructed from supporting patients at home because of the criminal or anti-social behaviour by relatives of the dying.

Theme 1) Prisoners as inpatients

Terminally ill prisoners or those whose ‘death is likely to occur soon’ can be released on medical grounds before the full term of their custody has been completed under the terms of the Prison Service Order (PSO 6000: 2002). This is only granted ‘in exceptional circumstances and under stringent requirements at the direction of prison governors, acting with medical advice . There are different legal routes to ‘release’ on compassionate grounds which create important distinctions for who is ultimately responsible for the prisoner. In the first instance, a prisoner may be released early on licence and under the supervision of a probation officer of social worker. They must comply with the conditions of their release into the community or have their licence revoked. Alternatively, a dying person may be transferred from prison to a hospice or place of care but remains the responsibility of the probation service. This normally occurs where there is evidence that the prisoner is bedridden, severely incapacitated and is not deemed to pose a risk to public safety (Williams et al 2011). However, dying prisoners who do not meet these tests may still be transferred to a hospice. As they remain the responsibility of the prison service, they are most visible because they are guarded by a prison officer.

Under the provisions of ….prisoners are entitled to the same standards of care at the end of life as other patients (Department of Health 2008) and admission to hospice is frequently presented as a positive step towards ensuring this outcome (Williams et at 2011). However, this study found that, even within a hospice setting, the quality of care could observably different for those who are admitted under the authority of the criminal justice system. Participants reported that they had mainly encountered patients who had been released and transferred under probation supervision. Encounters with prisoners who been transferred from prison and who remained in handcuffs and under the constant supervision of a prison officer was a less frequent occurrence. However, it was a much more intrusive element.

> “I’ve had more experiences when the prison authorities have released somebody earlier because they were terminally ill, than had someone come over still cuffed, and I think that’s a decision that the prison authorities make, and if they’re making that decision you kind of have to abide by some of their rules because presumably they’re there for a reason.” *(A)*

There was a clear consensus that being under the close and constant supervision of a prison officer within the hospice altered the way that care was provided.

> “Offenders who are patients are much, much harder because the prison is always with you, the prison comes in to the hospice and that’s a very, very different way of working to how the hospice normally works.” (A)

> “(He) constantly had prison guards next to him in the bed, his condition was deteriorating … and entering that terminal phase of his illness.” (D)

A second related concern was the use of handcuffs.

> “And it is different because you have this prisoner in handcuffs who is dying, you have the policeman (sic) who is there all the time, and even if you want to do the best, deliver the best care, it is different.” (H)

These factors were seen as particularly intrusive when there was a need to raise difficult and/or sensitive conversations with the patient or their relatives.

> “but when you’re having very sensitive, difficult conversations with perhaps him and his family and there’s a prison guard there, it does, I think, have an impact on your ability to do that and I think also on that family’s situation.” (D)

> “They (prison guards) are trained to deal with people in a very different way to the way that we are trained to deal with people. And I think that does affect how you can have conversations and the conversations you can have with them, with the patient.” (A)

Participants also acknowledged that it had the potential to change the way they viewed and interacted with patients, even if it did not affect the aims of care.

> "You feel a little bit insecure because you don't know what he did, even though he looks perhaps pathetic and unable to do anything different, and no crime probably, you just feel different because you have a different relationship with the patient. … Although we want the best care and the best everything" (H)

> "It's far less personal if you're dealing with somebody handcuffed. It feels more natural if you're working with somebody where they've been removed." (D)

It was acknowledged that the hospice environment and acute illness were alien environments for the prison guards, affecting their response to those in their custody.

> "I think the prison guards get scared sometimes. They're not expecting to come to work and deal with someone who's incredibly unwell, and they see you walking up with needles and they're terrified that this person's gonna leap off the bed and grab a needle and stab them!" (A)

Finally, it was noted that being in custody altered the way care was provided after death.

> "It's treated as a crime scene and they go to the coroner, even the people who die in the hospice as an expected death but still as prisoners, treated it as a crime scene." (A)

It was clear that the experience of dying under the criminal justice system, albeit within the hospice environment, influenced how the therapeutic relationship developed as well as care after death.

It is important that healthcare professionals uphold the dignity of all patients (NMC 2015) and maintain their right to privacy and confidentiality in all aspects of their care (NMC 2015). The use of handcuffs in other healthcare settings has been shown to result in distress and humiliation (Pickles at al 2015; Dignam et al 2014), to the extent that prisoners have opted not to attend screening programmes (Well 2012), with the consequence that health problems may be diagnosed at a very advanced stage, if at all. Similarly, the presence of prison guards has been reported to provoke feelings of acute distress when having to recount sensitive information (Pickles at al 2015, Dignam et al 2014). Hence, there is the very real potential that custodial measures may impede discussion of discomfiting or 'embarrassing' symptoms and other psychosocial concerns around the dying process. Moreover, open discussions between patients, family members and friends will also potentially be inhibited in these circumstances.

Nurses and other healthcare professionals are expected to act as advocatea for the vulnerable, challenging poor practice and discriminatory attitudes and behaviours relating to their care (NMC 2015). Although the Royal College of Nurses (RCN 2016) guidance on restraint does not specifically highlight the use of handcuffs, it clearly states that the use of any restrictive process needs to be proportionate to the risk of harm. An individual risk assessment process will have been undertaken prior to any escorted move to the hospice environment by prison staff (Home Office 2016). These decisions should be made in line with associated medical and healthcare information. Moreover, these restraint decisions are dynamic and there is an established protocol for the removal of restraint following the request by a healthcare professional (Home Office 2016). Restraints, including handcuffs, can sometimes be removed following consultation between the lead healthcare professional and the designated duty officer (Home Office 2016). Hence, there is the potential to negotiate a change of restraint practice as a patient's condition deteriorates, enabling more open communication and a more equal dying process.

Theme 2) Prisoners as Relatives

Research participants also reported on supporting terminally ill patients in community settings where the patient had an absent relative who was in prison. They reported that having an imprisoned relative was frequently a matter of embarrassment for the dying person, so that they were reluctant to request an opportunity to see their imprisoned relative.

> "But yes, it is almost like as if they're frightened to ask because they don't want to disclose, you know. I suppose there's an element of shame, isn't there, really?" (C)

As a consequence, and if the matter transpired, caring staff became involved in organising a visit from the prisoner at a very late stage in the disease trajectory.

> “it’s been very much, you know, almost sort of getting to almost the terminal phase really by the time they sort of pluck up courage to ask you or to tell you that one of their relatives is in prison.” (C)

As the process of applying for Release on Temporary Licence [ROTL] is protracted, and as the rules have become more stringent since 2015 (Clinks/Prison Reform Trust, 2016), there was often little time to organise a last visit.

Although the process for arranging contact between patients and relatives in prison was time consuming and burdensome, the eventual contact was perceived to be beneficial.

> “And the amount of effort, through time and phone calls and letter-writing, to try and actually allow that person to have a bit more dignity and time with his family at that final stage was incredible.” (D)

Participants were also aware that prisoners were easily overlooked because they were not routinely or consistently included in the bereavement support mechanisms of their organisations.

> “And then they come for the visit and then they go, and they don’t actually touch your radar in any other way, and the bereavement support that they get is negligible because they’re not actually on the list of people who are going to get written to because they’re known to be in prison, and everything seems to wait until they come out of prison for them to have any bereavement support or further visits with their relative if they’re still alive.” (A)

Indeed, although dying persons are routinely asked if there is a family member of other individual whom they would like to see, they are not systematically asked whether that person is in a closed institution. This points to a gap in current practice as it tries to balance the patient’s right to confidentiality and privacy with sensitivity towards some patients who may be reluctant to volunteer the fact that they have a close relative in prison because of the social stigma that can inform this issue.

> “I never, until this came up, I never really thought to ask, you know, when assessing families, whether anyone’s actually in the criminal justice system,” (B)

The silence and tacit stigma surrounding prisoners and their relatives underline the potential for the patient (and their imprisoned relatives) to experience disenfranchised grief. Doka (199:37) defined disenfranchised grief as a form of bereavement that cannot be fully socially sanctioned, either because it is not openly acknowledged or where the griever is not recognised. It occurs when the needs of a stigmatised individual or group to mourn and have their grief acknowledged are overlooked (Read 2009). In the case of prisoners, and their dying relatives, it can arise from the deprivation of opportunities to mourn, or social denial of a prisoner's 'right' to mourn (Santatzoglou et al, 2018)

This study highlights two interacting issues that need to be considered when assessing how to maximise the opportunities for dying people to be connected with all of their family, if that is what they want. It is an important time for families as they are working to reorganise their lives together following a common loss and tailored support can improve long term family functioning (Kissane et al 2016). Palliative care has a rich history of open communication around death and dying. Consideration should be given to how these skills can be adapted to support families to overcome any family shame or stigma associated with criminality that might prevent them disclosing a desire to be reunited with an incarcerated family member. Fears about raising the issue may be amplified by lack of awareness of potential services and a generalised mistrust of authority (Bender et al 2013).

More pragmatically, palliative professionals could be trained and supported to overcome the sometimes intimidating and complex security procedures they face when caring for a dying person on temporary licence. Because of the nature of their training, health professionals do not always appreciate the pre-eminence of security and risk-based considerations that tend to predominate in prison and probation settings. As a result, health professionals tend to encounter these processes as intrusive, distracting, time-consuming and stressful for their patients. More research is required to consider how being isolated from the dying person, or being absent at the moment of death, as well private opportunity for farewells, reconciliations and family meaning-making at this time contribute to the experience of disenfranchised grief.

Theme 3) Encountering offending behaviour in the home

All the participants had encountered scenarios where the criminal or antisocial behaviour of relatives had directly or indirectly influenced (or restricted) their ability to meet the needs of patients receiving community palliative care. Indeed, the issues of risk and safeguarding against such behaviours were at the forefront of their experience because of the particularly specialist nature of the organisation with whom they worked, which was why it was purposively sampled for this research.

> "I honestly only ever think - possibly if I cast my mind back – I safeguarded one person in the previous decade, but I come here (the service) and it's just like a regular thing. It's almost every week or so, every couple of weeks, that you hear about it, and there is something a little bit sad about that, at this particular place." (C)

All the participants were aware that anticipatory grief and the strong emotions associated with a death in the family could predispose some relatives to inappropriate expressions of anger.

> "[A]nd aggression, you know, and sort of… We're seeing people in really distressing times, you know, you sort of expect that that reaction is going to come, you know… anger and frustration: So, you do take it as the norm." (E)

These expressions ranged from low level criminal activity to behaviours which placed the patient and/or professional carers at risk. Three quite distinct approaches to this were reported.

a) Situations where issues were dealt with and resolved through discussion with the patient and the broader family.

> > "He was clearly quite distressed by what was going on with his grandmother, but that didn't stop him from stealing from her … And when I brought this up with the family, the main carers, they certainly didn't want it to go any further and they actually sorted it out and they retrieved the property that was taken" (B)

b) Situations where specific safeguarding measures were taken to protect carers. All healthcare professionals have right to work in a safe environment (Health and Safety at Work Act 1974), just as they are expected to ensure that identified risks are assessed and appropriate measures are put in place to manage the given risks to themselves and their colleagues (RCN 2015).

> "You get a big alert sent around that he's, you know, sort of previously got a conviction for kidnapping and assault and so then you start to think about single females, predominantly, going in and visiting on a daily basis, and so [sic] not just about patient vulnerability but your vulnerability as well." (E).
>
> "But you were still needing to go in twos for safety and, talking about exits, that's what you clocked as soon as you went in, but, unfortunately, there was only one exit and he locked it every time." (I)

These safeguarding measures only ameliorated the immediate risk to the healthcare professional. Dealing in the longer term with antisocial behaviour in the home meant that attention was diverted from the patients' needs to monitoring the behaviour of the relative.

> "They're not too poorly at the moment, but all the issues around threatening behaviour going on in the house, which is threatening at times, is focusing everybody on not-the-patient." (C)
>
> "And I felt I was bending rules and doing things to placate him. But she was suffering, she wasn't getting what she should have been getting and that's frustrating." (I)

All of the participants accepted and understood the need for safeguarding measures to protect themselves and their colleagues; nevertheless they expressed ambivalence about the effect of safeguarding on the quality of care patients received. They described the way safeguarding added to the difficulties of care in the home and indeed, distorted the priorities of care.

> "I think it actually mitigates against communication sometimes, because all you become aware of is that someone's safeguarded for some reason, and you don't necessarily sit down with everyone and talk about him." (C)

> "So that behaviour's actually had a negative effect of creating a barrier to people going in, an official barrier, a shield if you like, we'll say, regarding where they don't have to go in or they have to go in twos but, you know, everyone's complaining of shortness of staff and so on, so that the actual opportunity to go unless you have to is quite slim." (C)

Moreover, the participants were clear that safeguarding measures could not eliminate all risk, for example, carers encountered threatening situations.

> "My only experience with offenders in any way is in the community. In fact, one of them was the only time I've ever been attacked by anybody. He ended up in prison for a related offence" (B).

c) The third approach described offending behaviour that led to situations where the patient needed to be removed from the home for their own safety to the home of another relative or hospice.

> "we managed to get her into the hospice, but that was under police escort. So it quickly escalated quite significantly really." (I)

It wasacknowledged, however, that moving the patient to a new location was not a reflection of the patients' choice or preferred place of death but rather, the best of a limited ranges of options available in given circumstances. The need to preserve patient safety (NMC 2015) altered the choices available to patients at the end of life, to the extent that some individuals were not able to die in their own home.

Conclusion.

This study highlights how encountering offenders in community palliative care settings presents significant challenges to healthcare professionals by curtailing them from fully realising the aims of palliative care for patients and their families in ways that merit further consideration and research. The priorities of the criminal justice system, in terms of protecting public safety and maintaining the offender in secure custody, affected care provision for patients and relatives even when death occurred within the hospice setting. Moreover, there were comparable impediments to care when healthcare professionals in community settings encountered lawbreaking behaviour, independent of criminal justice involvement. Palliative care aims to build on the best to enhance existing care through embedding compassion and choice for everybody at the end of life (National Council for Palliative Care 2017). One key challenge is to provide the knowledge, support and leadership to ensure that this marginalised group are able to access equitable care, and that palliative carers are equipped with appropriate training and supports.

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