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End-of-Life in Prison: Talking Across Disciplines and Across Countries

Abstract

What a good end-of-life means, is a particularly relevant question in the context of confinement and prison. Most of the questions and issues raised by end-of-life for those living in liberty also apply to the correctional setting. However, the institutional particularities and logics of the prison create unique barriers and make it difficult in practice to reconcile concerns in regard to end-of-life – like care and comfort – with the mandate of corrections – confinement and punishment. At present the literature on end-of-life in prison is dominated by US contributions. We have therefore invited researchers from various disciplines in various countries to analyze the topic from their disciplinary perspective and within the respective institutional frame of their national context.

Keywords

End-of-life; ethics; practice; palliative care; prison

1 Introduction

Research on end-of-life in prison has predominantly been conducted in the USA and to some extent also in the UK (Stone et al. 2012; Maschi et al. 2014) and is only starting in other countries. The background for this research, nevertheless, is very similar across the globe. For instance, a general punitive turn (Garland 2001) that can be observed in countries worldwide. This has led to increased sentencing, longer sentences, and also more security measures resulting in a greater prevalence of different types of life-long confinement. In conjunction with an ageing of the population in general and also an increased offending at a later time in the life-cycle, this results in an increase in the share of older inmates in the prison population. Due to more punitive and security-driven regimes, the number of inmates who will face their end-of-life within the prison system is growing.

For a long time, prisons dealt primarily with young and healthy inmates who sooner or later would leave the system and return to society once their sentence was accomplished. This has changed dramatically over then past year as the growing body of literature on the needs of the ageing prison population is showing (see, for instance, Aday 2006; Deaton et al. 2010; Handtke et al. 2012). In previous times, deaths in prison were seen as a failure of the system in taking care of its inmates and providing a safe environment to prevent homicide and suicide (Rabe & Konrad 2010). Very often, such incidents have been kept secret and the issue was silenced also in research (Liebling 1992, 1998). This is now different, with the recent changes in sentencing, a growing number of inmates will die in prison of natural and non-sudden death. For both, prisons and the society end-of-life in prison is a new challenge.

Studies from various national contexts – including France, UK, Switzerland, and the United States – respond to this challenge. And we hope to broaden the US-centered debate by adding viewpoints that are inspired by research in other contexts and, to some extent, benefited from the fact of entering the debate at a later stage of the discussion and responding, at the same time, to local issues related end-of-life in prison that just start to

emerge in these local contexts. An example is, for instance, the ethical debate in Germany and Switzerland on whether end-of-life in prison is at all compatible with the Human Rights. Or, in the UK and in Switzerland, research focuses on the prison and its functioning or its logic and how the prison interacts with new forms of care in handling end-of-life in prison.

With this special issue, we wish to open a dialogue across the Atlantic, not least, by including a reflexive essay at the end of the collection. While the topic cannot be covered in a truly global manner, viewpoints from a European perspective are added and address a range of topics which will be discussed in the following sections.

2 Ethical considerations

One of the first articles published on end-of-life in prison puts forward a strong ethical argument why society should care about inmates' end-of-life in prison (Cohn 1999). Articles by Byock (2001) and Taylor(2002) followed Felicia Cohn's main argument. According to her, there are several philosophical arguments why society should care about dying inmates. The first argument deals with the "consideration of the value of persons" (p. 253). Following the categorical imperative by Kant Cohn suggests, that inmates should be treated like any other dying person and that health care has not distinguished between categories of people so far and should not do so when dealing with inmates. Second, based on the "social contract theory" (p. 254), society's practice of justice derives from a social contract that ensures fair and equitable treatment to all people, including inmates. Third, the definition of justice (p. 255), particularly, when put to practice in the correctional system focuses often mainly on the corrective and punitive aspect of justice and eludes thereby the rehabilitating aspect. For example, volunteering for end-of-life care can offer an inmate a path to rehabilitation. Fourth, in the context of the notion of just punishment (p. 256), the law provides a measurement of involvement and gravity of the crime and tailors the sentence accordingly. But when it comes to problems with health and the way a person dies, there is no such justice: a serial murderer might die in a peaceful way in his cell while a burglar may suffer of a long cancer illness. There is therefore no just base in order to determine differing levels of treatment among prisoners. Finally, in a "utilitarian calculus", societal benefits and burdens (p. 257) are weighted against one another. On the one hand, as for other disadvantaged groups, society takes care of inmates through public health programs and supports the basic needs of these people. On the other hand, there is also the vision of the society at stake, as Cohn indicates: "What kind of society do we want to be? Society's ethical imperative to provide proper end-of-life care arises from its commitment to care for its members" (p. 257).

Some of these arguments are taken up in the general debate. Above all the general ethical statement, that end-of-life care is necessary to provide humane treatment to dying inmates appears in most of the literature available (see, for instance, Dubler 1998; Maull 2005; Hoffmann & Dickinson 2011) and is considered as a more formalized Human Right (Penrod et al. 2013; Maschi et al 2014). Another prevalent argument is that society has a responsibility towards its members to provide care for all groups including prisoners (Byock 2001; Handtke et al. 2012) based on the principle of equivalence and the idea of the social contract.

A very different debate is evolving in Europe asking whether at all dying should happen in prison. Kinzig (2012) and Wulf and Grube (2012) use the notion that the only humane way of dying represents dying as a free person able to decide the important questions of where and with whom, dying should take place. In their view, it is not possible to die in a humane way in prison. In addition, at the moment of dying, inmates are no longer subject neither to the principles of general prevention nor of special prevention, because they will end to exist. From the legal perspective, in Germany for instance, the law contains the instrument of an interruption of confinement when end-of-life is near in order to allow a person to die in freedom (Wulf & Grube 2012). To die in freedom could also mean to choose the prison as a place to die, but out of free will (Kinzig 2012). Nevertheless, for a small number of inmates with sentences that include security measures, state authorities will not allow them to die outside of the prison system. However, these are extreme cases, when human dignity of an individual is valued less than the security of society.

This also leads to the second set of fundamental questions as to whether such long sentences that inevitably lead to an end-of-life in prison are not questionable from an ethical point of view (Liebling & Maruna 2005; Fleury-Steiner 2015).

3 Characteristics of end-of-life in prison

The occurrence on an increasingly regular base of non-sudden death in prison lead to research that deals with the specificities of end-of-life in prison. Most characteristics and issues of end-of-life in prison resemble challenges of end-of-life in society at large (Berzoff & Silverman 2004; Meisel & Cerminara 2004). However, the prison poses a series of unique barriers which have to be acknowledged (Linder & Meyers 2007, 2009). These barriers emanate from the special legal situation of confinement, and its effects for the lives of inmates. Confinement deprives them of their free will and, in particular, of their free disposal of their own lives. At least in principle, inmates are deprived of free choice regarding many decisions, like how and where to die, and who shall be present in this moment.

Studies report that prisoners experience end-of-life under specific ways when compared to other people. For instance, male (Aday 2006) as well as female (Deaton et al. 2010) prisoners fear death more than people in the community. Conditions such as bad physical health or psychological state as well as the number of medicaments taken or the number of illnesses interrelate are all aggravated by the stay in prison (Loeb & AbuDagga 2006) and increase the fear of death. Many inmates also consider death to be a stigma for them and for their families because it represents a final sentence. Nevertheless, death can also be seen as an escape to end a sentence that also entails physical and psychological pain and suffering (Aday 2006).

A reason for why death is feared more in prison than outside can be found in widespread perceptions among inmates of insufficient provisioning and support by the prison. Studies report a perceived lack of adequate care (Dubler & Heyman 1998; Deaton et al. 2010) and that needs of prisoners are often unmet (Loeb & AbuDagga 2006; Maschi et al. 2012). Some researchers attribute this to the indifference of staff towards dying prisoners (Deaton et al.

2010). But contrary to this, staff – internal as well as external – can also act as change makers and introduce notions and practices of compassionate care (Loeb et al. 2011).

It is also important to understand the specific differences that characterize the prison population of ageing and dying inmates when compared to the population at large. Age is a bad indicator because many prisoners undergo a process of hyper-ageing (Dubler 1998: 150). This process deteriorates their health and leads to polymorbidity and multi-medication faster than in the community. Inmates experience health problems which are different to those outside prisons. They have higher rates of infectious diseases (such as HIV and different forms of hepatitis), suffer more often of chronic and comorbid illnesses (Fazel et al. 2001; Kuhlmann & Ruddell 2005; Lemieux et al. 2002; Snyder et al. 2009; Handtke et al. 2012; Williams et al. 2012; Cloyes et al. 2015a). To our knowledge, only one study has compared so far populations of prison hospices and community hospices. Although this comparison is difficult, it already indicates that there are differences between inside and outside prison even at the very end-of-life (Cloyes et al. 2015a).

4 Palliative care entering prisons

With situations of dying prisoners a specific type of care enters the prison system. At the end-of-life curing care turns into palliative care. Palliative care represents an even stronger counter point to the logic of the prison than curative care does, which is associated with the medical service of the prison system. The notion of curative medicine matches much better with the needs of young, able-bodied inmates spending time in prison before being released again to society. Palliative care, in contrast, does not restore an inmate's health, but alleviates his or her pains, wants to provide comfort and, adopting a holistic attitude, accompanies a dying person towards death. The collision of these two different aims or logics has therefore been the topic in earlier works on end-of-life care in prison (see, for instance, Dubler 1998).

Particularly in the USA, where the number of end-of-life cases in prison has reached thousands per year (4,446 deaths in local jails and state prisons in 2013; see BJS 2015), the concern over the collision between the logics of care and custody (Dubler 1998) has given way to an acceptance of the fact that end-of-life in prison has become a reality (Ratcliff 2000). Therefore, the debate also focuses on practical solutions needed to deal with this reality.

Palliative care can enter the prison system in different ways. A first option can be observed in the USA where in-prison hospice programs introduce a palliative care unit into the prison system. As a second option, which is in practice in the UK, palliative care can be introduced as an in-reach service. The administration of this service, however, remains outside the prison. The administrative position of the palliative services has implications for the debate on care vs. custody: prison hospices can serve as an argument to retain people in custody instead of releasing them on compassionate grounds (Craig & Ratcliff 2002). At the same time, hospice professionals usually maintain contact with the community and can therefore also increase pressure for prison authorities to release inmates for their end-of-life. Thus, prison hospices are integrated into the prison system and, at the same time, they also alter the system by introducing their own professional standards in dealing with dying inmates.

The collision of different notions of sound treatment and the questions as to whether a person should be seen as an inmate or a patient continue to be important topics for discussion and research (Loeb et al. 2011). This applies in particular to countries, where palliative care is a rather new phenomenon in the prison system (Fletcher et al. 2014) and where it has not yet become an element of the prison organization, but rather is operated as in-reach service (see, for the UK, Turner et al. 2011, and for Switzerland, Marti et al. 2014).

5 Managing end-of-life in prisons

The high number of deaths in custody in the USA has fostered a rather broad discussion about how to make a good death possible in the prison setting. The development of different solutions is far ahead of most other countries. Since Fleet Maull – while being a prisoner – initiated in 1987 together with fellow prisoners and staff the first prison hospice program and later founded the National Prison Hospice Association in 1991 (Maull 2005), hospices programs have been installed in a number of prisons across the country (Craig & Craig 1999; Cahal 2002). This hospice movement was accompanied by research. Among others, a major research project – the GRACE project – provided first insights into the challenges of prison hospices (Craig & Ratcliff 2002; Ratcliff & Craig 2004). The GRACE project guidelines and the National Prison Hospice Association constitute today an important point of reference for most of the current prison hospice programs (Hoffmann & Dickinson 2011). Similarly, in the UK in 2011, the National End of Life Care Program published a guide of good-practice for practitioners in prisons (Hayes & Smith 2011).

Today, 25 years after the start of the first prison hospice program, knowledge about general obstacles of a humane end-of-life in prison and about elements of promising practice is growing. Among the general obstacles are ethical questions focusing on the ambivalence of care and custody (Craig & Ratcliff 2002; Penrod et al. 2013; Maschi et al. 2014). Mistrust between staff and prisoners, such as the fear that prisoners may abuse their pain medication represents another obstacle or the general concern of prisoners that the prison does not provide them enough care (Loeb & AbuDagga 2006; Deaton et al. 2010; Maschi et al. 2014). There is also a link to safety concerns because hospices are located within the prison system, an environment that must provide security for all people inside and for the society at large (Maschi et al. 2014). At the same time, barriers such as rules and protocols established to provide this safety should not become insurmountable barriers for adequate end-of-life care (Cloyes et al. 2015b). In addition, several studies detect an indifference of staff and the general public towards dying inmates (Byock 2001; Linder & Meyers 2007). This is also linked to claims that institutional solutions for end-of-life in prison should not result in additional costs (Penrod et al. 2013). Also the local organizational culture of prison plays an important role in the way a prison hospice program can be initiated and run (Penrod et al. 2013).

Various elements have been identified as promising approaches in providing a humane end-of-life in prisons. Palliative care is not just a technique or a variety of care, it includes principles such as patient-centered care (Penrod et al. 2013; Fletcher et al. 2014; Cloyes et al. 2015b) or flexibility and responsiveness (Turner & Payne 2011). Staff in prisons need to be prepared for their new tasks and therefore staff training is a prerequisite (Howe & Scott 2012; Fletcher et al. 2014; Maschi et al. 2014). At the same time, teams involved in providing

care towards the end-of-life should be multi-disciplinary (Ratcliff & Craig 2004; Maschi et al. 2014; Cloyes et al. 2014, 2015b). Team members should be able to provide more than medical care and therefore include, for instance, social workers (Blacker et al. 2005; Smith 2010). Apart from collaboration inside the prison, important expertise is located in existing palliative care centers in the community at large, such as community hospices. Partnerships with professionals from the general palliative system provide an important support from outside (Ratcliff & Craig 2004; Turner & Payne 2011; Fletcher et al. 2014; Maschi et al. 2014). The use of volunteers – volunteering community members or inmates – has proven a relief for tight budgetary restrictions (Maschi et al. 2014; Cloyes et al. 2015b). In particular voluntary inmates often also see their work as an important commitment, which also leads to emotional involvement and grief (Supiano et al. 2014). Finally, apart from medical and social aspects, there is also a need for legal codification of the inmate's last will, advance directives and do-no-resuscitate orders (Levine 2005).

6 The papers

The above issues provide a rich background for the papers included in this thematic issue. The first paper by *Alison Liebling,* provides a discussion of various ways of ending life in prison. Suicides in prison, natural life sentences and murder are discussed as three forms of non-natural death in prisons that challenge the 'legitimate penological purposes of imprisonment'. The paper provides a larger frame to the other papers by discussing non-natural deaths and carving out the ambivalence of dying in the prison as an environment that has the obligation to take care of the inmates living in it and preventing him or her from dying.

The following four papers present case studies from various countries, discussing different issues from the perspectives of national legislation and the diverging development of end-of-life care in the prisons. The first case study by *Irene Marti, Ueli Hostettler and Marina Richter* documents the "struggle" over care vs. custody in the context of Swiss prisons. By framing their analysis in the concepts of new institutionalism, they refer to institutional logics as an analytical principle and further the discussion about a simple binary opposition of care vs. custody by indicating the more complex constellations resulting from overlapping and blurring of these logics. Their analysis also takes into account the potential of the actors involved and how their negotiations deal with the ambivalences of the competing institutional logics.

The paper by *Kristin Cloyes, Susan Rosenkranz, Katherine Supiano, Patricia Berry, Meghan Routt, Sarah Llanque and Kathleen Shannon-Dorcy* focuses on prison volunteers as end-of-life carers. Such peer-care programs represent an important contribution to the caring problem and deal with questions of involvement of fellow inmates. The authors contribute to the debate by an analysis that includes the perspective of the volunteers, the nursing as well as correctional staff. They point out that apart from care practices developed through formal training and exerted in the prison hospice, the program also induces changes in norms and values such as stewardship or mentorship. It has often pointed out that palliative care introduces new values into the prison system. This paper gives an example of how care practices also evoke changes among the involved prisoner volunteers.

The involvement of inmates as volunteers in end-of-life care opens the path for a discussion of involved people not only as providers of care but also as people engaged in an emotionally demanding task. *Mary Turner and Marian Peacock* take stock of their long-term research in the prison settings of England and Wales to discuss the needs of the prisoners who are growing old and expecting end-of-life in prison as well as the practical and emotional challenges for involved people such as prison staff, healthcare professionals as well as fellow prisoners who are engaged in the care of their dying peers.

Finally, *Aline Chassagne, Aurélie Godard, Elodie Cretin, Lionel Pazart and Régis Aubry* discuss the needs of dying inmates in France. They contrast the inmates' needs with the experiences of representatives of healthcare and medicine, prison and law enforcement. They center their analysis on the role of the inmates with terminal illness. Despite of being in specifically medically coded places – in health units in prisons or in secure units in hospitals – the inmates were still not fully acknowledged as patients. This impeded a full deployment of palliative care. Therefore, they argue for a suspension of sentence out of medical reasons as the best way to provide end-of-life care to a person as a patient and not as an inmate.

The last paper by *Tina Maschi and Marina Richter* provides a discussion on the topics outlined along this special issue and draws conclusions for this exchange across examples from several countries and in particular between the US with a large production of articles on end-of-life in prison and the European context, where research in this field is just emerging. In particular, it recalls the importance of Human Rights as a guideline to develop laws and practices for people deprived of their liberty.

7 Literature

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