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ORIGINAL RESEARCH

Ageing Prisoners' Views on Death and Dying: Contemplating End-of-Life in Prison

Violet Handtke · Tenzin Wangmo

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Abstract Rising numbers of ageing prisoners and goals on implementing equivalent health care in prison raise issues surrounding end-of-life care for prisoners. The paucity of research on this topic in Europe means that the needs of older prisoners contemplating death in prison have not been established. To investigate elderly prisoners' attitudes towards death and dying, 35 qualitative interviews with inmates aged 51 to 71 years were conducted in 12 Swiss prisons. About half of the prisoners reported having thought about dying in prison, with some mentioning it in relation with suicidal thoughts and others to disease and old age. Themes identified during data analysis included general thoughts about death and dying, accounts of other prisoners' deaths, availability of end-of-life services, contact with social relations, and wishes to die outside of prison. Study findings are discussed using Allmark's concept of "death without indignities," bringing forth two ethical issues: fostering autonomy and removing barriers. Attributing the identified themes to these two ethical actions clarifies the current needs of ageing prisoners in Switzerland and could be a first step towards the implementation of end-of-life services in correctional systems.

V. Handtke (✉) · T. Wangmo
Institute for Biomedical Ethics, University of Basel,
Bernoullistrasse 28, 4056 Basel, Switzerland
e-mail: v.handtke@unibas.ch

T. Wangmo
e-mail: tenzin.wangmo@unibas.ch

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Introduction

End-of-life issues have received great attention in research. This is mostly due to the increasing number of adults living to very advanced ages with the help of medical technologies, which inevitably lengthens the dying process. Concerns about death and dying and meanings of a "good death" and a "death with dignity" have been explored in the general population. End-of-life care and decision-making frequently involve discourse on dignity (Street and Kissane 2001), epitomised by the right to die movement in the Netherlands and Oregon. This movement claims a right to "die with dignity," a concept on which palliative care and clinical decisions are based. Similarly, the concept of a "good death" is central to improving the care for dying people (Emanuel and Emanuel 1998) and is key to the hospice movement (Hart, Sainsbury, and Short 1998). Though both concepts are criticised for their vagueness, they have nevertheless led to changes in end-of-life care and the dying process. These two concepts address patients' concerns regarding a loss of dignity, decreased ability to exercise autonomy and control, and being dependent as well as a burden on others (Kissane, Street, and Nitschke 1998; Mak and Clinton 1999).

Yet, the attention and resources directed towards a good death and death with dignity in the general community may not be available to those who are incarcerated, since these advances seem to halt at the threshold of

prison walls. Prisons generally lack end-of-life services and the justifications for imprisonment (retribution, deterrence, rehabilitation, and incapacitation) are often in conflict with or impede the provision of quality care to prisoners. While prison palliative and hospice care units were created in the United States in response to large numbers of deaths occurring in custody, linked to high rates of imprisonment and HIV/AIDS-related deaths in the 1990s (Dubler 1998; Ratcliff and Craig 2004), such programs and research are still scarce in Europe. So far, only the United Kingdom provides information on the implementation of prison palliative care units (Stone, Papadopoulos, and Kelly 2012).

Death and Dying in the Prison Context

Deaths of prisoners occurring in custody usually are due to causes such as suicide, violence, accidents, and illnesses. Suicides are especially frequent in prison and are preventable (Konrad et al. 2007; Fazel et al. 2008). Suicide prevention guidelines exist that include the use of screening methods and the involvement of staff, family, and mental health professionals in the care of the prisoner-patient (Konrad et al. 2007). There is no comparable intervention concerning older and/or sick adults in the prison system. Natural deaths necessitating different care and interventions might become more frequent in the future due to the rising number of prisoners living to very old ages (Turner, Payne, and Barbarachild 2011), a trend visible in the United States (Glamser and Cabana 2003).

In Switzerland, an average of 14 deaths per year has been recorded between 2006 and 2011, of which 6.6 deaths were due to suicide (Bundesamt für Statistik 2012). The mean mortality rate in Europe was 28.6 per 10,000 prisoners in 2010 (Aebi and Y. Marguet 2013), making death in custody a rare phenomenon when compared to the 4,238 inmates who died in the United States in 2011 (Noonan and S. Ginder 2013). Nevertheless, ageing is a crisis for the correctional system (Williams et al. 2012) and it will lead to more disease-related deaths in custody in the future (Turner, Payne, and Barbarachild 2011), rendering the state accountable for the quality of end-of-life services provided to this population.

The rise in the number of elderly prisoners is attributed to demographic changes in society, trends towards longer as well as harsher sentences, and more older adults entering the prison system (Glamser and Cabana 2003)—although the latter is not responsible for the growing number of elderly prisoners in Switzerland (Schneeberger Georgescu 2009). The increasing older prisoner population is a challenge for various countries (Love 2013) as death and issues surrounding end-of-life care become a pressing concern for prison health care and administration. Furthermore, prisoners age faster than the general population (i.e., a prisoner who is 50 or 55 years old will have a similar health status to a 60- or 65-year-old in the general population) due to unhealthy lifestyles, lower socioeconomic status, and the prison environment (Loeb, Steffensmeier, and Lawrence 2008; Fazel et al. 2001). If prisoners live to very old ages like their counterparts in the community, then they are likely to face ageing and end-of-life care earlier and probably for longer periods. Thus "the mortality associated with an aging prison population" will often be evident within a shorter period of time (Glamser and Cabana 2003, 497). Related to accelerated ageing, the health of prisoners, both somatic and mental, is also worse than that of the general population (Fazel et al. 2001), with higher numbers of chronic diseases and greater indulgence in risky behaviours (Aday 2003). These health and behavioural factors, combined with possible low health literacy (Linder and Meyers 2007) and living in an enclosed environment with considerably diminished autonomy, make prisoners a vulnerable group with regards to many aspects of their life and health, including end-of-life care (Evans, Herzog, and Tillman 2002). This necessitates a deeper understanding of ageing prisoners' perceptions of death, dying, and the end of life in the prison context.

End-of-Life Care in Prison

Prisons are isolated systems with unique regulations, orders, and social functioning. Views on death and dying might be influenced by this system, which in turn may mean that palliative care needs to be customised to suit the purposes of this setting. The United Kingdom, for example, has developed end-of-life care standards for its prisons known as the "Macmillan Adopted Prison Standards," or MAPS, based on palliative care standards in the community. The goal of this development in end-of-life care in prison is to ensure access to high quality end-of-life care across the entire population, including prisoners (Department of Health 2008). Although progress has been made in United Kingdom's endeavours to provide a standard of care for dying prisoners, Stone, Papadopoulos, and Kelly (2012) and Fletcher et al.

(2013) suggest that prison end-of-life care is still in its infancy and data on needs and quality are lacking.

It is only from the United States, where the tradition of providing end-of-life services to dying prisoners in palliative units has existed for a few decades, that more research is available (Stone, Papadopoulos, and Kelly 2012). For instance, the Angola Prison in Louisiana developed its hospice program in cooperation with the community hospice to care for its dying inmates (Evans, Herzog, and Tillman 2002). This example illustrates that quality end-of-life care can be provided in prison while maintaining the necessary level of security (Byock 2002). The main aims of the Angola Prison's hospice program are to inform the prisoner of his care choices and provide him with adequate care such as pain management using an interdisciplinary team, including inmate volunteers. An important factor incorporated into this program is contact with family members and bereavement support. Another end-of-life program is the GRACE Project that began in 1998 (Ratcliff 2000; Ratcliff and Craig 2004). This project made all information on hospice programs available through a resource centre and developed guidelines to improve end-of-life care in prisons.

Ageing and End-of-Life in Prison

Literature on end-of-life care in prison and attitudes of prisoners towards death rarely use narratives of older inmates, with the exception of a few studies from the United States (Aday 2006; Deaton, Aday, and Wahidin 2009). Singer and colleagues point out the importance of patients' perspectives on the quality of end-of-life care as they are the "most affected" (Singer, Martin, and Kelner 1999). Accordingly, Aday (2006) investigated death anxiety and attitudes towards dying in prison among 102 prisoners. Results showed that different factors such as age, health status, and social support influence fear of death. Additionally, prisoners view death as an escape from their current condition of limited hope for the future. Deaton and colleagues (2009) examined attitudes of women offenders towards death and their findings were similar to that of Aday (2006). Prominent themes from their findings included fear of death, access to health care in cases of emergency, and the use of coping strategies such as denial and acceptance to deal with the prospect of dying in prison.

The guiding principle for health care in the correctional setting is the principle of equivalence of care, which suggests that the health care offered to prisoners should be equivalent to that received by individuals in the community (World Health Organization n.d.; United Nations 1990). Following this principle would entail making end-of-life services such as hospice and palliative care available to prisoners. But the problem remains whether this care should be provided outside the prison or inside. The former option would require granting prisoners access to these services available in the community, so-called "palliative care in-reach" (Stone, Papadopoulos, and Kelly 2012). Moreover, death and dying are not purely medical issues, as they involve many more facets because of their finality (Byock 2002). This complexity raises additional and even metaphysical questions regarding the limits of law and punishment, such as whether death in prison is justified by the goals of imprisonment and, if yes, under what conditions.

In order to contribute to the literature on death, dying, and the end of life, we present findings from our qualitative in-depth interviews with elderly prisoners in Switzerland. In this manuscript, death refers to the process of dying and thus incorporates "the period in which there is an awareness of what will end a particular person's life" (Allmark 2002, 255). Our analysis contemplates the criteria for a "good death" and "death with dignity" such as relieving pain and suffering, readiness, control, and autonomy using Allmark's (2002) concept of "death without indignities." This concept is useful as it identifies two important factors that allow an ethical analysis: measures that would reinforce autonomy and removal of barriers to dignity. The discussion of the results thus revolves around these two ethical dimensions.

Methods

A total of 35 semi-structured interviews with elderly inmates, defined as those who are 50 years and older, was conducted. In order to gain diverse opinions, those who were oldest and living in different prisons in Switzerland were recruited. Participants were specifically asked if they have ever thought of dying in prison and what worried them most when they think about it.

Participant Recruitment and the Interview Process

In the French- and German-speaking parts of Switzerland, 15 prisons agreed to participate in the study

and interviews were able to be conducted in 12 prisons. These prisons were pre-selected institutions in nine of the 26 cantons of Switzerland. Selection of participating prisons from the 113 Swiss prisons was based on the following inclusion criteria: (a) long-term imprisonments, (b) more than 20 places, and (c) housing older prisoners at the time of request. Excluded prisons were those that dealt with short-term imprisonments or custody prior to deportation, those that housed 20 inmates or fewer, and those that were not housing any older prisoners.

The interview process started in November 2012 and concluded in October 2013. Two to four interviews per prison were conducted depending on the number of elderly prisoners and the capacity of the prison. This ensured recruitment of different participants based on institutions' regime type, such as open or closed prisons that differ in their security levels. All interviews were conducted by two research assistants independent of the prison services and administration. These interviews took place either in German or French. In general, the oldest prisoners in an institution were interviewed. Correctional medical services informed participants about the study. Potential candidates (based on age) were excluded if (a) there was a language barrier, (b) prisoners' health did not allow them to participate, and (c) an inmate was judged too dangerous by the prison health service. Participants received study information ahead of time and again on the day of the interview. The researchers clarified for participants that they acted independently from prison administration and that a refusal to participate in the study would have no negative consequences. Informed consent was obtained from the participants and ethics committee approval was first gained from the EKBB (the ethics committee of both Basel-Stadt and Basel-Landschaft, which are two different cantons), followed by nine other local ethics committees.

A semi-structured interview guide was developed using existing literature and the expertise of researchers in the prison setting and other disciplines such as ethics, gerontology, geriatrics, and occupational therapy. The interview guide was first pilot-tested with two older adults from the community and edited based on their comments. It was further adapted after the first four interviews with older prisoners. In addition to questions on the end of life, death, and dying, other questions covered demographic and incarceration information, general physical health information, presence of diseases, mental health status and symptoms, medications, substance use, visits to medical services, and problems with activities of daily living. Interviews were followed by a geriatric evaluation consisting of five standardised tests. All interviews took place in the prison and the prison health care services arranged a separate room for this purpose. On average, the interviews were 96 minutes long, audio-recorded, transcribed verbatim, and anonymised by independent assistants. All names used in the results are pseudonyms.

Analysis

As stated above, the results presented here are part of the overall interviews conducted to understand ageing and health experiences of older prisoners in Switzerland. Thus, for analysis, we only selected portions of the interview transcripts pertaining to death, dying, and end-of-life issues. The extracted information from all 35 interviews was collected into a separate document for analysis. This document was then imported into the qualitative data analysis software MAXQDA 11, which was used to assist and streamline the analysis procedure. The authors first independently coded the interviews using thematic analysis (Braun and Clarke 2006). This was followed by a discussion and comparison of the coded themes. Differences in coding were mostly due to use of terminology and were resolved following an agreement on the interpretation of study results.

Findings

Of the 35 elderly prisoners interviewed for this study, five were female and 30 were male. The mean age of the sample was 61 years, with ages ranging between 51 and 71 years. On average, participants have been incarcerated for 6.13 years. Participants were living in a range of prison regimes, including halfway housing as well as open and closed institutions. They were incarcerated for crimes ranging from non-violent to violent, for which some had so-called "measures," meaning preventive detention with no definitive release date. By linguistic region, 12 participants were living in prisons located in the French-speaking part of Switzerland and 23 in the German-speaking part. The latter region is larger than the former, and thus, more interviews were conducted there. Additionally, the Swiss prison system is organised on a cantonal level and reflects various types of organisational structures, e.g., independence versus

dependence of health services from prison administration. Generally, the health care service of prisons located in the French-speaking region tend to be independent of the prison administration, whereas those in the German-speaking part are more likely to be partially or fully attached to the prison administration and thus usually represent dependent health care services. Recruitment of participants from the two language regions was done with a view to capturing the heterogeneity that exists in the Swiss correctional system and which may impact the accounts of the interviewees.

The thought of dying in prison had occurred to about half of the interviewees, which is not surprising since they have, on average, lived in prison for more than six years and some have aged there. However, their interpretation of our question differed: Several participants related it to suicide or suicide attempts and others to natural deaths occurring in prison either due to old age or disease. The reason that for a number of participants dying in prison meant suicide could be interpreted in two ways: Due to its high prevalence in prison (Konrad et al. 2007), participants may have witnessed suicides or they themselves have had suicidal thoughts. Those responding to this question by equating it with natural death may have interpreted the question in relation to their advanced age. The possibility of a variety of interpretations of this question was deliberately left open in order to seek varied responses of participants to thinking about end-of-life in prison. Participants' responses to the question point to two mutually exclusive possibilities: Not having thought about death, dying, and the end of life at all or having contemplated it, including some who may have avoided thinking about the topic.

Those who had not thought about dying in prison stated that they had not yet reached that age or that they would soon be released. It also seemed that they did not consider themselves old or they felt that they have not reached the age where dying is likely. Their perceived health status might also have influenced their response. Deaton and colleagues (2009) have shown that there is a relationship between health status and death anxiety in elderly female prisoners, with those women suffering from chronic illnesses or worrying about getting sick displaying higher death anxiety. However, one participant, Phillipp, who suffered three episodes of life-threatening illnesses, humorously pointed out that he still had "four lives left, so what should I be afraid of?"

For some, the thought of dying in prison seemed rather far-fetched and unlikely due to their impending release. One prisoner, Gerard, highlights this point:

> For me? No [the thought of dying in prison has not occurred to me], because first of all, I am very optimistic by nature. … I don't even think about it. Normally, in a year and a few months I will be released, if things go right.

As evident from the previous quote, length of sentence plays a crucial role in prisoners' contemplation of death, dying, and end-of-life care. A known release date impacts one's answer in a positive way, while those inmates in preventive detention often suffer from uncertainty as their sentence is open-ended. Francis underscores this uncertainty as follows:

> You know, those articles [for preventive detention], you know how it is? You don't know when you [will ever] get out of prison. They can keep you from one year to the next. You never know and that's terrible. You are 60 years old and you never know if one day you will be released or not.

A few participants said that they avoided thinking about dying in prison in order to protect themselves from discouraging thoughts. Although they have thought about dying, they were afraid to further engage with these thoughts as this would make them feel miserable and they were not in a position to influence their deaths in any way. Didier stated: "Nothing, I don't think about it. I try not to think about it at least. Because the more you think about it, the worse you feel." This finding is similar to avoidance of death thoughts presented in Aday's study (2006). Maull (1991) describes this coping strategy of denying death as useful.

Those participants who had pondered dying in prison mentioned thoughts and wishes they had about end-of-life care. They also drew from experiences they witnessed when fellow inmates approached death. From their accounts, we identified six major themes, which are presented below.

Attitudes Towards Death and Dying

A few interviewees described death as a part of life and something that they did not fear. Edouard stated: "When

I have to die, I'll die. That doesn't scare me." They referred to the unpredictability of death by mentioning that death is out of one's hands and, thus, cannot be influenced. Markus, pointing out the inevitability of death, reported:

> Yes, when it is—dying, when the time comes, then … it could be that one morning I don't wake up anymore, right? That's just how it is, it's like being born, life, dying is a part of it.

Additionally, two participants pondered the existence of an afterlife, provoking feelings of uncertainty in one inmate, while the other insisted that he had paid his dues. Dieter claimed: "Dying is one thing; death is another and what comes after, if it's just over or maybe not. If, perhaps one should have believed after all, it's difficult." Edouard, underlining that he has lived out his punishment, pointed out:

> If there is something: even better. If there is nothing: just as well. You see? But no, I am at peace with myself now. I paid for everything I have done. I admit that I made mistakes. I paid for what I did.

Experiences With Other Prisoners' Deaths and Accounts of Personal Life-Threatening Situations

Some participants' reflections about death in prison were based on their experiences of witnessing a fellow inmate's death, either directly or indirectly, and life-threatening incidents that they have experienced. They sometimes viewed these cases very differently. For instance, one inmate, Hans, described an incidence where a friend's life was saved due to better medical supervision and easier access to medical care in prison:

> For one friend I know that the doctors clearly said that outside [prison] it would probably not have been soon enough. Because the situation outside, that is at home, is different from prison. There, there are no people that are trained in a sense, who know how, when, and what to do. So outside, he would have had it more difficult.

Another prisoner, Gustav, fearing that because of lengthy processes of access to health care in prison, thought that an emergency situation would be very worrying:

> Of course the health service says that you first—you can't just come—"yes, fill out a form." … What? If you have a heart attack. you go there and fill out a form?! No, that's just petty. Always their rules.

Didier's near-death experience left him critical of the prison's lack of timely access to health care. His account is negative and ripe with anger, as he felt that the situation could have been avoided if the physician had taken him seriously:

> Anyway, when I arrived at the hospital they told me that five minutes more and it would have been too late. … Afterwards I thanked them for having saved my life. But here I told them [the health care personnel in prison], it is not you I am going to thank, especially to the physician. "But after all we still did." … "What did you do?" I told them. "Are you kidding me?!" They said, "But no, you see, we have to be a little strict." [I said,] "Listen, when I tell you that I really am in pain, it means that there is something, I am not messing around!" And then they told me, "Okay, but it wasn't that serious." I said, "Sorry, what?!" There I really lost it. I said, "Are you freaking kidding me?!"

Similar hurdles were also present in Gustav's experience of an emergency situation. This fear of missing medical attention and perceived indifference on the part of medical personnel have been reported as being common among inmates (Deaton, Aday, and Wahidin 2009).

Another common criticism was the handling of deaths by prison personnel and administration who treated inmate death as taboo. Even deaths of long-term prisoners were not appropriately acknowledged. Accordingly, participants experienced such attitudes towards the death of a fellow inmate as callous and disdainful. Gustav described it as such:

> "You, have you heard? Hans died." And then, every week we have a meeting and then someone gives a cue: "So, what? Is that true?" "Yes, yes, he died last week." Bam, that's it. Completely indifferent. Completely. He snuffed it. Thank God. … I already asked, "Do you have a tally sheet?" "What for?" "Well, when he snuffed it, check [crossing off the prisoner's name from a list], thank God."

> "That is mean." Then I said, "Yes, sorry, but this is how it seems like." They don't have to make a big fuss out of every death, be it due to age or because of a disease, but they could [at least] make an announcement, a little paper, where they say inmate so-and-so has died.

The reasons for this behaviour from prison personnel and/or administration seemed to puzzle the inmates. One interviewee explained this conduct as fear of bad press for the prison and therein a perceived lack of care for the inmate. However, it could also be that prison personnel and administration are unaware or uncertain about what prisoners would view as an appropriate or dignified way of handling deaths occurring in custody. Gerard, highlighting the political nature of media reporting on death, concluded:

> Because you understand, there is also a political problem: Those at risk of dying, who arrive at the end and are old, they are put outside because if they are put in prison and later journalists ask: "What's happening? New deaths? That already makes eight in four months, etc." … You see? So they get rid of them, I think it's that, it's politics in fact.

Suicide and Suicidal Thoughts

Almost half of the participants reported having thought of committing suicide. Those who had not thought about ending their lives mentioned obligations towards their family, life's beauty, and the availability of psychiatric or psychological support in prison during crises. The trial period, including court appearances, was mentioned as having been a particularly difficult time for those inmates who had thought about or attempted suicide. This is similar to what is already known about suicides in prison: that it can happen at any point during incarceration but that the initial periods of incarceration and court appearances are special periods of risk (Konrad et al. 2007). One participant, Francis, stated that, despite his wish to die, he did not want to commit suicide, illustrating the idea of death as an escape found in another study (Aday 2006):

> Yes, it was predominantly before judgement, because I saw the judgement approaching, I saw the disgrace, the disgust, despise, and everything. And I saw especially the lies that were coming. … And there was this fear, you're tarnished. Well, in short, I apprehended [feared] this moment and I wanted it to end, yes. And then, I thought of my adopted sister, I thought of her and if there was one person for whom I would not do it, it would be for her, she needs me. But I am telling you, if someone would offer me to die now, I would say "yes, please" in an instant. I don't value this life anymore.

Others stated that they wanted to live but that the only options available to them were imprisonment or death due to their incarceration. Death in this way is equivalent to freedom from incarceration. For instance, Daniel revealed:

> And, yes, I have already been through one suicide attempt. When I was in prison, yes. I wanted to hang myself. I don't want to be dead, not at all, but I don't want to be imprisoned, either. And those are in fact the two things I can choose from.

Realities of End-of-Life Services Available in Prison

Participants felt that infrastructure was missing and that end-of-life services such as palliative care, hospice care, or someone to respond to dying prisoners' spiritual needs were unavailable. Martin elaborated on the need and value of hospice care, explaining that "not everyone has family." He found "a hospice or something like that … [to be] a very dignified environment."

Several participants believed that end-of-life services would be beneficial but clearly pointed out their inaccessibility. They also stated that a unit within prison for patients needing extensive care at the end of life would be desirable. None of the participants talked about access to palliative services outside of prison, which could lead one to assume that they are generally not available or at least that there are no regulations in place informing inmates about access to such services.

Another context-specific end-of-life service mentioned was physician-assisted suicide, which is decriminalised in Switzerland and is available through organisations such as Exit and Dignitas. Some participants had contacted Exit indicating their wish to die, giving "prison tedium"—meaning that they are tired of their life in prison—as a reason for their request. Daniel supported the availability of assisted suicide when he

said that "it should really be offered in prison. And not for medical reasons but really because of tedium of life, or rather tedium of prison."

Some participants reported having advance directives and preparing for needs following death. This included planning their cremation or deciding on the inscription on their gravestone. Bernadette revealed her plans in this way:

> I wrote to the cantonal cremation society … I prepared everything, my last will, everything is taken care of. I gave my last will to my lawyer and I prepared all the documents to be able to … so that I am cremated and that my ashes are sent to my family. I have thought about all of this, yes.

Importance of Maintaining Relationships With Family and Friends at the End of Life

Although not all participants had family or were in contact with them, for many it was important that family members be present at the end of life and that family be informed about the condition of their loved ones in prison. Extra time that could be spent with family either through early release or allowing flexible visitation arrangements was considered crucial. In the latter case, concerns about security that could hinder relaxed visitation schemes, including staffing, have to be taken into account. Beat shared his disappointment with his prison's stringent rules on visiting hours:

> And a difficult case that happened here … I actually took it a little personal how this person died. If it is time, I think it should be more, more transparent for his family. You know, there are these strict visiting hours, right? And they are stubbornly following these visiting hours and…
>
> Q: And they weren't changed, adapted, or increased?
>
> No, nothing. That's because for security this is a big risk, but I have the feeling, if something doesn't fit into their routine, that needs more work, then, it's simply not possible.

One participant, Bernadette, mentioned that dying in prison would mean that she would be deprived of the possibility of reuniting and mending her relationship with her family, which is something she had thought of doing upon release:

> Well, I thought of my family, that I wouldn't see them again … because what I wanted to do, is rebuild my family that is estranged since my mother's death. … I couldn't do this anymore, I thought of all this.

Therefore, two ideas related to family are important: (a) receiving support and comfort from family members at the end of life and having the chance to spend quality time together and (b) "tying up loose ends" in order to bring incomplete things, like conflicts with family or friends or financial issues, to a conclusion, which might put the mind of the dying person at ease.

A few inmates also stated that being in prison is difficult because it is impossible to help dying family members or friends who live outside prison. For example, Martin did not have the possibility of assisting his family member/friend during the dying process or even the chance to attend the funeral: "It's actually worse that people are dying outside, because especially in my age all relatives are of an advanced age and you can't even attend the funeral or so." As pointed out by Martin, as he grows older in prison it is likely that family members and friends of the same or advanced ages will pass away, ultimately resulting in the loss of one's social network post-release. Participants blamed strict prison regulations for not being able to remain connected with family members or friends at the end of life. This issue is exacerbated if the inmate is a foreigner and his or her family is living abroad. Wolfgang described his inability to assist his dying father:

> One year after my arrest he died. Nobody took care of him, I tried from prison. I asked the community nurse to look after him, but he refused to let anyone in, he didn't want to. He wrote to me, asking when I would finally be back. What could I do?

Wishes to Die Outside Prison

The wish to die outside prison was strong and often coupled with expressions of hope. Accounts of "making it until the end of the sentence" were prevalent. Therefore, while some participants, like Francis, saw no difference in dying inside or outside prison—"No,

dying outside or here, it's simply a question of finishing"—others, such as Hans, emphasised their desire to die in freedom: "So dying, in any case not here, that's clear."

The question about dying in prison likewise prompted expressions related to the difficulty of life in prison, with all of its deprivations and problems and fulfilling prison duties even with worsening health (Baumeister and Keller 2011), in some cases leading to feelings of having missed out on life. For example, Reto said: "So, when I imagine that I would have to live here and stuff, then I would have the feeling of having missed life." Finally, claims for a right to live in freedom took precedence over some participants' worries about dying in prison, such as for Daniel: "So a basic right would more be a life in freedom rather than death. For me personally, death in prison wouldn't be … so yeah."

Discussion

Death, dying, and end-of-life care are extremely personal, and opinions on these issues vary based on different personalities and situations of the individual concerned. In our study, we sought to understand and conceptualise the perspectives of 35 elderly prisoners on this topic. The themes that were evident from our analysis highlight several issues, also found in other studies (Aday 2006; Deaton, Aday, and Wahidin 2009). Below we discuss these findings using Allmark's (2002) concept of "death without indignities," which brings forth two ethical issues: fostering autonomy and removing barriers.

Fostering Autonomy

Fostering autonomy in end-of-life care implies supporting positive attitudes towards death and dying. From the study findings, we recognise three instances that point to the role of autonomy and in which fostering autonomy may be overdue. These instances are (a) fear of death, (b) preparation for death, and (c) involvement in treatment decisions.

Some participants displayed reduced fear of death, whereas others presented the opposite. In these cases, inmates' right to make decisions concerning their last stage of life and maybe even develop resilience to depressive thoughts from pondering death behind bars could be supported by a positive attitude towards death, such as its acceptance. This could be fostered in two ways: providing positive reinforcement to individuals who display reduced fear of death and helping those who have a heightened fear of death. For instance, older prisoners who did not fear death and considered it a part of life, like Edouard, may have developed a sense of death acceptance (Deaton, Aday, and Wahidin 2009). Acceptance of death may reduce or prevent feelings of fear and despair associated with it. Similar accounts were mentioned by participants who reported repressing thoughts about dying. In these cases, it is important to support positive attitudes. Alternatively, to encourage and develop similar approaches among those who are rather fearful of death, it will be useful to nurture acceptance of death by offering counselling or, at the minimum, fostering open communication. This is important because acceptance of one's death is one of the goals in palliative care (Zimmermann 2012) and is associated with healthy behaviours and "increased meaning and enjoyment in life" (Martin and Salovey 1996, 451). However, death acceptance might be especially difficult for those prisoners with a measure—the Swiss equivalent to preventive detention—because of uncertainty concerning when and whether release would ever happen, as described by Francis. Indeed, the majority of elderly prisoners in Switzerland are and will be those who are incarcerated with a measure in closed institutions (Schneeberger Georgescu 2006). Their number continues to rise due to changes in the law that have created additional hurdles for the release of inmates declared as "dangerous," following a greater call for safety from the public and politicians (Schneeberger Georgescu 2009).

Making arrangements for one's funeral and formulating an advance directive, as Bernadette did, are steps participants take in order to retain some control over their death and the dying process (Emanuel and Emanuel 1998). In deciding upon the disposal of one's body, the person extends his "influence of control and autonomy even beyond the moment of death" (Mak and Clinton 1999, 102). Likewise, drafting an advance directive is an extension of a person's autonomy to a state in which he is no longer able to express his will or defend his interests. Allowing and facilitating prisoners' realisation of such advance planning will further support their autonomy and give them a sense of control in an environment in which they have limited choice.

Respect for prisoners' autonomy means their inclusion in treatment decisions and their informed consent for the selected treatment or care plan. Practices described by some interviewees are disturbing in light of

bioethics' emphasis on individuals' right to make decisions and their ability to consent. Such practices include keeping a dying prisoner incarcerated as long as possible and only transferring him to a hospital in the last days of his life. This clearly does not abide by the principle of respecting one's autonomy. On the contrary, it deprives the prisoner his access to end-of-life services and takes away the right to make treatment decisions. According to international guidelines and the principle of equivalence of care, prisoners have the right to access the same end-of-life care as non-incarcerated populations. However, there are also those prisoners that may choose to die in prison, as they may have come to consider it their "home." While such wishes have not been expressed by our study participants, they are not uncommon (Schneeberger Georgescu 2006) and should be taken into account.

Removing Barriers to Liberty

Similar to diminished autonomy in the prison context, there are inherent barriers that deprive prisoners of their liberty. Specific barriers to good end-of-life care from our study results are: (a) restricted opportunities to engage in social relations; (b) reduced access to end-of-life services, including physician-assisted suicide; (c) lack of bereavement; (d) handling of inmates' deaths by the prison administration; (e) negative experiences of death; and (f) limited choice regarding the place of death.

Involving family and friends in end-of-life care planning is a common practice in palliative care provided in the community. However, as demonstrated by Martin's comments, such practices have not to date been translated into the prison setting due to a number of factors, including restricted means of communication and visiting hours. Nevertheless, flexible visiting arrangements for dying inmates are a crucial component for most programs envisioning good end-of-life care in prison (Ratcliff 2000). Family members may find it difficult to arrange visitation during defined prison hours. It could also be uneasy for dying inmates and their families to share a visiting room. Allowing for privacy and, as far as possible, some semblance of "family life" will lead the way to removing an important barrier for prisoners at the end of life. Moreover, as a result of long sentences, it often happens that all ties with family and friends are severed due to the distant location of the prison, restricted visitation or calling hours, and death of friends and family members. Lessons could be learned from prison hospices in the United States where efforts are made to contact old friends and family members when prisoners are nearing the end of life (Granse 2003). Such re-establishment of relationships gives an opportunity for dying prisoners to resolve conflicts that might have led to estrangement and thus helps achieve a sense of completion (Mak and Clinton 1999).

A second barrier that must be removed to ensure equivalent end-of-life care concerns provision of quality palliative care to control pain and symptoms during the dying process. Palliative care is provided in the community through, for example, hospitals or nursing homes. Prison health care services may or may not be adapted to ensure such care on site. Additionally, correctional physicians often lack the expertise to provide necessary care (Byock 2002). These two factors, compounded with a mutual distrust between inmates and prison health care staff (Granse 2003; also shown in our participants' accounts), possibly hinder provision of end-of-life care. The lack of appropriate end-of-life services in prison necessitates planning on the part of prison health care services when a prisoner must be transferred to such an institution willing to take in the dying prisoner and provide necessary palliative care. Therefore, building strong relationships with community services could be beneficial for prison health services. Either providing palliative care in prison or ensuring that prisoners receive this care in another institution is in line with the principle of equivalence and human rights law (Gwyther, Brennan, and Harding 2009). This provision is likewise important to an inmate's family as it helps them accept their loved one's death (Byock 2002). For prison staff and everyone concerned with end-of-life care, role clarity and specific training are essential to ensure its good functioning (Byock 2002; Baumeister and Keller 2011).

The situation in Switzerland is special in that assisted suicide is decriminalised and organisations such as Exit or Dignitas are available to provide this service. Indeed, some participants were already in contact with Exit, but the question of assisted suicide for prisoners has, so far, not been discussed. If assisted suicide is considered an acceptable choice at the end of life like other services such as palliative or hospice care, then following the principle of equivalence its access should be granted to prisoners as well. Participants' oft-cited reason for seeking assisted suicide was "prison tedium," where death is viewed as a relief. While requests due to "weariness of life" (Fischer, Huber, and Imhof 2008) are common in the general population and are discussed as a valid

reason for euthanasia in the Netherlands (Pike 2010), such requests are often refused elsewhere, because having a fatal and debilitating disease is usually a prerequisite for assisted suicide (Fischer, Huber, and Imhof 2008).

The third barrier to liberty, lack of bereavement support, as comments by Gustav suggest, is still common in the prison context in Switzerland. However, such support is an essential component for good palliative care and helps those left behind in accepting the death of a loved one (Byock 2002). While prison chaplains are usually available to prisoners in Switzerland, these services can be viewed critically in the context of the country's pluralistic society, secularity, and possibly even mistrust towards religious representatives, as stated by some prisoners in our study. Furthermore, it does not reflect what is found in community hospice care, which includes services provided by a range of individuals: health care staff, social workers, chaplains, and volunteers (Field et al. 2007).

The accounts from our interviews show a fourth barrier, death as something unwanted and even feared in the correctional system, possibly threatening institutional security (Granse 2003). This is emphasised by the negative image of prison that is construed in popular media when deaths occur in custody. However, this "institutional uncertainty" (Marti, Hostettler, and Richter 2014) might be remedied by creating greater transparency. Deaths occurring in prison should be acknowledged by prison administration and prison staff members. Co-prisoners should have the possibility to bid farewell and pay their last respects, emphasising the "importance of funerals and memorials" (Byock 2002, 4). Such openness in communication could benefit not only other prisoners but also prison staff, as it provides all concerned parties the ability to discuss death freely, accept it as a natural process of life, and neither fear nor feel the need to hush when a prisoner dies (Dubler 1998). Acknowledgement of death might be particularly important for long-term prisoners who might not have any contacts outside prison and whose social supports are limited to their co-prisoners and prison staff members. Glamser and colleagues (2003) reported that staff members who have known long-term inmates for a significant amount of time might be affected by their death in much the same way as they would be by that of a family member. Therefore, a change towards acceptance rather than exclusion of death in prison serves the dignity of those dying in this context. In Switzerland, with overwhelmingly small and medium prisons for long-term detention and measures (Schneeberger Georgescu 2007), acknowledging an inmate's death might be all the more important, as this is a less anonymous context than big or even super-sized prisons.

The combination of the barriers discussed above leads to the overall negative experiences of our interviewees when they witness the deaths of fellow inmates. In her account, Granse (2003) describes similar or worse experiences from her practice as a prison hospice worker. Research has shown that even witnessing a "good death" can have a positive effect (Honeybun, Johnston, and Tookman 1992). Accordingly, negative experiences might increase fear and mistrust prevalent towards health care services in prison (Dubler 1998). However, one positive result of our research is that interviewees did not relate death in prison with homicides (Glamser and Cabana 2003), indicating that they did not consider the prison environment and fellow inmates as threatening. Prisoners may need the opportunity to bereave the death of a fellow inmate, not to mention the loss of close family members or friends, as such losses during incarceration can have a significant impact on an inmate's life (Ferszt 2002).

The last barrier, the choice of where to die, is more complex and revolves around the question of whether dying in prison is in itself an indignity. This question extends to the issue of compassionate release, which will not be discussed here as it is beyond the scope of this paper. Still, in Switzerland such alternatives are only available to those prisoners suffering from a terminal disease and who are not classified as "dangerous" (Marti, Hostettler, and Richter 2014). These two conditions severely limit the number of inmates eligible for compassionate release. However, for suicide, this question might be easier to answer. If the reason for committing suicide is imprisonment itself or its conditions, it can certainly be viewed as an indignity, especially since Switzerland adheres to the principle of normality (*Swiss Criminal Code* (1937) art. 75(a)(2)). This principle states that prison conditions should be as close to those of normal life as possible. Indeed, prison conditions can prove to be in violation of Article 3 of the European Convention on Human Rights concerning "inhuman or degrading treatment or punishment" and even lead to suicide (e.g., *Renolde v. France*). It can also negatively impact an inmate's mental status. In this case, the prison health care service and other staff can improve suicide prevention (Glamser and Cabana 2003)

through thorough screening of inmates at risk of suicide, the provision of psychiatric care, and reducing risk factors including environmental, psychiatric, and criminal history (Fazel et al. 2011). Prisons and, by extension, the state are "responsible for protecting the health and safety of their inmate population" (Konrad et al. 2007, 113).

Limitations

As a qualitative study, participants' responses may be influenced by social desirability. Participants may have tended to provide more acceptable responses, for example relating to the occurrence of suicidal thoughts. Additionally, the views expressed by older prisoners from Switzerland cannot be generalised to all elderly prisoners in other countries. However, our participants raised several concerns related to death, dying, and end-of-life care similar to other available studies. Thus, we would argue, the findings are valuable to the field of ageing, prison studies, and end-of-life research.

Conclusion

Accounts of older prisoners concerning death, dying, and the end of life in prison illustrate a range of attitudes such as death acceptance, avoidance and fear of death, and seeing death as relief from living (Martin et al. 1996). Themes that are identified could be attributed to two ethical actions supporting "death without indignities" (Allmark 2002), namely fostering autonomy and removing barriers to liberty. Autonomy enables prisoners to take control of arrangements and to plan for the last stages of their lives within the constraints of the prison system. It thus supports a more positive attitude towards death and possibly its acceptance. The removal of barriers involves major changes in the handling of an inmate's death within prison, access to end-of-life services, and suicide prevention. Following these actions and removing all possible external "indignities" is in line with general aims in prison health care, namely equivalence of care. In the best case, successful end-of-life care inside prison can create "a space of freedom inside" for dying inmates (Byock 2002, 6).

The state must organise its correctional system to adequately address the different needs of prisoners arising throughout the life course. This includes end-of-life care for those who are older and for those whom death is more imminent. So far, Switzerland has not organised end-of-life care in its correctional facilities (Marti, Hostettler, and Richter 2014); however, as our research shows, it is neither an alien topic to prison administrations nor inmates. Some models of end-of-life care for prisons are in existence, particularly in the United Kingdom and the United States. Yet, research on the quality and specificities of end-of-life care for prisoners is still scarce. Moreover, Switzerland faces two critical challenges: determining whether end-of-life services should include assisted suicide as an option and, given that the organisation of prison health care is cantonal and not federal, addressing the complexity of ensuring equal access to end-of-life services.

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