

Time to act:  
Vulnerabilities of aging prisoners in  
Switzerland

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*Sometimes I think this whole world  
Is one big prison yard  
Some of us are prisoners  
The rest of us are guards*

*Bob Dylan, George Jackson, 1971*



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## Summary

The worldwide phenomenon of population aging and a rise in indeterminate and long-term sentences due to a “punitive turn” in justice have led to rising numbers of aging prisoners. Unlike older adults in the community, aging prisoners are defined as those aged 50 years and older. Their health needs are distinct when compared to other inmate groups or the general population. They suffer from higher somatic and psychiatric morbidities, making them frequent users of prison health services. This great demand for health care strains prison budgets and capacities as prisons are not adapted to respond to such a specialized population. This thesis discusses vulnerabilities of aging prisoners in order to identify moral obligations that can be derived from them to provide older prisoners with specific interventions that respond to their increased health care needs. One type of care will receive special consideration, namely end-of-life care. This will lay the groundwork for designing appropriate interventions and policies for this group.

To identify vulnerabilities of aging prisoners, two definitions will be used: Luna’s layers of vulnerability and Hurst’s claim-based model. The first makes a general distinction between vulnerabilities of aging prisoners arising from the prisoner status and those that are attributable to old age, and how they impact on health. The claim-based model is specific to detecting vulnerabilities that result from an unfulfilled health care claim, which for aging prisoners, is the same that applies to all prisoners, namely the principle of equivalence of care. Based on this principle, aging prisoners should receive a level of care equivalent to the one received by older adults in the community.

This thesis draws from the results of the study about health care of older prisoners (Agequake-study) as well as the study with mental health professionals working in prisons (Confidentiality-study). Both studies were conducted in Switzerland, which is a research context that presents specific challenges by way of its fragmented and diverse prison health system, for example in terms of language-diversity and organizational differences. The findings showed that confidentiality between prisoner-patients and mental health professionals is compromised due to dual-loyalty conflicts and paternalistic breaches of confidentiality. Aging prisoners are presenting challenges especially related to housing and end-of-life care and necessitate specific interventions. Elderly female prisoners, representing a double-minority in prison, suffer from vulnerabilities, such as social isolation and limitations in their access to health care. These vulnerabilities are attributable to a lack of gender and age specific interventions. Concerning end-of-life in prison, prisoner-participants

shared their views on dying in prison, revealing obstacles in fostering their autonomy and removing all barriers to a “death without indignities”. Questions were raised about the acceptability of assisted suicide for prisoners. Finally, compassionate release, which is the early release of seriously ill and aging prisoners, is confronted with several obstacles: the prevalence of a punitive strategy of crime control and obstructions in the underlying legal processes due to competing justifications.

The results allowed the identification of several vulnerabilities relevant to aging prisoners. The prisoner-layer, revealed a loss of autonomy, social isolation, and psychological suffering that is induced, especially when the prisoner-layer overshadows all other aspects of a person. As a consequence, prisoners are only being treated as criminals and no longer as persons, causing a loss of dignity. In health care, the doctor-patient relationship suffers because of issues related to dual-loyalty of physicians and when the duty of protection of prisoners merges into paternalism. Additionally, access to health care is not always up to the standard set by the principle of equivalence. The age-layer exacerbates some of these vulnerabilities, as aging prisoners use health care services more often and have more complex health needs. Other vulnerabilities are specific to old-age, such as negative health outcomes resulting from an unsuitable prison environment and the uncertainty and lack of perspective that accompany indeterminate sentences. Thus three obligations arise for the care of aging prisoners: avoiding double-loyalty and paternalism in the doctor-patient-relationship, adapting the environment to the health needs of older prisoners, and facilitating access to all types of care available to older adults in the community.

The vulnerabilities identified for aging prisoners are also relevant to end-of-life care for seriously ill and older prisoners. First, the access to all types of end-of-life care is mandated by the principle of equivalence but raises questions about autonomy, paternalism, and possibilities to grant more social contacts. Second, a death with dignity necessitates control over treatment decisions and a supportive environment, while natural deaths in prison are often treated in the same way as prison suicides. Finally, providing prisoners with adequate end-of-life care includes offering such care inside prisons or making outside services available to prisoners. One possibility to grant access to outside services, namely compassionate release, is underused as it faces challenges that could be resolved by better communication between the professions that are involved and an improved design and application of legal provisions.

Thus, aging prisoners are a group characterized by a number of vulnerabilities whose combination leads to specific obligations that need to be translated into interventions and policies to safeguard their dignity and rights.



## Introduction

*“Geriatric prisoners - In it for life: old prisoners are suffering from poor care – and putting a strain on jails, too”*

Such was the headline of one of many newspaper articles referring to a recent trend in prisons, also called the “aging crisis” (Maschi et al., 2013b; Williams et al., 2012), and published in *The Economist* in March 2013. The article underscores the rising number of geriatric prisoners<sup>1</sup> in several countries. Challenges arising from aging prisoners are first of all rooted in the way prison facilities were designed, based on a stereotypical offender type in mind: young, healthy, able-bodied and predominantly male, as these individuals represent the highest proportion of inmates (Wahidin, 2006). Long corridors, bunk-beds, and multiple stairs shape the prison environment, while handrails, low beds, and elevators are lacking. Along with this recent age-related demographic shift in the prison population, it becomes clear that prisons are ill-equipped to deal with the health, environmental and social needs of the aging population they shelter. Thus, the correctional setting is unprepared to respond to the specific health needs of this growing group but will quickly have to adapt to this unparalleled phenomenon.

### What is an aging prisoner?

Research shows that aging prisoners constitute a specific group among the prison population (Watson et al., 2004). Yet, a universally agreed upon definition of older prisoner does not exist. While some researchers use 55 years to denote older prisoners, others use the cut-off age of 50 years (Aday, 2003; Loeb and AbuDagga, 2006). It is however clear that the cut-off age used to define older prisoners is lower than what is considered an older person in the general population (i.e., 60 or 65 years). This is because it has been demonstrated that aging prisoners have a health status comparable to someone 10 to 15 years older in the community (Loeb and AbuDagga, 2006; Loeb et al., 2008). Reasons for this “accelerated aging” process among prisoners are a number of health and behavioral factors such as smoking, poor diet, chronic health conditions, lack of self-care, and stressful prison conditions (Aday and Krabill, 2012; Loeb and AbuDagga, 2006; Maschi et al., 2013a). The combination of such risk factors has been shown to increase the likelihood for the early onset of physical and mental illnesses, such as dementia (Maschi et al., 2012). Therefore, reasons why their chronological age does

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<sup>1</sup> In this thesis I will use the terms older, elderly, aging and geriatric to denote prisoners aged 50 years and older.

not coincide with their biological age (Maschi and Aday, 2014) are intrinsically linked to aging prisoners' health status.

### **Aging prisoners in numbers**

With 10.2 million people behind bars worldwide, the prison population has reached an unprecedented number, increasing about 25-30% in the last 15 years (Walmsley, 2013). The United States (US) has by far the highest incarceration rate with 716 detainees per 100,000 persons compared to a median of 98 in western European countries. Also the number of aging prisoners is highest in the US, with 17.9% of prisoners aged 50 years and older in 2013, representing a total of 271,521 people (Carson, 2014). This number explains why most literature on aging prisoners stems from the US. Europe, including Switzerland, while dealing with altogether lower numbers, is no stranger to this phenomenon. Statistics from England and Wales show that the proportion of prisoners aged 50 years and older in 2013 was 12%, representing 10,231 prisoners (Berman and Dar, 2013). This group of prisoners was the only one that had a 5.2% increase compared to the previous year. Moreover, the proportion of 4% of prisoners aged 60 years and older was the highest ever recorded in England and Wales. According to a report of the Prison Reform Trust (2013) studying the demographic change in the older prisoner population in England and Wales, in the last decade between 2002 and 2011, this group has risen by 103% making it the fastest growing prisoner sub-group. At the same time the proportion of prisoners serving indeterminate or life sentences has also increased (Prison Reform Trust, 2013). Inmates with such convictions are the prisoners most likely to age and possibly die in prison. In other European countries, the number of prisoners aged 50 years and older is also on the rise. Between 2007 and 2012, this number rose from 7,713 to 8,600 in France and from 7,078 to 7,378 in Germany (Aebi and Delgrande, 2009, 2014). Similarly, Switzerland has seen a growth from 295 older prisoners in 2003 to 616 in 2013 (Bundesamt für Statistik, 2014), of which most represent those serving indeterminate sentences (Schneeberger Georgescu, 2006, 2007, 2009).

### **Reasons for the rise in aging prisoners**

The increasing older prisoner population is the result of two distinct phenomena (Maschi and Aday, 2014): the punitive turn in criminal justice (Garland, 1996) and population aging (WHO, 2001). The latter is a demographic change visible worldwide with the proportion of older individuals composing a larger share of the total population (WHO, 2001). Population aging is the result of a decline, both in fertility and mortality in our societies. It has impact on

various economic, political and social conditions. Examples are the sustainability of intergenerational social support systems, rising health care costs, increased use of health care services, and the effectiveness of social security systems (WHO, 2001) for which solutions need to be found. As for the punitive turn, it has led to harsher and longer sentences and fewer paroles for offenders. Garland (1996) bases this development on a strategy of crime control by authorities that is one of denial, which by using punitive measures tries to reassert the sovereign power of the state and is built on emotions of fear and insecurity (Garland, 1996). It is responsible for mass incarceration as a consequence of harsher punishments and the use of prolonged sentences as part of governments' policy of "creating a safe society", which results in many prisoners becoming old while serving long sentences and possibly dying in prison. Additionally, in some countries, an unmatched number of so-called "historical offences" has been solved due to advances in forensic science leading to the incarceration of perpetrators late in their life and often for the first time (Wahidin, 2006). Finally, there are also more older adults committing offences (Maschi and Aday, 2014) and hence entering prison at an old age.

### **The health and health care needs of aging prisoners**

Aging prisoners' health has been researched in the last decades. It is known that in the case of aging prisoners' health both their somatic and mental health is worse than that of the general population and that of younger prisoners (Fazel et al., 2001). Older prisoners suffer from a high number of chronic diseases, such as cardiovascular conditions and endocrine disorders (Aday, 2003; Loeb and AbuDagga, 2006). Studies have investigated self-reported health status of older prisoners, often finding that prisoners reported that their health had deteriorated since incarceration (Loeb and AbuDagga, 2006), while some evidence points to age as stronger predictor than time spent in prison (Wangmo et al., 2014). Advanced age is also often accompanied by physical and cognitive impairments. The occurrence of these debilitating phenomena among prisoners is substantiated by research (Colsher et al., 1992; Williams et al., 2012) and shows that while there are differences between aging prisoners and the general population, they nonetheless share features of the aging process in terms of declining health. Thus, they could benefit from similar interventions as available to older adults in the community.

Based on geriatric care models for older adults in the community, adequate responses to aging prisoners' health needs comprise addressing chronic health conditions and supporting

healthy aging (Williams et al., 2012). It also includes models that are connected to how older adults cope with their environment and whether they can stay independent. Such models are the functional impairment model, based on Activities of Daily Living (ADLs) and geriatric syndromes such as cognitive impairment. Ultimately, in light of older prisoners' increasing numbers and greater health burden, ensuring their health would also encompass providing necessary end-of-life care. On the basis of what we know so far about elderly prisoner and older adults in the community, it can be assumed that they need complex health care interventions that should specifically be tailored to their needs. What exactly these health care needs are remains unidentified and further investigation is needed since "knowledge about the health, functional and cognitive status of older prisoners is limited" (Williams et al., 2012: 1150).

### **Challenges for prison health care**

Access to care in prison is often limited. For example, older prisoners' multimorbidity, their medication needs or their access to end-of-life care often remain unaddressed (Fazel et al., 2004; Williams et al., 2012). The same is true for social care which is often not possible for older adults in prison (Williams, 2013) but which will become necessary when older prisoners are no longer able to navigate the prison environment independently. At the same time, access to outside health care facilities as an alternative to prison care is very restricted. Consequently, older prisoners do not receive appropriate care inside prison due to limited resources, nor can they properly access it outside. Still, already now, the combination of changes accompanying old age and higher morbidity in older prisoners results in a high usage of prison health care services (Lindquist and Lindquist, 1999) and a higher frequency of transports to outside facilities (Williams et al., 2012). These increased health care needs are generating high costs (Maschi et al., 2013b; Williams et al., 2012). As a result, elderly prisoners are putting a strain on prison budgets and capacities.

Reasons for problems in providing aging prisoners with cost-effective and adequate health care can be attributed to the organization of prison health care. Most importantly, it is not very specialized. The primary health care providers are general practitioners and nurses. Their presence and availability depends on the number of prisoners. Access to specialized health care is usually limited to mental health professionals, dentists, gynecologists (in women prisons) and physiotherapists. The availability of these specialized services is however very restricted. All other health care needs can only be accessed using health care

facilities outside the prison, which apart from creating additional costs, are accompanied by administrative hurdles. Prisoners must be transported under supervision and this requires the cooperation of prison health services with prison administration as they are responsible for the security, thus it weights heavy in terms of organization and capacities (Brunicardi, 1998). While the reduced dangerousness of older prisoners, some chronically ill, and low recidivism rates (Fazel et al., 2006) could allow them to access the needed care independently outside through medical parole, they are rarely released on medical grounds (Chiu, 2010).

The delivery of health care in Swiss prisons warrants special attention. First, due to its federal structure, the legal basis for the health care of prisoners is organized at the cantonal level (Hillenkamp, 2008). This means that there are different models for the organization of prison health care and they often depend on the respective institution. There are however, some regional trends in the French-speaking part of the country where health care is independent from prison administration. In the German-speaking cantons, health care is often organized by the prison administration, making health care personnel dependent of it. There are also mixed-models with independent physicians and nurses employed by the prison. Attempts to harmonize the Swiss prison system have been made by creating three prison concordats that are agreements to provide cooperation and uniformity. However, they mainly regulate penological issues, while health care is not standardized and thus, remains very diverse in different institutions. Second, the prison population in the country is relatively small, especially the number of older prisoners. Consequently, prison sizes are also small, with a proportion of 55.5% of prisons having 50 places or less (Bundesamt für Statistik, 2012). This impacts how health care is planned, including how frequently basic primary care can be accessed. For older prisoners this means that their number per prison might never exceed the critical mass necessary for them to receive specific interventions or adaptations made to the environment. Thus, Switzerland deals with a large number of models for the delivery of health care while at the same time only housing a small number of prisoners.

As is often the case, political, legal, and organizational changes lag behind recent developments. Bretschneider and colleagues (2012) concluded that while soft-law such as guidelines concerning the health care for elderly prisoners exist, there is no hard law to protect the health care rights of elderly prisoners. Rulings of the European Court of Human Rights (ECtHR), like *Papon v. France* or *Farbuths v. Latvia*, show that the Court does not consider old age sufficient for warranting the release of such prisoners, if it is not accompanied by other factors such as the incompatibility of the prisoner's health status with

continued detention. Yet, it remains vague on decisive criteria, as to what are the criteria for incompatibility and details on how aging prisoners should be cared for. Also, research is still comparably scarce, especially in Europe. Still, the need to develop policies concerning older prisoners' health care grows with their increasing numbers. For that, the question is whether there is any moral obligation to provide aging prisoners with the specific health care interventions they require? And if so, what are these and how can they be identified?

### **Vulnerabilities of aging prisoners**

In health care, specific obligations usually arise if an individual or a group is considered vulnerable and has a claim for special protection (United Nations Educational Scientific and Cultural Organization - UNESCO, 2005). Demonstrating that aging prisoners are vulnerable would therefore provide them with a claim to such protection and entail a duty to care for them. For that, it is necessary to identify how they are vulnerable, specifically in relation to their health in order to evaluate what the duties are in terms of their health care. This will allow the development of policies and interventions that respond to the needs of older prisoners as they will be derived from specific obligations towards them. The aim of this thesis is to demonstrate: a) the vulnerability of older prisoners because of their prisoner status and their advanced age, b) what claims to health care their vulnerability entails and what duties arise, and c) how these duties towards aging prisoners can be put into practice. A specific focus will be the end-of-life period and consequently end-of-life care. This focal point is chosen due to end-of-life care being one type of care older prisoners currently have no access to and because by way of the finality of death ethical issues in the care for them become exacerbated and consequently more pressing. Such aims require a definition of vulnerability that can accommodate multiple sources of harm older prisoners might be vulnerable to and that links vulnerability to health care claims.

### **What is vulnerability?**

There is great dissent about the definition of vulnerability. In her paper, Ruof (2004) lists multiple definitions of vulnerability and their application in health care and human subjects research. This led some scholars to advocate for the use of other concepts, such as susceptibility, which delineates vulnerability as a human condition from a state where one is harmed (Kottow, 2003; Kottow, 2005) or for an abandonment of the concept in research altogether (Levine et al., 2004). Others have tried to unify existing definitions and respond to critiques of the concept of vulnerability, such as it being stereotyping, by that paternalistic,

and too broad (Brown, 2011; Forster et al., 2001; Schroeder and Gefenas, 2009). These scholars attempt definitions that are neither too narrow, thus limited to only one feature, such as the ability to give informed consent, nor too broad, by that encompassing all of humanity (Hurst, 2008).

Broad definitions of vulnerability consider it to be inherent to the human condition (Kottow, 2003; Levinas, 1961). It describes the human venture of self-realization as fragile and risky. Due to the universality of the principle, we are all in need of protection (Kottow, 2003; Sellman, 2005). Such definitions of vulnerability are used in the basic ethical principles in European bioethics (Rendtorff, 2002) and the Universal Declaration on Bioethics and Human Rights (United Nations Educational Scientific and Cultural Organization - UNESCO, 2005), that adds the category of “special vulnerability” to refer to individuals in need of additional protection.

Narrow definitions of vulnerability are more strongly adapted to their area of use, for example research or health care. Hurst classified “restrictive definitions” (2008: 192) of vulnerability into three categories: the consent-based, the harm-based and the comprehensive. The consent-based definitions focus on the risk of giving faulty consent and thus consider the ability to make informed choices in research and health care as sufficient protection against harm. The harm-based definitions accept broad interpretations of vulnerability and what warrants special protection are only additional harms some individuals are more susceptible to acquire due to some disease or other biological weakness (Kottow, 2003). According to such definitions, groups that are typically considered vulnerable are for example children, pregnant women, older persons, minority groups or the institutionalized (Council for International Organizations of Medical Sciences - CIOMS, 2002; The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). What they share is that they are viewed as disadvantaged and at special risk of harm, often due to unequal power relationships making them susceptible to exploitation (Lott, 2005). Finally, comprehensive definitions mix criteria of the above two types of definitions. Such comprehensive definitions specific to health care define vulnerable groups as “those less able to safeguard their own needs and interests adequately” and “who may incur different health outcomes traceable to unwarranted disparities in their care, or stemming from special needs for care or barriers to care.” (Hurst, 2008: 195)

In this thesis, two definitions of vulnerability will be used that respond to the problems described above. These definitions are coined by Luna (2009) and Hurst (2008). These are

selected because they avoid being too broad and too narrow definitions, while still remaining comprehensive and are not unnecessarily stigmatizing or stereotyping. These two definitions are needed for this thesis as they capture different aspects necessary for the description of the vulnerability of older prisoners.

In her definition of vulnerability, Luna avoids the often mentioned critique of stereotyping a group (Brown, 2011) by labeling it as vulnerable. She understands vulnerability as risk of harm concerning multiple dimensions of a person, what she calls “layers”, arising from “conditions of economic, social and political exclusion” (Luna, 2009: 123). As such, a person has several layers of vulnerability that can change according to the context, rather than one feature that makes that person vulnerable. By that, this model is flexible and dynamic and does not consider vulnerability to be inherent to certain people or groups, but very much dependent on the circumstances that render a particular individual vulnerable (Luna, 2009). In the prison context, this definition is especially helpful, as it is an amalgamation of groups commonly labeled as vulnerable: there is an overrepresentation of minorities, mental illness, substance use, histories of violence and abuse, and low educational background (Fazel et al., 2008; Pettit and Western, 2004; Sarteschi, 2013). Even the group of prisoners itself is labeled as vulnerable (Hurst, 2008; Lott, 2005). The layer model resolves problems arising for individuals who belong to several of these groups, such as our older prisoners: they have a “prisoner-layer” and an “age-layer” that might render them vulnerable in prison. Other layers can be added if necessary, such as a minority-layer for example. Still, Luna’s layer model has two short-comings for the purpose of this thesis. First, it was not designed for health care but for research or for health policy, which can limit its applicability (Luna, 2009; Luna and Vanderpoel, 2013). Second, it does not detail what obligations flow from the different layers or sources of vulnerability (Lange et al., 2013).

Hurst also refrains from stereotyping and defines vulnerability as an “identifiably increased likelihood of incurring additional or greater wrong” (Hurst, 2008: 195) warranting special protection. To be wronged is what people incur, when they are denied something they have a valid claim to (Hurst, 2008) and if they have a higher than ordinary likelihood of that happening. She calls this the *Special protection Thesis (SPT)* (Tavaglione et al., 2015). In this context, a claim is defined as an interest an individual or a group has that is morally protected by which a duty arises for other(s) to promote it. Such moral claims can also be legally protected. Hurst’s definition applies to both research ethics and health care (2008). In health care, there exists such morally protected interests, termed ethical requirements that need to be

fulfilled. From literature, Hurst compiles a list of such requirements, such as: health care access, confidentiality, self-determination or financial coverage (Hurst, 2008). Far from only stating claims that need to be fulfilled, Hurst's definition of vulnerability gives a moral impetus as to the efforts that will be made to achieve these claims. Using such a paradigm will allow a more thorough examination of what can be considered a violation of the claims of older prisoners to health care, once it is clarified what their claims to health care are. However, some questions remain unanswered, even with this definition. It does not detail how different claims from various groups can be balanced against each other to be just. Also, it offers little guidance on "whose duty it is to fulfill these claims" (Hurst, 2008: 201).

If we consider Hurst's definition of vulnerability in health care, the question arises whether prisoners have a claim to it. Indeed, such a claim exists: the guiding principle for prisoners' health care is the principle of equivalence. It suggests that the health care delivered to prisoners should be equivalent to the one received by the general population (Niveau, 2007). The meaning of "equivalence" is at the heart of debates surrounding this principle. Practitioners often call for the necessity of it to mean "at least" equal to what would routinely be offered to the general population insisting on the specificities of the prison population, including its high somatic as well as mental morbidity in need of even higher standards of care (Lines, 2006; Niveau, 2007). The principle can be in itself problematic if it is not clarified whether it signifies equivalence of access or equivalence of outcomes and how health should be conceptualized in this specific context (Jotterand and Wangmo, 2014). The question of equivalence is a reoccurring theme in the care for elderly prisoners. As such, equivalence will also be used in this thesis as defining the standard against which the health care for older prisoners should be measured. Furthermore, vulnerabilities will be defined on the basis of this standard.

Finally, the two definitions of vulnerability capture different aspects of the vulnerability of older prisoners. Luna's definition of vulnerability allows us to compile the vulnerabilities of older prisoners according to their different layers that are a result both of their status of prison inmate and their advanced age. Specifically related to health care for older prisoners, Hurst's definition will be useful as it is possible to establish whether this group is more likely to be denied its valid claim to equivalent health care. Potential guidance as to how to respond to these vulnerabilities in terms of duties of health care personnel and public policy will be addressed.

## **What are the gaps in the research on vulnerability of aging prisoners?**

Considering the knowledge about older prisoners available to date, a considerable number of questions remain unanswered. The focus of this thesis will be to investigate the obligations that exist for aging prisoners' health care, with a focus on end-of-life care, and by identifying the vulnerabilities of older prisoners. This will serve as a basis for the future development of interventions and policies tailored to older prisoners. For that, I will address the following questions:

- What makes older prisoners vulnerable in relation to their status and age?
- What are the implications of being vulnerable for aging prisoners' health care in terms of duties?
- How can these duties towards aging prisoners be put into practice?

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## Goals and Aims of the study

The aim of thesis<sup>2</sup> is to explore the vulnerabilities of aging prisoners in relation to their health and health care and to derive duties from them that can inform practice. End-of-life care will be a special focus. For that we will have two subparts with specific objectives to answer the research questions stated above:

- ❖ Vulnerabilities of aging prisoners in Switzerland
  - General claims of all prisoners to equivalent health care will be investigated exemplified by one requirement, namely confidentiality. The goal is to see how far requirements of medical ethics are compromised in prison, especially for groups considered as vulnerable.<sup>3</sup>
  - There is need to clarify the principle of equivalence in relation to older prisoners in Switzerland in order to demonstrate how they can be wronged if the claim to equivalent health care is denied to them. Two specific concerns will be presented: housing and end-of-life care as those are areas with specific risk of wrongful harms.
  - To explore the layers of vulnerability of older prisoners according to Luna's definition of vulnerability, a special group will be investigated that has another layer of vulnerability, namely elderly female prisoners. In this way it is possible to show how constructions of gender and age are relevant and how different layers interact.

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<sup>2</sup> The goals and aims of this thesis fall within the general mission of the overarching project: "Agequake in Prisons: Reality, policies and practical solutions concerning custody and health care for ageing prisoners in Switzerland", funded by the Swiss National Science Foundation (SNF). The "Agequake-study" was designed to investigate the status quo of the situation of older prisoners in Switzerland and propose solutions that are ethically, legally and economically sound.

<sup>3</sup> For this part data from another study than the Agequake project were used, from the "Confidentiality-study". The study was designed by Bernice Elger. The interviews were conducted by V. Lauf, A. Taberska, M. Ducotterd and C. Brueggen.

- ❖ The impact of prisoners' vulnerabilities on end-of-life care
  - By analyzing prisoners' views on death in prison, vulnerabilities at the end-of-life will be identified. Obligations such as removing barriers and fostering their autonomy will be explored.
  - Requests for assisted dying by our participants in the interviews will be discussed from an ethical point of view. Consequently, it will shed light on the availability of treatment choices in prison and in how far their autonomous choices are influenced by the environment.
  - In another study, the beliefs of older prisoners concerning the early release of terminally ill inmates will be discussed. It addresses access to end-of-life care according to the principle of equivalence. Also, it will link end-of-life care to theories of punishment.
  - Based on the legal examination of provisions in Europe and stakeholder interviews, hurdles to the process of early release for seriously ill and elderly prisoners were identified. Solutions on a policy level will be addressed based on justifications for early release, among them, the principle of equivalence.

Accordingly, the thesis includes the following articles (in the same order). Contributions of each author will be listed:

- 1) Elger, B., Handtke, V., Wangmo, T. (2015a). Informing patients about limits to confidentiality: a qualitative study of mental health professionals working in prison settings, *International Journal of Law and Psychiatry*, 41, p. 50-57.
- 2) Elger, B., Handtke, V., Wangmo, T. (2015b). Paternalistic breaches of confidentiality in prison: mental health professionals' attitudes and justifications, *Journal of Medical Ethics*, 41, p. 494-500.
- 3) Wangmo, T., Handtke, V., Elger, B. (2014). Disclosure of past crimes: An analysis of mental health professionals' attitudes towards breaching confidentiality. *Journal of Bioethical Inquiry*, 11(3), 347-58.

For these three publications the first authors Bernice Elger and Tenzin Wangmo took the lead. My role for the above 3 publications included analysis of the interviews,

contributing in drafting the manuscripts, reviewing and adding to the quality of the manuscripts.

- 4) Handtke, V., Bretschneider, W., Wangmo, T. & Elger, B. (2012) Facing the challenges of an increasingly ageing prison population in Switzerland. *Bioethica Forum*, 5, 134 -141.

This publication was a joint effort of the Agequake research team. Specifically, I wrote the housing segment and ensured that the group work was well coordinated. Tenzin Wangmo worked on the section on end-of-life, Wiebke Bretschneider was in charge of the definition of the principle of equivalence and Bernice Elger provided her expertise for the discussion of the identified issues.

- 5) Handtke, V., Bretschneider, W., Elger, B., Wangmo, T. (2015a) Easily forgotten: elderly female prisoners. *Journal of Aging Studies*, 32, p. 1-11.

I conceptualized and wrote this manuscript. I and the co-authors coded the interviews according to the layer model of vulnerability. They reviewed and commented on the drafts versions and approved the final manuscript.

- 6) Handtke, V. and Wangmo, T. (2014). Ageing prisoners' views on death and dying: contemplating end-of-life in prison. *Journal of Bioethical Inquiry*, 11(3), 373-386.

This paper was a collaborative work between the two authors. As the first author, I took the lead in the writing process. The coding was done by both authors.

- 7) Handtke, V. and Bretschneider, W. (2015b) Will I stay or can I go? Assisted suicide in prison. *Journal of Public Health Policy*, 36, p. 67-72.

This article was jointly written by me and my co-author, Wiebke Bretschneider. We equally contributed to the manuscript from the initial conceptualization to the writing of the final manuscript.

- 8) Handtke, V., Bretschneider, W., Elger, B., Wangmo, T. (2016). The collision of care and punishment: older prisoners' view on compassionate release. *Punishment and Society* (online first).

This article was a result of the previous work on compassionate release that was done. Therefore, I took the lead as the first author. All co-authors again supported in the coding, editing and review process.

- 9) Handtke, V., Wangmo, T., Elger, B., Bretschneider, W. (accepted by *The Prison Journal*) New guidance for an old problem: Early release for seriously ill and elderly prisoners in Europe.

I initiated the theoretical framework as well as the writing process. My co-author, Wiebke Bretschneider, who has a law background was responsible for the legal issues captured in the paper. All co-authors contributed to the coding process and reviewed different versions of the manuscript.

## Methodology

### The Agequake project

This thesis uses the qualitative data of the Agequake-study. For that, interviews were conducted with two groups: stakeholders and aging prisoners<sup>4</sup>. In the interviews different themes were addressed. As all articles only present one theme at the time, the French and German versions of the questionnaires for prisoners and the French stakeholder guideline containing all questions that were asked to participants are in the appendix.

#### Prisoner interviews

A total of 35 interviews were conducted with aging prisoners in 12 prisons in Switzerland. General themes of the qualitative semi-structured interview-guide were demographic information, social contacts, health status before and after imprisonment, access to care, substance use, quality of life, spirituality and death and dying, and alternatives to incarcerating older adults. For a detailed description of the interviews with prisoners see (Handtke et al., accepted; Handtke and Wangmo, 2014).

#### Stakeholder interviews

The research team interviewed 40 stakeholders from three European countries. General themes they were asked about were: their experience with older prisoners, the access to health care for them, health care delivery, barriers to health care, circumstances of aging in prison, a cost benefit analysis and two vignettes depicting difficult situations involving older prisoners. For a detailed description see (Bretschneider and Elger, 2014; Handtke et al., 2016).

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<sup>4</sup> Data collection was a joint effort of the core research team including: Bernice Elger, Tenzin Wangmo, Catherine Ritter, Wiebke Bretschneider, and myself. The overall study was supported by a team of collaborators: Christophe Büla, Bruno Gravier, Astrid Stuckelberger, Reto Kressig, Julie Page, Marcelo Aebi, Alberto Holly, Karine Moschetti, Nicola Biller-Andorno, Cornelia Hummel, Jens Sommer, Andreas Stuck, and Olivier Guillod

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## **Chapter I: Vulnerabilities of aging prisoners**

Prisoners' claim to health care is defined by the principle of equivalence. To explore whether this principle is respected one key requirement of mental health care was investigated: confidentiality. According to the principle of equivalence as stated by the Swiss Academy of Medical Sciences (SAMS), confidentiality is an integral part of health care for prisoners (Swiss Academy of Medical Sciences - SAMS, 2012). In that way, confidentiality can serve to verify the fulfilment of valid health care claims of prisoners according to the principle of equivalence. Duties on the part of health professionals will be discussed when providing care to mentally ill prisoners (Elger et al., 2015a; Elger et al., 2015b; Wangmo et al., 2014), a vulnerable sub-group among prisoners (Johnston, 2013). While older prisoners are not dealt with directly when discussing confidentiality and equivalence of care, it is still very relevant for them and other groups, that are at increased risk of harm. Indeed, as a group that is a higher user of prison health services as compared to other prisoners (Lindquist and Lindquist, 1999), confidentiality can be considered to be of heightened importance for aging prisoners.

In order to investigate if aging prisoners are at increased risk of incurring greater wrong, it is necessary to examine whether their claim to equivalent health care is denied to them on grounds of their advanced age (Hurst, 2008). For that it is indispensable to clarify the ramifications of this principle, especially in relation to its context, which for this thesis, is Switzerland. To verify if their claim to equivalent health care is in fact denied to them, two concerns related to health care will be addressed: the environment and end-of-life care. The environment will be examined as it impacts health of older prisoners, whose "aging bodies" are not adapted to it. End-of-life care was chosen because it involves questions surrounding the access to health care, also mentioned by Hurst (2008) as requirement. Additionally, it necessitates complex care encompassing an interdisciplinary team rather than access to one specialized service. It therefore "tests" the capacity of prisons to fully adhere to the principle of equivalence more than any other health care service. Both concerns will show whether shortcomings in adhering to the principle of equivalence will lead to wrongful harms for aging prisoners. Additionally, it will clarify duties, especially for medical professionals, that flow from the identified vulnerabilities, see (Handtke et al., 2012).

Concerning the prison environment and the possible impact it has on aging prisoners, it is necessary to empirically investigate which vulnerabilities arise with age. It is also important

to separate them from vulnerabilities shared by all prisoners. For that, the layer model that Luna (2009) devised is helpful, as it is possible to separate several layers or rather dimensions of a person in order to see what vulnerabilities arise due to which layer. To examine what the age-layer entails in prison it is essential to compare it to constructions of age in society in general. What happens if social markers such as retirement do not exist in a given environment? Similar are constructions of gender. This is why this layer will be added to the investigation, based on prisoner interviews, see (Handtke et al., 2015a). Indeed, elderly female prisoners (EFPs) constitute a “minority within a minority” and it is recognized that the combined needs of EFPs remain largely uninvestigated (Leigey and Hodge, 2012). By identifying vulnerabilities according to layers, it is possible to shed light on challenges arising due to constructions of age and gender and for prisoners in general.

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**Vulnerability of prisoners in the doctor-patient relationship: the case of confidentiality**

**Informing patients about limits to confidentiality: A qualitative study in prisons**

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**Abstract**

Confidentiality is important in healthcare practice, however, under certain circumstances, confidentiality is breached. In this paper, mental health professionals' (MHPs) practices related to informing imprisoned patients about confidentiality and its limits are presented. Twenty-four MHPs working in Swiss prisons were interviewed. Data analysis involved qualitative thematic coding and was validated by discussing results with external experts and study participants. For expert evaluations and court-ordered therapies, participants informed patients that information revealed during these consultations is not bound by confidentiality rules. The practice of routinely informing patients about confidentiality and its limits became more complex in voluntary therapies, for which participants described four approaches and provided justifications in favour of or against their use. Further training and continued education are needed to improve physicians' ethical and legal knowledge about confidentiality disclosures. In order to promote ethical practices, it is important to understand and address existing motivations, attitudes and behaviours that impede appropriate patient information. Our study adds important new knowledge about the limits to confidentiality, particularly for providers working with vulnerable populations. Results from this study reflect typical ethical and practical dilemmas faced by and of interest to physicians working in forensic medicine and other related settings.

## **Introduction**

In healthcare, confidentiality ensures trust between the physician and patient. It is a cornerstone of the patient–physician relationship and an important component of patient privacy and thus safeguarded by law in most countries (Higgins, 1989). If this trust is not to be undermined, exceptions to confidentiality must not only be limited, but also be clearly defined and justified by law or medical ethics and known to patients (Appelbaum, 2002). Thus, both healthcare professionals and patients should be aware of the limits to confidentiality (Bok, 1983; Moodie and Wright, 2000; Rachlin and Appelbaum, 1983). While literature has examined the limits of confidentiality and duties to warn (Mills et al., 1987; Pinta, 2010), discussions remain limited about how physicians’ should inform patients about these exceptions (Bok, 1983; Green, 1995; Moodie and Wright, 2000; Rachlin and Appelbaum, 1983).

It is accepted that confidentiality must be balanced against other interests such as the life and integrity of patients or third persons (Bok, 1983; Pinta, 2009; Rachlin and Appelbaum, 1983) and the ‘public interest’ (Bourke and Wessely, 2008; Kampf and McSherry, 2006) or the ‘collective good’ (Konrad, 2010). As the World Psychiatric Association (1996) states, ‘[b]reach of confidentiality may only be appropriate when required by law (as in obligatory reporting of child abuse) or when serious physical or mental harm to the patient or to a third person would ensue if confidentiality were maintained’. Likewise, the Royal College of Psychiatrists (2010) of the United Kingdom underlines that ‘[h]ealthcare professionals may have ethical duties to disclose confidential information, without consent, if serious and imminent dangers are present for a third party and they judge that disclosure is likely to reduce or eliminate the danger’. Ethically difficult situations may occur, however, if sensitive information about mental illness, psychiatric symptoms, thoughts and behaviours revealed during consultations are disclosed to third parties, rendering the patient vulnerable to stigma and social alienation. Thus, the World Psychiatric Association (1996) recommends that ‘whenever possible, psychiatrists should first advise the patient about the action to be taken’. Although it is certainly important to inform patients directly before breaching confidentiality, it should be noted that this means informing patients at the moment when the patient has just disclosed the information to the physician. The question thus remains as to whether and how patients should routinely be informed at the beginning of any therapeutic relationship that confidentiality may be breached under certain circumstances in order to promote trust and to maintain a healthy relationship between patient and physician.

Confidentiality rules and its limit apply equally to prisoner-patients seeking mental healthcare services. Federal law in Switzerland provides strong protection of confidentiality. Its violations are punished by imprisonment or a fee. International *soft law* imposes the principle of equivalence for prisoner care (Swiss Criminal Code, 2014; Council of Europe, 1998; United Nations, 1982). The professional guidelines of the Swiss Academy of Medical Sciences concerning “Medical practice in respect of detained persons” restate the importance of medical confidentiality and explain that “[m]edical confidentiality is to be maintained under the same legal provisions as are applicable for persons at liberty (Art. 321 Swiss Criminal Code)” (SAMS, 2002). Informing prisoner-patients about limits to confidentiality may be particularly important based on the crimes they have committed and their present mental conditions. If a prisoner-patient divulges past crimes or intentions of harming self or others, he may be unaware of the consequences of such disclosures made in confidence. According to a cantonal law in Switzerland, serious past crimes for which a prisoner was not incriminated must be disclosed by the healthcare provider (Gesundheitsgesetz Basel Stadt (GesG), 2012). Also, Art.10 of the SAMS (2002) guideline state that in “exceptional cases, if the life or physical integrity of a third party is seriously and acutely endangered, physicians may themselves decide to breach confidentiality and directly inform the competent authorities or the third party at risk.” Thus, informing patients at the outset of treatment about limits to confidentiality would enable them to think through decisions and possible consequences before revealing certain information to physicians. This is important because they may not be fully aware that exceptions to confidentiality exist such as their information being routinely shared with all team members involved in patient care or that information shared that could pose real and serious harm the patient self, identifiable third persons, or the general public (Moodie and Wright, 2000). Studies have also shown that physicians have various individual thresholds as to when they find it ethically appropriate to disclose information to third parties and that patients’, lay persons’ and legal and health professionals’ attitudes towards disclosure of confidential information vary widely (Bruggen et al., 2012; Elger, 2009b; Fennig et al., 2000; Fennig et al., 2005; Schutte, 1995). These varying attitudes of healthcare professionals make it difficult to foresee when and whether the limits of confidentiality would be clarified to the patients.

A well-established practice, known by most physicians, in relation to non-therapeutic encounters (such as expert testimony for insurance companies or the justice system) is to inform patients at the beginning of the first meeting about limits to confidentiality. In order to

be examined, individuals are made aware that confidentiality rules in these contexts differ from therapeutic relationships since information will be provided to the party who requested it. In contrast, recommendations for ensuring patients' knowledge about limits to confidentiality in routine clinical consultation are somewhat less clear-cut. Professional perspectives exist supporting the idea that information exchange should be two-way. For instance, the General Medical Council of the UK underlines that patients must be informed about confidentiality disclosures for purposes that patients would not 'reasonably expect' (General Medical Council, 2009). Therefore, health professionals must enquire that patients have already received information about such disclosures. Similarly, the Royal College of Psychiatrists (2010) reminds providers that clinical responsibility in psychiatry includes informing patients about how information is used: 'Particularly in the situation of multi-agency working, patients need to be made aware that, in order to provide optimal care, some information sharing will usually be desirable'. While healthcare professionals in general may face situations where they must balance confidentiality against other interests, in the context of prison healthcare such situations are more often likely to occur. As a consequence, sensitivity to the importance of informing patients about limits to confidentiality within prisons should be made clear.

Guidelines also exist as to the appropriate steps physicians should take when deciding whether they can breach confidentiality in regular medical practice. It could be assumed that similar guidelines apply to physicians working in prisons. However, prison is a unique setting and has a culture of its own. For instance, prisons are closed environments where it might be particularly challenging to ensure confidentiality because of the myriad of individuals involved in the care and security of the prisoners. Others who are directly or indirectly involved in prisoner care, particularly, non healthcare staff members may be able to deduce something about a patient's health by simply observing which professional, i.e., nurse, general physician, psychiatrist, or specialist the prisoner is visiting.

To date, limited literature about how confidentiality is maintained in the prison environment is available. Thus, this study was designed to explore mental health professionals' (MHPs) experiences to ensure and/or beach confidentiality; and sought to understand their attitudes regarding confidentiality within the prison setting. Given the lack of previous research and the study's exploratory character, a qualitative methodology was used. This article examines the experiences of and approaches used by MHPs with regards to informing patients in

prisons about limits to confidentiality, and highlights MHPs' justifications in favour of or against these approaches.

## **Methods**

### *Participants*

From 2008 to 2009<sup>5</sup>, face-to-face interviews were carried out with 24 MHPs working in Swiss prisons. Participants were selected using purposive and convenience sampling. Our goal was to ensure the greatest possible diversity among participants with regard to background, gender, professional experience, therapeutic orientation and cultural context. Thus, participants were selected to obtain maximum variation of opinions representing two major linguistic regions and varying levels of experience. Participants were not selected randomly as random selection is characteristic of quantitative or experimental study design, but not of qualitative study.

Board members of the Swiss Society of Prison Physicians (SSPP) assisted with participant identification. Since the SSPP notes that different approaches concerning confidentiality in prison occur in the French- and German-speaking parts of Switzerland, the sample was stratified to include similar numbers of participants from both language regions. After receiving approval from the appropriate cantonal research ethics committee, the senior prison or forensic physician responsible for the canton was first contacted and his/her consent and permission to approach MHPs working in prisons was obtained. Either all MHPs working in prisons or a selected sample of the most experienced MHPs were approached for an interview. Prospective participants were contacted by phone or e-mail and oral consent was obtained. The head physician was not informed whether members of his or her team did or did not participate. All interviews were conducted confidentially. After the interviews, participant names were deleted and any data that would permit identification of a person or particular situation were removed.

### *Interview guide*

Based on previous experience with interdisciplinary qualitative studies (Manai et al., 2010), an interview guide was designed, starting with open-ended questions about participants' experience with and views on confidentiality. Interviewees were asked to describe their standards of practice as well as cases they found difficult. If the subject of informing patients

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<sup>5</sup> Although the interviews took place in 2008 – 2009, the attitudes described have been stable over the past 20 years. Through the interviews, we have been able to characterize the attitudes of the MHPs in Switzerland.

about the limits of confidentiality was not raised spontaneously, probing questions were asked as to whether, how, and when patients were informed and whether this was an exception or reflected participants' typical approach. Towards the end of the interview, participants also were asked to consider four vignettes concerning confidentiality and the sharing of information. Interviews were carried out in French or German by BE and three assistants hired and trained specifically for this purpose. Interviews lasted approximately one hour, and were audiotaped and transcribed. Translations of quotes into English were carried out by VH and TW and were cross-checked by BE to ensure transferability of meanings.

### *Data analysis*

The authors first read the transcripts multiple times to gain familiarity with the data. They then thematically coded the responses and grouped them by major ideas or themes identified from participants' words, phrases and examples (Bryman and Burgess, 1994; Strauss and Corbin, 1998) . This was followed by a study of important and frequently reported ideas or themes and a search for patterns that justified grouping themes into broader categories. Provision of information on confidentiality or informing patients about its limits emerged as a broad category and one of the most important themes. We did not find any pattern related to training, although MHPs with varying years of experience and training were interviewed. Major results were compared between the two subgroups of French- and German-speaking MHPs and the subgroups are noted in the voices of participants reproduced in the Tables<sup>6</sup> to reveal their opinions.

### *Validity*

In order to ensure the quality of data and to promote validity during data collection, interpretation and analysis, we discussed the interview guide as well as our preliminary results with a group of multidisciplinary researchers, including experts with extensive experience in qualitative research and physicians with experience in ethics, law and prison healthcare. We also sent final results to a representative group of seven MHPs from different cantons, several of whom were study participants, and requested feedback. We did not send the results to all participants because this might have interfered with confidentiality. Two out of seven provided some critical comments, which were addressed, but all agreed that the findings were accurate and valid.

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<sup>6</sup> In qualitative studies, the number of individuals stating an opinion is not important, but the opinion itself. Statistical significance is not a concern of qualitative study design.

## Results

Of the MHPs identified and approached for an interview, including head physicians, only three declined to participate, stating that their opinions would not differ from those of other MHPs participating in this study. Of the final 24 who were interviewed, ten had working experience not only in Switzerland, but also in other countries. Characteristics of participants are shown in Table 1. All participants had previous therapy experience outside of the prison context and many reported that, at the time of the interview, they were simultaneously working with patients both inside and outside of prison, either in psychiatric hospitals or with forensic outpatients.

**Table 1:** Participant Characteristics

Characteristics of mental health professionals	Participants from French-speaking cantons <sup>a</sup> n=12	Participants from German-speaking cantons <sup>b</sup> n=12
Sex (men : women)	8 : 4	10 : 2
Training: Psychiatrist : Psychologist	9 : 3	11 : 1
Place of Employment:		
Psychiatric clinic	8	5
Forensic medicine and/or psychiatric clinic	4	4
Department of justice	-	3
Work experience in prison		
2 – 6 years	4	5
7 – 10 years	4	3
>10 years	4	4
Experience in other countries		
No	7	7
Yes	5	5
Types of experience:		
Expert opinions	10	11

Regular therapies	12	12
Mandatory therapies	12	12
Mental healthcare outside prison	12	12

<sup>a</sup>French speaking cantons (n=3); <sup>b</sup>German speaking cantons (n=6)

Based on participant responses, two time points emerged where patient information about confidentiality and its limits plays a significant role. The first is characterised by provision of information on limits to confidentiality during the initial consultation encounter (either at the beginning of or during the consultation) with the patient. The second type occurs at a later point when MHPs inform patients about breaches of confidentiality before they plan to transmit information to third parties. All participants indicated that it depends on the type of consultation whether or not information about confidentiality takes place systematically during the first encounter. They distinguished three settings: (a) expert evaluations, (b) court-ordered therapies and (c) patients seen in a therapeutic relationship on a voluntary basis. In the cases of expert evaluations and court-ordered therapies, the rules related to informing patients were quite clear; however, when it comes to voluntary medical services, the rules were less well-defined and justifications were highlighted by the participants to explain which disclosure measure they choose to use and which they do not. The responses of participants describing standards of practice during the initial patient encounter as well as MHPs' explanations in favour of or against routine patient information about confidentiality and its limits are reported below.

#### *Expert evaluations*

There was a high level of agreement regarding when and how MHPs inform individuals about the limits of confidentiality in the context of conducting expert evaluations (e.g., for insurance companies or the judicial system). For such cases, participants reported informing patients about their role as experts at the beginning of the first encounter and obtained patients' consent either orally or in most cases in writing (Table 2, Participants 2 and 6).

**Table 2:** Standard information about confidentiality limits during the first encounter<sup>a</sup>

	<b>Expert evaluation to provide written expert opinion</b>
Standard written information and written consent	(2) It is important that from the start I inform that the therapy concerns an expert assessment. Everything that he [the patient] informs will be made written in the report. Therefore, he should only inform those things that he wishes. Additionally, it is very important to advise him that there is no obligation to provide information.
Standard information and consent, but oral is sufficient	(6) Ok, I clarify that very carefully in the beginning so that there is a clear distinction. I say, listen, I am a doctor and I respect confidentiality, but not when it comes to the government... And because of that, it comes to what is important for me concerning an expert opinion. You can lie to me. You can tell me what you want, whether that is good for you, I do not know. That I tell [the patients]. <i>Interviewer: Do you do that in writing?</i> (6) No. This is just a set phrase that I have in each report. Yes, it is stated in the report as a fixed phrase.
	<b>Court ordered therapy</b>
Standard information and written consent to treatment contract	(18) So this is what I tell them, when they have a court ordered therapy, I say, okay, you are under the obligation to come and see me. Sometimes the authorities, even if this happens rarely, the authorities explain why [the therapy was ordered] and the objectives of the therapy and I explain to them [the patients] that I will make my report in relation to these objectives, normally this is an annual report for the authorities, about how far along one is in regard to the objectives and the rest that is not crucial to know for the authorities, I take the example...I don't know, for example if they tell me about a trauma they experienced during childhood but that has no immediate connection with "is he empathetic towards his victim" for example, that will then stay in the confidential sphere of the therapy, but everything that is related to the objectives fixed by the  <b>Court ordered therapy</b> authorities, I will report, however, I will make them sign a written authorisation...that I will report to the authorities.  (4) Yes, this is our daily work. For the patients, a written treatment agreement is discussed from the start, put down in writing, signed, and mutually agreed on. In the agreement, it is stated that information related to the crime they committed, contact with children, and other things will be worked on during the therapy. These discussions will appear in the report as well as where their position in the therapeutic process. Then the patients know what is related to the subject and that this will be written in the report.
Standard oral information during first consultation	(17) In principle, yes [I explain during the first consultation that a report will be written], but like a lot of things that one explains in the beginning, I am not convinced that the patient understands and I am fairly certain that after six months, a year, he will have forgotten, so you need to repeat it every time that there is a request for a medical report.
Standard oral information later during the therapy	(22) It has happened to me at the beginning of my practice to work differently, because it is unusual to work like that. Normally you would let a person settle in, talk about themselves. It has happened to me to have to write reports after only one session with the patient and that made me feel, ethically speaking, I felt very uncomfortable. I told myself, that basically the patient didn't know that I would write something and I wrote something anyway and there I decided [to change my practice]. They have to know.

<sup>a</sup> 1-11 & 15 =MPHs in German speaking cantons; 12-14 & 16-24 MHPs in French speaking cantons

*Court-ordered therapies*

For court-ordered therapies, participants described three approaches (Table 2). In the first, the patient is asked to sign a treatment contract that describes the limits to confidentiality (Table 2, Participants 18 and 4). With this agreement, the patient consents to the delivery of regular reports to judicial authorities, and the sharing of crime- and treatment-related information with other appropriate agencies. Participants indicated that their reports are usually several pages long and contain sufficient details on prognosis. In the second approach, the therapist provides oral explanations to the patient about which type of medical information will or will not be included in the report to the justice system (Table 2, Participant 17). Participants using oral explanations revealed that their reports are short summaries focussing on therapy goals. The third approach mentioned by one participant concerned past practice. This MHP was convinced that explaining the limits to confidentiality during first consultation was incompatible with traditional psychotherapy; however, he changed his approach towards providing routine information since reports must be written (Table 2, Participant 22).

*Voluntary treatments*

The highest variation concerning provision of information about confidentiality was found for voluntary treatments, where four prevailing approaches were identified. In German-speaking regions, MHPs routinely informed all patients about confidentiality limits, independent of whether treatments are court-ordered or voluntary. This approach (A, Table 3, Participants 15) is recent in practice and was adopted by these MHPs as a result of prison authorities pressuring providers to communicate medical information about their patients on a regular basis. The MHPs felt that the only way to resolve the conflict between obligations of confidentiality and needs of prison staff was to inform all patients about the lack of confidentiality in these settings and to obtain advance consent for future transmissions of information. Several participants noted, however, that patients may feel pressured to consent as treatment cannot proceed without such an agreement (Table 3, Participant 9). Nevertheless, the reasoning provided for following this approach was that the MHPs would rather be transparent from the beginning than be forced to employ different types of compromises where some information is shared and patients discover the breach of confidentiality later.

**Table 3:** Standard information about confidentiality limits in case of voluntary treatments

<p>A. Standard explanations of limits to confidentiality and advance patient consent to information sharing</p>	<p>(15) First, there is the difference between those doing the therapy voluntarily and those with a measure. In theory, for those who do the therapy voluntarily it should be the same in regard to confidentiality as for any person outside. However, this is not really practicable in prison and this is why, here, we ask for people to discharge us from medical confidentiality so that an exchange is possible, between the employees, the people from prison, so that we can have a good contact. This is sometimes a little delicate.</p> <p>(9) Yes, we have told that and therefore the patient information. We would like to solve this problem so that we remain transparent on the one hand and on the other hand that we are freed as much as possible from medical secrecy because otherwise working in prison is very difficult. It is naturally a problem, if someone really wants to receive treatment on a voluntary basis and the patient says, I have a problem and I want to be treated but I do not want the prison to be informed about it. The patient may feel pressured to release me from general confidentiality and could then prefer not to do a therapy at all. But this has not yet happened to me.</p>
<p>B. Routine information that confidentiality is guaranteed except in certain situations</p>	<p>(24) That nothing apart from suicidal thoughts will come out, that's what I tell them. And the only thing that could allow me to give out other information is if my medical secrecy is lifted and the patient has signed a corresponding document.</p> <p>(18) For me, I have a precise rule, that is, at every first meeting that I have with the detainees, I explain the frame in which I work and the rules of confidentiality that I apply. Systematically during the first session I explain to them what stays confidential and what doesn't, I ask them if they have questions and I ask them if they understood everything...and I do this systematically. [...] So I tell them that for the most part everything they say in my office is confidential. I don't discuss any details of what is said in this office with the police, the guards, the judicial authorities, nor with the rest of the team. [...] and then I tell them that I have two exceptions to my confidentiality rule : this is, if I think they are dangerous to themselves, I will talk to the medical personnel as well as if I think that they are dangerous for third parties, and I give them notice that if their attorney asks me to speak to him, which happens quite often, they have to give me a written authorisation that I am allowed to speak to their attorney.</p>
<p>C. Information is shared in their best interest</p>	<p>(5) I do not see any necessity for that [to inform the patient that medical information is routinely provided to the prison administration and guards]. Normally information is shared so that the patient receives adequate care.</p>
<p>D. No routine information, case by case basis</p>	<p>(3) When I have a schizophrenic patient, who is susceptible to criminal behaviours, I agree with the patient that I would like to discuss his case in greater detail with another person in the department. Or that I regularly keep in touch with someone from social services or so on. That can be specified.</p> <p>(7) There is both. It is so that I tell a patient..., I also have an office in the same floor with the social services and insofar, the patient sees that there will be general contact naturally. So that is a part, but I tell also that these are superficial exchange of information because I receive [formal] information from the social services. But when something is special, I tell explicitly that this will be discussed with social services, so that I specifically point that out again.</p>

The second approach used predominantly by MHPs in French-speaking areas also was described as a systematic provision of information about confidentiality to patients at the beginning of a consultation. Here, however, patients are informed that confidentiality applies in the same way in prison as it does outside a prison environment (Table 3, Participants 24 and 18). Therefore, neither prison staff nor the judicial system is given any information (as long as patients do not pose any harm to themselves or others). Additionally, some MHPs reported nearly total confidentiality, not even sharing with colleagues or nurses from the healthcare team what was discussed during therapy sessions. Others informed patients that most information is usually shared with the healthcare team for the purposes of treatment. Approach B is characterised by the fact that MHPs explain to patients that no information will be provided to prison staff without their consent, except in cases of foreseeable self- or third-party harm.

In the third approach (C), used by few MPHs of both regions, no routine conversation on confidentiality limits takes place with prisoner patients seen for voluntary treatment (Table 3, Participant 5). MHPs justified this approach by stating that patients, because of their imprisoned status, already know that information is transmitted to a wider range of persons, including guards and social workers, for their own benefit (to protect patients from self-harm or to protect others). Other MHPs pointed out that exigent needs within the prison setting and certain medical conditions sometimes create barriers to confidentiality or confidentiality notification.

MHPs belonging to both regions indicated that they use an intermediate approach D, where patients are informed on a case-by-case basis (Table 3, Participants 3 and 7). From the different approaches mentioned, it is clear that, although, there are four common approaches, there is no clear standard as to how patients should be informed about exceptions to confidentiality.

*Factors that motivate routine information — Approaches A and B*

In support of routine information, MHPs stated that patients have the right to know whether information is going to be transmitted because this enables them to adapt the amount of information they choose to disclose. Routinely providing information about limits to confidentiality at the beginning of the first consultation also upholds confidentiality as a basic principle governing the patient–physician relationship. This was eloquently explained by participant 8:

One should find a way so that the responsibilities of both sides are fulfilled. Confidentiality must be maintained as a basic principle. But in circumstances where the basic principle is not upheld, there should be transparency. The patient must know about it which enables him not to tell everything. For example, for expert opinions, it is very clear that there is no confidentiality between the patient and the doctor and that everything will be stated in the report. One should tell this to the patient at the beginning. The patient can then make a decision for himself about what he wishes to say and what he should not say.

MHPs provided several explanations favouring information at the beginning of the first consultation in voluntary therapies. For approach A, MHPs indicated their own benefit as an important motivating factor (Table 4, Participant 9). Systematic information given to detainees before obtaining consent for future breaches of confidentiality was described as a way to avoid conflicts situations where MHPs are pressured by prison staff to reveal confidential information (Table 4, Participant 15). Patients are told that confidentiality will be disregarded not only when they pose an imminent danger to identifiable persons but also in relation to less-defined future dangers as well as past crimes. Routine information about limits to confidentiality was perceived to generate trust and reinforce the role of an MHP as looking out for the best interests of the patient (Table 4, Participant 9).

**Table 4:** Reasons in favour of routine information during the first consultation

<b>Approach A</b>
(9) I have had bad experiences with it that they relieved themselves from their burden when the trial was over. It was somehow possible for them to conceal other crimes they committed, but from which they suffer – and that results in psychological pressure. Then they come and tell us about it, but inform us that we should not discuss it with others. That is an unacceptable situation for the colleagues who must do so.
(15) For us it is easier, you don't have to be that careful yourself and it avoids possible conflicts with prison employees who don't necessarily understand confidentiality and don't see the point sometimes of it being so strict. So, it can avoid certain conflicts and it is possible to communicate more freely.
(9) The case-studies also serve to it. We say that we have heard, he [the patient] is constantly harassed or threatened, and then we receive information from the group home or work, whether it was true or was it just told. We discuss together to decide what the response should be. This is a good example: where we tell the prisoner, there are good reasons why discretion related to confidentiality should be partial. Because in these cases we can say that, he has told us that he is being threatened or was even a victim of a fight. We can then discuss with the management to move him to another department or group home or workplace. This way we can get to something concrete.

<p><b>Approach B</b></p> <p>(12) I had a very suspicious patient, paranoid, who had been incarcerated for many years and was particularly dangerous, to whom I expressed that this is a privileged relationship in which total confidentiality reigns, and he confessed four more murders, of which I could never really talk in an explicit manner. See, this is what's important. It was important for him to talk about it, it was important for his progress. [...] It would</p> <p><b>Approach B</b></p> <p>have made a difference if this would add to his dangerousness on his release. But he would never have told me this under different conditions. It is really an important guarantee to be able to talk about certain things.</p>
<p>(24) You have to reassure them and tell them that what is said during this session and future ones is under the seal of medical confidentiality, so we cannot give any information to the guards or anyone else, even to the judge and the attorney, without a written authorisation from him. So when I receive a request, I will talk to him about it.</p>
<p>(18) So, I chose this approach because with time, I realised that it was fundamental to be extremely precise and clear with the detainees. They are in an environment where they are subjected to different authorities in a very comprehensive way, they are quite passive in their choices and I, in my experience, the clearer you are on the rules, the easier it is to work. And I think these are very important rules. Confidentiality, ethics in prison, for me it's fundamental. And in my experience they are pleased with this way of working; they appreciate it a lot and often tell me that it is rare to have people being that clear and that this reassures them in fact.</p>

In approach B, patient benefit was mentioned as the predominant motivating factor. Effective therapy and patient trust were said to depend on high levels of confidentiality (Table 4, Participant 12). MHPs felt that patients need to be reassured that without their consent neither prison staff nor judicial authorities will be provided any health-related information (Table 4, Participant 24). Benefit for the MHPs also played a role in this approach, since routine information about and protection of confidentiality offer a transparent and safe framework that facilitates the work of mental healthcare and avoids conflicts of interest and manipulation (Table 4, Participant 18).

#### *Barriers to routine information — Approaches C and D*

MHPs defending approach C were convinced that no systematic information about confidentiality is needed because patients are supposed to know that confidentiality is different in prison. Participants believed that patients do not need further information because the provider has patient's best interest in mind and that patients have no choice but to accept the situation and whatever protections or limits are associated with it (Table 5, Participant 5).

**Table 5:** Reasons against routine information during the first consultation

<b>Approach C</b>
(5) No [We do not provide routine information about limits of confidentiality], because it is rare. In cases that come up, we find that they are special situations. You may be able to get an exempt from the Health Department on an individual case basis.
(5) I think it goes well for us. I say this not because I want to be right. But I see it [the strict respect of medical confidentiality] only as a hindrance and cannot imagine what would be gained if this has to be such a strict rule, also for patients. Protection of victims and the interests of patients are not mutually exclusive. At least in some little part of each offender, there should be an interest not to engage in criminal activity anymore. Therefore, there is no conflict for me. As for the basic service, if someone is suicidal, it is important that others know about it so that they can respond adequately. I cannot imagine a compromise that we take ourselves back or that must conclude a contract before we give have our treatment approved. There would be no solution for me to say that one must strike a balance between two extreme positions. It is good as it is with us.
(13) I have a paranoid patient who forbids me to say anything in his case discussion. And afterwards he tells me “why haven’t you said anything during my case discussion, because this plays against me”.
(13) On the other hand there are cases for confidentiality where it can be overrun by the speed of events, I think of preventive detention where patients are often seen in emergency, when they are in states of crisis and have just been admitted and there the care can range from one to several sessions. It is true that on the spot, it is important to establish a relationship, to fathom an alliance and make a crisis intervention. And there it is true that I don’t think of, I simply forget or there are other priorities. And there could be some grey zones where one would need to readjust a bit.
<b>Approach D</b>
(1) In Psychiatry it is anyway totally normal for all patients to sign an authorisation for everything. In Internal medicine and Surgery as well as with the Family doctor it is so that doctor’s report and medical records are shared without confidentiality agreements, because it is easier as the consent of the patient is assumed and not explicitly obtained whereas in Psychiatry, already for decades, nothing is presumed. Psychiatric data are always classified as sensitive and therefore it is very common for us that everything goes with the signature of the patient. And there is relatively little difficulty.
(11) If someone comes, I actually tell nothing. This is totally common that confidentiality is applicable here too. I maybe say that, of course, what is said here will not be reported either to the court or to the officials. And when something must be reported to the officials, it will only be information about the health status. Therefore, things that are relevant for trial or the criminal process will not be given. The health of the patient is most important.
(7) Yes. I do not do it that explicitly. [...] If someone comes voluntarily, then there are a few who ask whether everything that is said remains here in this room, and that I have confidentiality obligations. Then I confirm that it applies or when I feel that someone is mistrusting, I tell that whatever is discussed in this room stays here. But to those who came voluntarily, it is not standard protocol for me to explain about confidentiality and what it means in everyday life.
(21) Here in prison, frankly no, not always. Also, it isn’t true. Well, it is very delicate. Some questions clearly belong to the realm of medical confidentiality, be it anamnestic elements or questions related to the diagnosis, evidently there the principle is to say as little as possible. But for questions concerning the suicide risk or the possible harm to thirds, those are questions that are brought up constantly within the prison. So for me those questions don’t belong to the realm of confidentiality. Clearly, sometimes, I don’t even ask

**Approach D**

myself any question concerning this anymore, but somehow you ask them regularly after all, but they are already discussed so many times in simple terms, of course you would not reveal any elements of his previous life but I don't remind myself constantly of these things as they are always present, from the beginning. [...] sometimes you forget this more formal part that would be better [respected] outside the prison system.

Other participants who theoretically favour approach B admitted sometimes or regularly using approach C because of additional barriers that prevent confidentiality or disseminating information about confidentiality to patients (Table 5, Participant 13). For example, they mentioned patients with disorders such as paranoia who often cannot appreciate the benefits of routine information or even the trust-creating aspects of confidentiality itself (though this does not diminish the duty to maintain confidentiality within the healthcare relationship). Also, time constraints in the prison setting and prioritizing treatment in emergency situations were mentioned as factors impeding routine information about confidentiality.

MHPs reporting approach D said that the patient–physician relationship suffers when medico-legal explanations of confidentiality dominate the beginning of a consultation. They believe that patients in prison should be treated exactly like patients outside of prison where it would be perceived as strange to start a consultation with explanations about limits to confidentiality (Table 5, Participants 1). Many stated that patients know that information about mental health is kept strictly confidential and is transmitted only in their best interest (Table 5, Participants 11). Interviewees considered that it is sufficient to inform selectively those patients who seem worried about confidentiality (Table 5, Participant 7). One participant who employs approach D felt it is difficult to discuss confidentiality with imprisoned patients because it is inaccurate to emphasise confidentiality if in fact, due to high prevalence rates of self-harm and aggressive behaviours in prison, information is transmitted to guards all the time (Table 5, Participant 21).

**Discussion**

Ethical guidelines insist upon informing patients in advance about limits to confidentiality (Royal College of Psychiatrists, 2010; World Psychiatric Association, 1996). To our knowledge, however, there exist no data as to whether and how healthcare personnel should carry out this task. Our study adds important new knowledge in this field, particularly for healthcare providers working with vulnerable populations. Results from this study reflect typical ethical and practical dilemmas faced by and of interest to physicians working in

forensic medicine and other related settings. Study findings reveal contextual factors that may be partially overlooked in framing guidelines pertaining to confidentiality. For instance, while practitioners acting as expert evaluators systematically provide patients with information about the limits of confidentiality at the beginning of a first encounter, a number of our participants were concerned about doing so in a therapeutic setting with prisoners because this is unusual outside of prison and may create negative consequences for the patient–physician relationship. On the other hand, MHPs also acknowledged a need to be forthcoming about limitations for the sake of both their patients and their own professional integrity. This dilemma is resolved inconsistently in practice and, thus, needs to be addressed further. Additionally, many participants expressed confidence that they are acting in the best interests of their patients when disclosing information to third parties. However, as most do so without exploring the patient’s view, this may represent a form of unjustified paternalism.

Study results also indicate that some participants changed their practice towards routine information upon realizing that patients appreciate transparency and clarity when it comes to confidentiality. Transparency and clarity are especially important when practitioners are tasked with high patient loads or during emergency situations when discussions about confidentiality may be deprioritised. Thus, healthcare professionals need to be educated about simple solutions to surmount these barriers. Explanations about confidentiality and its exceptions can be offered to patients in the form of brochures and then briefly discussed during the consultation. Even in emergency situations, patients may be more likely to collaborate if they experience a climate of openness and sincerity that affirms the importance of confidentiality in medical practice.

Our study highlights that MHPs overestimate which types of disclosures patients may reasonably expect. The fact that physician’s and social worker’s offices are on the same floor does not necessary allow a reasonable person to conclude that health information is routinely shared between them. Also, some of the motivating reasons for disclosure reported by participants — such as patient benefit, patient know anyways that information is transferred — indicate a lack of adequate ethical and legal knowledge regarding confidentiality. It is critical that these types of assumptions and faulty ‘justifications’ are carefully addressed. One way this can be accomplished is through post-graduate training, although existing attitudes and behaviours of physicians that impede appropriate dissemination of information about confidentiality to patients must first be identified and understood. Furthermore, routine explanations about confidentiality discussions with patients may positively encourage

physicians to begin reflecting upon their own practice, including their personal thresholds. This is particularly important for multi-agency teams because physicians need to ‘be aware that different team members may adopt different thresholds for disclosure’ (Royal College of Psychiatrists, 2010). In community settings as well as in prisons, it is common practice to form mixed teams that consist not only of healthcare providers but also of professionals from social services and other disciplines. Healthcare providers must not assume that these teams are similar to healthcare teams that exist in hospitals and thus should understand that in such multi-agency settings confidential information ‘should not be shared without explicit consent’ (Royal College of Psychiatrists, 2010).

A sizable number of our participants struggled with requests from prison guards to routinely share confidential patient information with them. While in one centre MHPs systematically obtained broad advance patient consent, others shared information without consent, explaining that most patients are aware of this practice. Whether this is in fact the case, this behaviour also might be explained by an incorrect understanding of dual loyalty (Pont et al., 2012). The participants who adopted this behaviour did so in order to keep the peace with prison surveillance staff, but potentially at the expense of not fully respecting patients’ rights. It is important that MHPs and all healthcare providers understand and act upon not only their legal and ethical duties with regards to confidentiality but also their obligation to educate members of other professional groups with whom they may interact. They need to make the latter aware that in multi-professional meetings physicians ‘have a duty of confidentiality which must be respected for sharing to take place. It must also be recognised that notes of such meetings should not be circulated to other parties without the written consent of the patient’ (Royal College of Psychiatrists, 2010). Improving healthcare providers’ legal knowledge also improves their ability to refuse inappropriate requests for healthcare information from guards and other prison personnel.

Evidence exists that breaches of confidentiality often result in requests by individuals for physician organisations to take action against their members. Respecting patient autonomy includes discussing confidentiality and means that patients are informed in advance about how their information will be handled. Imperatives in guidelines such as ‘[y]ou should make sure that information [about confidentiality] is readily available to patients’ (General Medical Council, 2009) are empty admonitions if they are difficult or even impossible to put into practice. The General Medical Council (2009) reminds that ‘information can be provided in leaflets, posters, on websites and face to face and should be tailored to patients’ identified

needs as far as practicable'. But what is 'practicable' and can be reasonably expected still remains to be defined. As our study shows, similar to previous studies (Bruggen et al., 2012; Elger, 2009a), varying information styles and thresholds between centres and among individual physicians are significant barriers to providing written explanations about confidentiality. Medical associations and those who develop guidelines should be encouraged to design information templates that can easily be adapted to different healthcare settings so that universal standards regarding confidentiality practice could be adopted. More research is thus needed on how healthcare providers understand and apply confidentiality in different settings; and in other countries which will motivate medical and legal entities to reflect on and potentially correct current practices. There is need for research and policy development that would make rules regarding confidentiality and disclosure more transparent to patients. Education and guidelines should not only address legal requirements, but also ethical principles.

As with any interview-based study that is susceptible to social desirability bias, our results may overestimate the presence and/or prevalence of more acceptable or favourable behaviours. However, we believe that this bias is of a limited nature: first, we guaranteed confidentiality; and second, participants reported engaging in several different types of practice. Of course, as a qualitative exploratory study, the opinion of Swiss MHPs is not generalizable to all MHPs in other countries. As a qualitative study, the aim was neither to gain representativeness of the sample nor generalizability of the data, but rather to explore this little known area of research in order to find prevailing notions or practices. Nonetheless, our results do provide an insight into the practice of limits to confidentiality in Swiss forensic settings. Additionally, it offers important insight into the field of prison medicine and other related healthcare settings where multi-agency teams are employed in patient care, which may be useful for practitioners in similar contexts. Despite limitations, to our knowledge, this study is the first to capture the experiences of how MHPs actually practice confidentiality in forensic settings and inform prisoner-patients about its limits. Thus, the results are unique in this respect and form the basis for future studies.

In conclusion, it is important to remember that there are two possible reasons for non-compliance with legal and ethical duties: the first is that MHPs lack knowledge about the law and the other is their more deliberate choice not to comply, while knowing the law. It is clear that in the first case, compliance can be achieved through better information. In the second

case, the more difficult task is to convince MHPs, for example, through training in law and ethics, that the legal provisions are well founded and worth to be respected.

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**Paternalistic breaches of confidentiality in prison:  
Mental health professionals' attitudes and justifications**

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**Abstract**

This manuscript presents mental health practitioners' (MHPs) practice, attitudes, and justifications for breaching confidentiality when imprisoned patients disclose suicidal thoughts or abuse by others. 24 MHPs working in Swiss prisons shared their experiences regarding confidentiality practices. The data was analysed qualitatively and MHPs' attitudes and course of action were identified. Analysis revealed paternalistic breaches of confidentiality. When patients reported suicidal thoughts and abuse, MHPs believed that forgoing confidentiality is necessary to protect patients, providing several justifications for it. Patients were informed that such information will be transmitted without their consent to medical and non-medical prison personnel. With reference to suicidal attempts, MHPs resorted to methods that may reduce suicidal attempts such as transfer to hospital or internal changes in living arrangements, which would require provision of certain information to prison guards. In cases of abuse, some MHPs convinced patients to accept intervention or sometimes overrode competent patients' refusals to report. Also in the case of abuse, provision of limited information to other prison personnel was seen as an acceptable method to protect patients from further harm. Breaches of confidentiality, whether limited or full, remain unethical, when used for competent patients based solely on paternalistic justifications. Institutionalizing ethical and legal procedures to address suicidal and abuse situations would be helpful. Education and training to help both medical and prison personnel to respond to such situations in an appropriate manner that ensures confidentiality and protects patients from suicide and abuse are necessary.

## **Introduction**

In the prison context, healthcare providers are faced with the challenge of whether or not to disclose information when patients report suicidal thoughts or abuse. Suicide is one of the most frequent reasons for death in custody (Fazel et al., 2008; Fazel et al., 2011; Felthous, 2011), with rates in prison exceeding those in the general community (Fazel et al., 2011; Fruehwald et al., 2000). In addition, the risk of abuse, particularly for vulnerable detainees, either by other inmates or prison staff is high in prison settings (Morash et al., 2012; Struckman-Johnson and Struckman-Johnson, 2006). Abused detainees are often threatened by their aggressors and hesitate denouncing the abuse and the abuser because they fear retaliation.

Confidentiality is important in prison and has to be respected based on the same ethical principles as outside prison (Elger, 2011). Given the high prevalence of suicidal thoughts as well as violence and/or abuse from co-detainees and prison guards, it is important to educate health personal in advance about ethically justified strategies to prevent such occurrences. In situations where the mental health provider is aware of abuse or suicidal thoughts, he may breach confidentiality to prevent death or significant harm to the patient or third persons (Pinta, 2009; Sadoff, 1996). However, studies report that the stigmatization and fear of sensitive information being disseminated defers patients from seeking appropriate medical help (Derlega et al., 2010; Pinta, 2009). Hence, it is important that the overriding of confidentiality is justified.

Disclosure of medical information is acceptable if it occurs upon patient's consent. Confidentiality breaches may also take place if permitted by law. Most countries have legal provisions that require such breaches to prevent imminent substantial harm to identified persons (Appelbaum, 1985; Goldstein, 1993; Pinta, 2010). However, little is known about how often and why physicians violate confidentiality for the benefit of patients themselves. A reason for this could be that such breaches of confidentiality, particularly with regards to self-harm and abuse by others, might seem justifiable since the disclosure serves patient's best interests and thus may not be viewed as a form of violation. However, respect for patient autonomy requires that 'information should not be disclosed on the basis of a patient's 'best interest' where an adult with capacity refuses consent to a particular disclosure' (p. 13) (Royal College of Psychiatrists, 2010). This right to self-determination also implies that patients are allowed to harm themselves (General Medical Council, 2009). The only exception where confidentiality can be breached in a patient's best interest is when the patient

becomes a victim of abuse and is incapable of providing consent for disclosure (Royal College of Psychiatrists, 2010). Not respecting a competent patient's right to self-determination amounts to paternalism (Elger and Harding, 2004). To our knowledge, there is no literature describing medical practice in relation to disclosure of information when healthcare personnel know of suicidal thoughts or abuse. Thus, in this report, we summarize new data on mental health practitioners' (MHPs) practice, attitudes, and justifications to disclosing confidential information when a prisoner patient reveals suicidal thoughts and abuse in prison.

### **Methods**

Twenty-four MHPs with many years of practice in the prison context were interviewed between 2008 and 2009. They represented two major language regions of Switzerland: French-speaking (n=12 from three cantons) and German-speaking (n=12 from six cantons). Before initiating the interviews, consent was obtained. MHPs were asked to describe their standard of practice regarding confidentiality, how they deal with provision or maintenance of confidential information, and problems they have experienced. They were solicited to comment on vignettes illustrating a psychotic patient during crisis (i.e., expressing suicidal thoughts), detainees confessing to previous crimes unknown to the justice system, detainees reporting abuse in prison, and detainees revealing violent fantasies. The situations exemplify the confidentiality dilemmas faced in prisons. Interviews were carried out in French or German, lasted between 40 and 90 minutes, were tape-recorded, and transcribed verbatim with no information that could lead to participant identification. Interview data were coded qualitatively (Corbin and Strauss, 2008; Silverman, 1993)<sup>7</sup>. The study, including the interview guide, information and consent forms, was approved by the competent cantonal research ethics committee (research ethics committee of the University Hospital of Geneva)<sup>8</sup>.

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<sup>7</sup> For detailed methodology, refer to Elger B, Handtke V and Wangmo T. (2015a) Informing patients about limits to confidentiality: a qualitative study of mental health professionals working in prison settings. *International journal of law and psychiatry*. And Wangmo T, Handtke V and Elger BS. (2014) Disclosure of past crimes: An analysis of mental health professionals' attitudes towards breaching confidentiality. *Journal of bioethical inquiry* 11: 347-358..

<sup>8</sup> Approval number 08-171/Psy 08-023 Confidentialité en psychiatrie et psychologie forensique et pénitentiaire

## Results

### *MHPs' regular practice to protect suicidal patients*

MHPs often treat suicidal patients, and the plans of actions in these situations as described by study participants were relatively similar. For instance, when they know of a patient's suicidal thoughts or plans, they sought to transfer the patient to a safer place (Table 1, Interviews 20 and 10). Such a move might include MHPs requesting the prison guards to place the prisoner in a cell with other inmates, remove possible dangerous objects, and observe the prisoner more closely. In many cases, prison guards are informed that a detainee is suicidal to guarantee the safety of the patient. In situations where suicidal patients refuse disclosure of this information to prison guards, MHPs reported ordering a hospital transfer instead. Some interviewees believed that involuntary hospitalisations of suicidal patients enable them to help the patient without breaching confidentiality (Table 1, Interviews, 9 and 14). Several participants nevertheless revealed that hospitalisation can be difficult or may even be impossible because the inpatient unit is full or transportation is complicated. Another alternative to protect suicidal patients was putting patients' names on the prison guards' suicide list (Table 1, Interview 6). However, participants also highlighted that suicidal patients are not sufficiently and actively identified and successful suicides have been committed by patients who had not discussed their plans with anyone else (Table 1, Interview 9).

**Table 1:** Medical Confidentiality will be breached to safeguard patient safety

Providing safe circumstances	20	'I must find a way to somehow protect the patient, particularly to move him. And it does not work without other people knowing, the nurses are of course informed. But if they cannot pass along the information, then we are at the same point [the danger still remains]. That means that the prison administrator must be given this information.'
	10	'Well, for a patient with suicidal tendencies... we have protocols that are in place in all prisons: to put him in a cell with other inmates, so that he can be supported by someone else [...].'
Involuntary commitment - no breach occurs	9	'In most jurisdictions if she has a real suicidal risk and the patient has a mental disease, the conditions for a non-voluntary hospitalisation is fulfilled. If the suicidal risk is not so high at the moment, we continue the care on the ambulatory level.'
Transfer to the hospital without breaching confidentiality	14	'This situation belongs to the realm of the medical decision-making and those are case by case decisions... There is an allowance at discretion where there is no right or wrong but where you would want to take full responsibility for the way you act. Generally you have to admit the patient [to a hospital] if he is clearly suicidal. If the patient is not suicidal, but only has suicidal thoughts and there is no indication to take any measures, then I will not report it.'

Suicide List	6	So if I have someone in front of me whom I consider suicidal I will try to evaluate precisely the risk and if I see that he has overwhelming ideas of dying, plans of how to do it and so on, I would ask for him to be hospitalized...in the first place. Now, if that's not possible, I will try to negotiate with the patient, can I see him one or two days later, I will re-evaluate, see if he can commit himself for that period and I will tell him: I will put you on that list because I think you are dangerously, well, very actively suicidal...I explain to him what that implies, from what I know and that it is to protect him from himself.
	9	'I don't think this is a useful approach [list the guards have with the names of the suicidal patients] I was not in favour of this approach that the GPs and nurses liked. The suicides that I experienced, these ten cases were rarely on that list [of suicidal patients]. The physicians and the nurses were simply not very competent to predict the real suicidal risk.'

### *Justifications towards breaches of confidentiality with regard to suicide*

Most interviewees reasoned that not only medical personnel such as nurses need to be informed, but also prison guards, social workers, and sometimes even prison administrators. Participants pointed out that informing prison guards is crucial, as they are responsible for the suicidal patient's safety (Table 2, Interview 9). Patients were in general told that informing prison guards is an obligatory part of the MHPs' duty to protect them and several mentioned that, in their experience, a detainee has never refused this transfer of information (Table 2, Interview 6).

**Table 2:** Paternalistic justifications for informing non-medical personnel

Prison guards must be informed	9	'The information is shared with the security personnel for the simple reason that it is they who carry out the instructions we give them, particularly if the prisoner should be allowed to do this or that or if the prisoner should be supervised regularly during the rounds of the guards or not.'
Assumed consent due to prior experience	6	'I have never had a situation where someone said to me: "no, no, no, I don't want this". I have the hypothesis that if you explain things clearly and respectfully to the patients, it is always in their best interest, it is pretty rare, except maybe for very serious personality disorders, that they oppose it.'
Guards know: no breach of confidentiality	2	'It's an open secret, because most of the time it's the guards that brought this or that person to our attention because of their behaviour or incoherent speech, so I just confirm to the guards that their observation was correct.'
	20	'But there again it is like this, with such patients it has never happened to me that such suicidal thoughts were known to me and not to the guards.'

Confidentiality breaches to reassure prison staff	17	‘If the prison personnel are worried, we tell them that although a patient has suicidal thoughts, he is not actually suicidal. We frequently get the request from prison personnel to talk to a patient because Ms. So and So has said to him that she is sad and that she often thinks about death, could you talk to her. We [then see the patient to] form a professional opinion and check whether she is depressed or thinks about death. But if she is not acutely suicidal and we inform the prison personnel that she can stay in prison and that she is not acutely suicidal in order to give them some relief.’
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Several participants justified their actions by stating that in many situations no violation exists because prison guards are often the first ones who know of an inmate’s suicidal tendencies based on observations made during their shifts (Table 2, Interviews 2 and 20). Additionally, participants believed that prison guards should be informed since they are the ones who implement the safety instructions provided by MHPs. MHPs preferred to provide information also to reassure prison guards who are worried about prisoners’ safety (Table 2, Interview 17).

*Justifications for confidentiality disclosure in the case of abuse*

Many interviewees stated that they experienced cases in which imprisoned patients reported violence by other inmates. When asked about situations where a patient does not want to disclose the abuse or violence to authorities, the majority of participants reported that they would breach confidentiality and that this is necessary to protect the patient from further harm (Table 3, Interview 24). Some interviewees would seek to convince their patients that an intervention is needed and would then explain how they, in their professional capacity, would proceed to protect the patient. Other arguments given to justify violations of confidentiality include protection of possible other future victims (Table 3, Interview 23), and the obligation to maintain institutional security. Additionally, a victim’s refusal to report abuse is believed by some participants not to represent his real wishes regarding the matter (Table 3, Interview 10). To them, the fact that detainees mentioned the violence during consultation signifies their desire for an intervention to prevent further abuse (Table 3, Interview 6). Participants highlighted that patients’ ability to make autonomous decisions in this setting cannot be ascertained because, first, they lack information about the risks they may be putting themselves in and, second, their decision is directed by fear and is therefore not voluntary (Table 3, Interview 9).

**Table 3:** *Reasons for circumventing confidentiality in case of abuse*

Duty to protect patient is a higher good	24	‘When it is too dangerous, we must take action. There is even a legal process, an investigation might be a better word here, where a prisoner has murdered another and it is asked whether this should have been predicted before. And the question is, whether someone was told before about it and I mean in a case where someone is really threatened, there is nothing else left but to breach confidentiality.’
The duty to warn other (future) victims	23	‘They are all afraid. Most of the patients say that they are afraid of retribution and they do not want the truth to come to light. I explain to them that perhaps there are other cases too, and such individuals could be protected, if we can investigate their case. I have never had problems with that.’
The real wish is a request for help	10	‘I will first and foremost try to protect him. [...] So I will do anything to encourage him to talk about it. But there it is clear, it will be difficult to keep silent. I will offer him a medical certificate and we will try to make him move to another cell but I would only tell if I see him take more hits etc., then, there will be an intervention. [...] And then I would act in his best interest. There too you need a specific environment but I would say that usually when people talk about it, they want to be protected.’
	6	‘And finally I would tell him “you came to talk to me about it, so, on some level, you wanted me to do something about it”. This is what I would tell the inmate and of course I would try to get his consent, even using a “little force” but I would try to negotiate, for him to understand why I do it.’
Refusals invalid	9	‘A case that really troubled us was a young man ... [who] had fallen prey to torture or mistreatment by other inmates. When confronted with this fact, he did not deny it but refused passing information to the prison administration. So there we thought that his refusal to waive medical confidentiality was motivated by his fear and worries. We bypassed him and informed the prison administration of the situation and were able to relocate the prisoner away from these mistreatments.’
Confidentiality assured but MHP stays alert	16	‘If he [the patient] insists on not passing on the information, I would not do it. However, I would still keep an eye on it and if it would get worse then I would contact the security service, even if such violent attacks among detainees in prison are relatively frequent.’
Confidentiality is kept	21	‘If I believe that the patient can deal with the situation by himself, and if I have the feeling that the consequence would be worse if I pass the information on, then I refrain from doing so.’
Negative experiences of breaching confidentiality	18	‘It has probably already happened to me to talk to people and then to say that I would speak to the detainee afterwards. [...] I have heard that, can you do something for this detainee. And it happened that I made a mistake and talked to the wrong person and that had consequences. Even when I had talked to the detainee. It had negative effects for him. And you really regret it and you also lose your credibility.’

Some participants preferred not to intervene when a patient refuses permission. They would remain alert in order to intervene when necessary (Table 3, Interview 16). Additionally, several MHPs stated they respect their patients’ wishes and would withhold information as long as they believed that the patient can handle the situation on his own or that revealing

information would cause more harm than good (Table 3, Interview 21). During therapeutic sessions, they provided support to the patient by discussing coping strategies, but if the abuse continues or worsens, the MHPs would intervene. It should be noted, however, that intervention in the interest of the patient does not always result in positive outcomes for the patient (Table 3, Interviews 18).

*Attitudes and practice — disclosure of limited information*

Several of those MHPs who were convinced that confidentiality should be breached to protect patients justified this attitude by indicating that the breach is limited, as information is only given selectively to certain individuals (Table 4, Interviews 12). This selective information is the bare minimum necessary to safeguard patient safety. Some furthered this argument by mentioning how confidentiality can be maintained while ensuring patient protection. The method that they employed included passing on information either anonymously or indirectly without explicitly stating the name of the patient or of the aggressor (Table 4, Interview 3). Indeed, several respondents qualified that a distinction must be made between a limited breach of confidentiality and a full breach of confidentiality. Respondents stated that limited breach is a reasonable option because it respects almost fully the wishes of victims while still protecting them against further abuse. One MHP indicated that it is important to use breaches of confidentiality only in rare and severe cases in order to protect trust in the healthcare encounter and remain credible (Table 4, Interview 6). Those who favoured full breach of confidentiality explained that disclosure of detailed information is needed to stop the aggressor and to prevent future abuse of other possible victims (Table 4, Interviews 23 and 9).

**Table 4:** Limited breach of confidentiality in the case of abuse

Information only provided selectively	12	‘But there too you discuss it [with the patient] and you say: no, I won’t talk to everybody, I will try to approach the people in total confidentiality to see if we can something to protect you. So this is a reduced and delimited exception.’
Protecting the patient without violating confidentiality	3	‘So, if it is a prisoner that is of age, it seems to me that a priori there is no exception to the medical confidentiality. I say “a priori” because I haven’t had any experience contradicting that yet. [...]Or maybe by indirect means but in this case one wouldn’t say the name of the person so that the anonymity is kept which means that confidentiality is kept which is important after all. But I think this is a very difficult case, because you owe yourself to protect that person.’
Breaches should remain rare and limited to severe cases in	6	‘We will say, okay, there is violence inflicted on someone, which is credible, you need to change him instantly to another cell and they didn’t discuss it. But there I think it also had to do with the fact that I already work here for a certain amount of time. I intervene very rarely on behalf of the

order to remain credible		detainees, I only intervene as a last choice, I rather try to have them solve the problem themselves, instead of me in their place. So in this case it was clear that my advice was readily followed, because for me, intervening was a sign that something important was going on. Well, this is my interpretation of what was going on, it maybe had nothing to do with it, but this is what I think.’
Avoidance of possible future victims	23	‘I wouldn’t just close my eyes and allow for more victims. I had a client once, who has said that he was threatened by another prisoner. We went to investigate to see if there were other prisoners who were also threatened [...] he had groped him. We tried to understand it and exchanged information with the prison director, who is responsible for the security.’
Patient does not want to confront the perpetrator	9	‘I had a situation like that, where a detainee was complaining that he had been raped by another inmate, of whom he was absolutely terrified. So he came to talk about it and in the end I tried to evaluate the situation together with him but in the end he said that he did not want to press charges, that he did not want to do anything with it. But finally the only thing he asked was to change cells and I told myself, well, there I had an ethical conflict because I knew that the other detainee was someone who was known to be dangerous and I told myself, my God, it could happen to any of the other detainees.’

### **Discussion**

Several of the justifications that MHPs provided are paternalistic as they interfere with patient autonomy although they may be motivated by the patient’s good (Elger B, 2010). Respect for persons implies that when mentally capacitated prisoners refuse disclosure of suicidal plans or abuse, the MHP must respect this wish. Most consequentialist justifications can be criticized because generalized benefit is unproven or unlikely. For example, it is possible that patients who express suicidal thoughts may not be at risk of committing suicide and those with suicidal ideation may not disclose such thoughts as noted by study participants. Thus, informing prison guards about suicidal thoughts and the compilation of a ‘suicide list’ could even lead to overlooking those prisoners at high risk, who never voiced such thoughts and thus, were unidentified. Such actions may eventually not provide any benefit, while breaching confidentiality. Similarly, reporting of abuse, whether mandatory (as it is in some jurisdictions for child or elder abuse, while in others, deliberately not, see (Elger, 2009)) or in the best interests of patients, may be ineffective or even harmful for victims without an appropriate victim-centred system in place to adequately protect the victim and prosecute the perpetrator.

Another type of paternalistic argument that we found from the results occurred when MHPs deemed that patients’ autonomy was impaired. For example, participants reported that some detainees underestimate risks of abuse and that abuse and post-traumatic consequences

compromise detainees' abilities to make informed decisions. The prison environment where the victim is not able to move freely and lives in close proximity to the aggressor may be an additional factor contributing to MHPs' assessment that overriding patient's wishes to protect them is justified. These, however, represent some form of "soft" paternalism where patients may be legally competent but are considered to be incapable of making the best possible and fully autonomous decision (Elger B, 2010). In these cases, MHPs have an obligation to thoroughly discuss the harms that patients face when they believe that patients are making a poor decision. That said, in the absence of a danger to others, breaching confidentiality amounts to unjustified paternalism if the patient's informed decision is to accept higher risks than MHPs find tolerable.

In general, disclosure in the best interest of a patient may be justified only if the patient lacks sufficient autonomy (i.e., is judged incapable of giving or withholding consent). However, even in cases where disclosure could be justified, it has to be necessary and proportional (Royal College of Psychiatrists, 2010). The conviction that "minimal breaches" are acceptable because information is limited to what is necessary to prevent harm is another example of unjustified paternalism if patients perceive this information as significant for their privacy, and it is protected by medical confidentiality. From a consequentialist point of view, providing limited information to guards and warning them about those with suicidal thoughts and/or who suffered abuse may look correct, but it still risks breaching a fundamental trust in the doctor-patient relationship. The belief that prison guards "know already" is an invalid reason to override patient consent except when information openly available is exchanged, for example, that a patient has an amputated leg. In the case of abused patients, MHPs equated patients' disclosure of abuse as their "real wishes" of asking for help and therefore, justifying disclosure. Such presumption of patients' wishes and disclosure of information on this presumption is unacceptable in any medical setting and must not be practiced.

It is necessary to ensure that detainees can trust healthcare professionals to prioritize confidentiality and act independently of prison authorities on their behalf. In the prison MHPs face context specific challenges (Elger, 2008; Elger et al., 2002). For instance, they need to distinguish clearly their roles as therapist and expert, especially in the case of mandatory therapies where MHPs have to report to authorities regularly and where confidentiality is at least partially compromised from the outset (Elger et al., 2015a) and (Wangmo et al., 2014). Furthermore, MHPs may be under pressure from the prison administration to ensure that no death occurs in prison. This pressure and surveillance measures offered by the prison

administration (i.e., having guards look after prisoners, placing prisoners in cells with others, measures not available outside) might induce MHPs to disclose information in order to make use of these often coercive measures to protect prisoners especially if ethically appropriate alternatives such as psychiatric hospitalisation are unavailable.

To conclude, there is a need to improve the practices and attitudes of MHPs towards confidentiality in the prison context. This could be achieved by institutionalizing ethical and legal procedures that address suicide and abuse in ways that can be upheld by healthcare and prison personnel (e.g., prison administrators, prison guards, social workers) to respect confidentiality. Education and training on evidence-based measures to protect detainees from suicide and abuse as well as sound ways to respond to typical difficult cases are needed. This would not only help to protect detainees as well as enforce confidentiality, but also create trust between both professional groups and respect for their distinct obligations.

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**Disclosure of past crimes: An analysis of mental health professionals' attitudes towards breaching confidentiality**

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**Abstract**

Ensuring confidentiality is the cornerstone of trust within the doctor-patient relationship. However, health care providers have an obligation to serve not only their patient's interests but also those of potential victims and the society, resulting in circumstances where confidentiality must be breached. This article describes the attitudes of mental health professionals (MHPs) when patients disclose past crimes unknown to the justice system. Twenty-four MHPs working in Swiss prisons were interviewed. They shared their experiences concerning confidentiality practices and attitudes toward breaching confidentiality in prison. Qualitative analysis revealed that MHPs study different factors before deciding whether or not a past crime should be disclosed, including: (1) the type of therapy the prisoner-patient was seeking (i.e., whether it was court-ordered or voluntary), (2) the type of crime that is revealed (e.g. a serious crime, a crime of similar nature to the original crime, or a minor crime), and (3) the danger posed by the prisoner-patient. Based on this study's findings, risk assessment of dangerousness was one of the most important factors determining disclosures of past crimes, taking into consideration both the type of therapy and the crime involved. Attitudes of MHPs varied with regard to confidentiality rules and when to breach confidentiality, and there was thus a lack of consensus as to when and whether past crimes should be reported. Hence, legal and ethical requirements concerning confidentiality breaches must be made clear and known to physicians in order to guide them with difficult cases.

## **Introduction**

To ensure trust within the doctor-patient relationship, it is critical that information shared by the patient is guarded by confidentiality rules and that patient privacy is respected. In the prison context, it is recognized that medical secrecy toward detained persons should be observed according to the same legal provisions applicable to persons who are not detained (Swiss Criminal Code, 2014; Council of Europe, 1998; United Nations, 1982). This is the basis of the principle of equivalence of care in prison medicine to ensure that prisoners are not disadvantaged due to their legal status (Birmingham et al., 2006; Elger, 2008; Niveau, 2007). However, the prison setting could add an additional complication to the doctor-patient relationship, as third parties such as prison officers and judicial authorities may be involved to some extent (Konrad, 2010). Hence, there could be circumstances where health professionals must maintain confidentiality towards their patients but at the same time may be forced to disclose information. Such situations place health professionals in the uncomfortable position of acting as “double agents” owing loyalties to both their patients and their employers (IACFP, 2010; Pont et al., 2012). Supporting the absoluteness of confidentiality, Kottow (1986) claims that any exception to confidentiality erodes the value of the concept, resulting in a lack of trust within the doctor-patient relationship. He highlights that any confidentiality breach violates the right to secrecy of the confider. This right to medical secrecy is important to ensure that patients are able to freely disclose any information to their physician without the fear that doing so would result in negative consequences. Thus, avoiding potential harm to third persons cannot, in Kottow’s opinion, be weighed against harm caused to the patient when confidentiality is breached. In addition, he argues, such unauthorized disclosures cause harm to the concept itself.

Safeguarding confidentiality is an important duty of the physician, but it is not absolute. According to medical guidelines (General Medical Council, 2009; World Psychiatric Association, 1996), health care providers both outside and inside prisons have an obligation to serve not only the interests of their patients, but also the interests of potential victims. It is thus widely accepted that confidentiality may or should be breached when harm to patients themselves or third parties is evident (Bonner and Vandecreek, 2006; Konrad, 2010; Pinta, 2009). Additionally, in many jurisdictions laws define situations where denouncing is obligatory, typically in the case of child abuse, elder abuse, communicable diseases, or gunshot wounds (General Medical Council, 2009; Rodriguez et al., 2006). However, in situations where disclosures are not obligatory and where interests of the patient collides with that of others, the health care provider must decide whether it is legally or ethically justifiable

to breach confidentiality. Such judgments to breach or not to breach medical secrecy depend on various factors and attitudes of the health care provider (Bruggen et al., 2012; Elger, 2009a). It is generally known that any breaches of confidentiality must occur with the consent of the patient, unless, as stated above, is mandated by law or in the interest of the public (General Medical Council, 2009).

Although a few guidelines delineate when and how confidentiality breaches should occur, in many cases it may not be clear for the health care provider what his or her course of action should be, since two or more ethical principles (e.g., non-maleficence and beneficence) might be in conflict with one another. In these circumstances, it is up to the health care provider to decide which principle should be given priority based on the particularities of each clinical case. Therefore, in many situations, it remains difficult to know in advance whether a decision is legally correct as well as ethically justifiable or not. If the particular case is challenged in the courts, the final decision will be made by judges or juries according to the jurisdiction (Appelbaum, 2002; Appelbaum and Meisel, 1986) and health care providers must have sound arguments to justify their actions.

The question of how health care professionals should react to circumstances where they must breach the confidential doctor-patient relationship has been troubling for generations of mental health providers (MHPs). The most prominent example of such a challenge is the *Tarasoff* case in the United States<sup>9</sup>, which called for a duty to protect identifiable potential victims by notifying the police and warning the party under foreseeable threat (Anfang and Appelbaum, 1996; Appelbaum, 1985; California. Supreme Court, 1976; Melamed et al., 2011). However, the *Tarasoff* duty may not be so straightforward, as a case from Israel illustrates where an MHP informed the police that his patient threatened to kill his father (Margolin and Mester, 2007). The court's decision acquitted the patient and stated that the physician reacted too quickly without ensuring whether the patient presented a firm intention to act upon his threat and without adequately evaluating if the risk to third party was concrete.

Cases exemplified by *Tarasoff* and its successors point to the heart of the problem faced by MHPs: What should physicians do if their patient discloses a desire to harm someone else, violate institutional rules, or take part in other "illegal" activities? Stated earlier, an obligation to warn exists on the part of MHPs (Felthous, 2006; Melamed et al., 2011; Pinta, 2009), but detailed guidelines regarding recommended actions in a range of specific situations remain

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<sup>9</sup> *Tarasoff v. Regents of the University of California* (1976) 17Cal. 3d 425, 551 P.2d334, 131 Cal. Rptr.14.

unavailable. It may be impossible to develop such a list of situations that could arise during the therapeutic relationship with a prisoner-patient, thus making recommendations, whether standard or customizable, also difficult. Despite a lack of guidelines, MHPs are nevertheless expected to make judgment calls and take appropriate action when faced with unknown situations. The deficiency of clear ethical and legal guidelines and consensus as to how MHPs should act in cases of third-party danger or how to appropriately balance their duties toward their patients remains problematic. In this study, we address the example of how MHPs should act if prisoners seeking care mention past crimes for which they were never held responsible.

From available literature on physicians' attitudes toward confidentiality, we know that MHPs are often uncertain as to how strictly confidentiality should be respected, under what circumstances they could, should, or would breach confidentiality, and how such breaches are justified (Schutte, 1995). This lack of understanding of confidentiality obligations has been found amongst medical and law students (Elger and Harding, 2005) and can continue well into professionals' practice. Varying factors have been reported to affect physicians' attitudes toward confidentiality breaches, including ethics education, years of experience, and gender (Elger, 2009a). Furthermore, upon studying professionals' attitudes toward confidentiality using case vignettes, Brueggen and colleagues (2012) found that their attitudes differed based on the cases. They also found that medical professionals had greater threshold of breaching confidentiality than legal professionals in the forensic setting, with legal professionals agreeing to disclosure of information more frequently. This suggests that, if we want to better understand the issue of disclosure of confidential information within the prison setting, this should be done from the viewpoint(s) of MHPs working within this particular context. This is particularly important given the various constraints and emergencies that occur in the prison environment and render it even more difficult for MHPs to come to legally and ethically correct and unbiased decisions (Pinta, 2009). Moreover, higher rates of mental health issues have been found among imprisoned persons (Eytan et al., 2011; Fazel and Baillargeon, 2011; Wilper et al., 2009), thus making confidentiality within this population that much more important and complex.

To our knowledge, studies examining thresholds for confidentiality disclosures are lacking in the prison setting. There also are no existing qualitative studies exploring MHPs attitudes toward disclosures of medical secrecy when a prisoner-patient informs them about past crimes or information that could harm a third party. To fill this gap in the literature, the overall goal of our exploratory qualitative study was to examine how MHPs in Swiss

correctional settings make decisions concerning confidentiality breaches, perceive reasoning and difficulties associated with ensuring confidentiality or disclosing information, and understand the legal and ethical principles of confidentiality in general and in prison.

This article highlights the attitudes of these MHPs when patients disclose information on past crimes. Examinations of how MHPs inform prisoner-patients about limits to confidentiality (Elger et al., 2015a) and paternalistic breaches of confidentiality (Elger et al., 2015b) —both important topics related to our overall project—are discussed elsewhere. Revelations of past crimes unknown to the justice system and for which the prisoner-patient has not been incriminated raises several questions: Why is this information being divulged now? What is its significance? Does this new information change the dangerousness or the situation of the prisoner-patient? Is there a possibility of harm to a third person? What could or should be done in relation to harms committed against third parties that exist not in the present or future but in the past? The attitudes of MHPs toward disclosing confidential information, as will be shown below, very much depend on how they process and respond to these questions.

### **Methods**

For this study, 24 semi-structured face-to-face interviews took place between 2008–2009 with MHPs who work or have worked in correctional settings as forensic psychiatrists or psychologists. A purposive and convenience-based sampling method was employed to ensure the inclusion of experienced MHPs from a range of geographic regions, prisons, and forensic settings in order to achieve maximum variation of opinions and practices. Approval from the responsible ethic committee was obtained. Before contacting prospective participants, we first contacted the senior prison or forensic physician responsible for the canton to gain his or her consent and permission to approach MHPs working in prisons. Thereafter, with the aid of the Swiss Society of Prison Physicians, either all MHPs working in prisons or a selected sample of the most experienced MHPs were approached by phone or e-mail for an in-person interview. Oral consent was obtained before initiating and recording the interviews, which were conducted confidentially. The head physician was not informed as to whether members of his or her team did or did not participate.

Of the 24 participants selected, 12 hailed from three cantons in the French linguistic region and 12 from six cantons in the German linguistic region of Switzerland. Recruitment based on the linguistic region is significant as MHPs belonging to the cantons of Geneva and Lausanne (i.e., French linguistic region) are independent of both the justice system and the prison administration since they are employed as part of health care services attached to

universities, whereas MHPs from most German-speaking cantons are directly employed by the justice system. Thus, regional differences were an important factor to consider during data analysis. Our participants, most of whom were men (n=18), had anywhere from two to more than 10 years of experience working in prisons, and each reported performing a range of different tasks associated with the provision of mental health care. For instance, all currently work or have worked in mental health settings outside of prison and have been involved in providing regular as well as mandatory therapies inside prison. Almost all also reported providing expert opinions for legal cases as part of their job responsibilities.

An interview guide was developed which consisted of a number of open-ended questions about the practice of confidentiality and problems that MHPs have experienced as well as hypothetical cases describing moral dilemmas concerning confidentiality. The hypothetical case relevant for this paper refers to a prisoner-patient who admits to having committed a crime in the past for which he has not been charged or punished. After each participant responded to this initial scenario, the vignette was then further clarified to suggest that an innocent person instead was wrongly incarcerated and convicted for this crime. Participants were asked what they thought was the appropriate action to take after the original confession and upon learning the additional information. Follow-up questions were posed as necessary to clarify responses. Interviews took place in either French or German, based on the preferences of the interviewee, and lasted between 40 and 90 minutes. All identifying information such as participant name, workplace, and reference to particular cantons were coded to ensure anonymity. All 24 interviews were recorded and transcribed.

Transcribed data were read several times and then analyzed using qualitative analysis where main themes were identified from participants' words, phrases, and examples (Bryman and Burgess, 1994; Corbin and Strauss, 2008; Strauss and Corbin, 1998). In addition, patterns among the strategies proposed by the interviewees to solve the case as well as arguments used to defend these strategies were identified (Silverman, 1993). Data analysis was discussed among the authors, and differences in coding and interpretation were discussed to reach agreement. All quotes were translated from German or French into English and double-checked by a third person fluent in these languages. Participants' voices are highlighted in the presentation of the study results in order to ground the findings as close to the data as possible. In order to ensure anonymity, participants are represented using only a letter identifier and the linguistic region (German or French).

## **Findings**

The reactions of MHPs who participated in this study to newly acquired information of past crimes committed by prisoner-patients and attitudes towards whether, when, and how to disclose past crimes are presented below. MHPs considered different factors before deciding whether or not the past crime should be disclosed. These included (a) type of therapy (court-ordered or voluntary), (b) type of crime (serious or not), and (c) evaluation of the danger posed by the patient.

### *Disclosure Based on Type of Therapy*

The first reaction of many participants was to distinguish between the type of therapy the patient was receiving, that is, whether it was a voluntary therapy or a court-ordered therapy. This distinction was important because, for court-ordered therapy, the patient is informed about written reports sent once or twice per year to the responsible authorities delineating the patient's progress, where all relevant information discussed during the therapy is included—i.e., the patient is informed at the beginning of the therapy about the limits to confidentiality (Elger et al., 2015a). Thus, for court-ordered therapies, many participants referred to the direct legal obligation of disclosing past crimes. However, there was ambiguity whether prior crimes should be disclosed in all cases. When the patient was seeking voluntary therapy, participants indicated that information about a past crime would only be disclosed if there was the chance of it happening again. It is clear from participants' responses that the harm-benefit analysis for such a disclosure varies depending on the type of therapy. This decision-making process is revealed succinctly by one MHP (A) from the German linguistic region:

If it is a patient who is not in court-ordered therapy, I would by no means pass on the information, unless the circumstances of that serious offense in the past would suggest that the same could happen again. [...] With patients who are in court-ordered therapy, I would report it [only] if that offense in the past was related to the current offense. If it is an old offense, any sin of his youth, which has nothing to do with the current offense and will not affect the future, I would not report it. I would evaluate each case individually.

This differentiation of therapy type was later compounded with the type of crimes disclosed. Participants' opinions varied concerning the types of crimes that should be disclosed and suggested that the way in which it should be mentioned in the reports was dictated by the type of therapy the patient was under. Most agreed that past crimes should be reported in detail if the crime changed the evaluation of future dangerousness. (The evaluation of future

dangerousness was a recurring theme that will be discussed in more detail below.) As participant B from the German linguistic region explained:

If it is a serious crime that is related to the past, and if it is a voluntary therapy, it is something that I will keep an eye on during the therapy. Now, one has to see the nature of the past crime. For example, if he tells me that he raped 20 women, the probability he will rape more is so high that the situation is different. Moreover, I would ask myself: “Is there an immediate risk for the future?” [...] If there is a strong risk, one should think about disclosing this information by requesting to be released from confidentiality rules [Swiss law provides for cantonal bodies where physicians may make a confidential request to obtain release]. If it is someone in a court-ordered therapy, then the question is a bit more difficult: Is this something that goes into the report or not, do you remain vague by saying this person has admitted to having committed other crimes in the past, will you concretely name the things? ... [T]here is no clear guideline for this.

#### *Disclosure Based on Type of Crime*

*Serious Crimes.* Even for serious past crimes, the question of when to disclose such information was not perceived to be easy and participants’ opinions varied. On the one hand, there were some who did not know what should be done, while, on the other hand, some were quite certain that serious crimes should be reported with or without patient consent, since there is an ethical and a legal obligation to do so. For example, one MHP, C from the French linguistic region, indicated he would not disclose the past crime if it does not affect dangerousness. His opinion is shared by many others concerning crimes related to using or dealing with illicit drugs:

I think of someone who is accused of breaking the law on drugs and who tells me, “You know, basically, I already did something like that two years ago.” Honestly, I do not care at all. Of course, this is a serious offense, but it has absolutely nothing to do with the medical care, nor with an immediate dangerousness. So, in this case, I will clearly not go ahead, I will talk about it within the team and all that, but I would not worry that much.

Participants’ uncertainty about disclosing the information was also due to the absence of reporting laws for certain types of crimes. For example, D, a participant from German linguistic region remarked that there are reporting requirements for certain cases, but not for

murder: “In the case of epidemics ... different diseases must be reported. But for crimes, there is no rule. I had thought that homicide had to be reported, but it is not the case.”

Another MHP, E, also from the same region stated:

I would get advice from my colleagues, if you are legally obligated to report someone who says that he has committed a murder. I would discuss this and also talk with the cantonal physician [i.e., the cantonal body where according to Swiss law physicians may make a confidential request to obtain release], it is not that they have to know which patient it is about.

Where participants were certain that serious crimes ought to be reported, they would tell patients that they are obligated to do so even if the patient refuses to do so himself or does not consent to it. They also would seek authorization to be relieved from confidentiality, as explained by participant F from the French linguistic region: “If he refuses to confess then I guess I would stop the therapy but I would not necessarily report him. [...] Or, if I think it is serious, I write to the cantonal physician and I ask him for the authorization.”

Similarly, other participants stated they would justify disclosure without patient consent for serious crimes if it was likely that similar crimes would be committed again or there is the possibility of harming third persons:

After analyzing the situation and concluding that this man was not dangerous, we decided that there was no reason to ask for the release from professional secrecy. [...] We would have done so if we had had the impression that this man still had a combined sadistic pedophilic pathology that posed a significant risk of recidivism (Participant G from German linguistic region).

If it was likely that serious crimes would not result in the immediate endangerment of third parties, then there was agreement that MHPs would not breach confidentiality.

Past crimes, that are not relevant for what I am concerned with in the therapy, I do not report. ... It is something completely different, if it is a serious crime that is to be expected, that he announces. There, I handle things differently. But if it is a past serious crime, that was never solved and I come in as a clinician and he tells me this and it does not result in any immediate endangerment of third parties that would justify breaching confidentiality, then I say nothing (Participant H from German linguistic region).

Several respondents mentioned child abuse as a particular case because, while federal law stipulates a right but not a duty on physicians to report child abuse, in some regions, cantonal law imposes a duty to report this crime. Thus in these cantons, when the unknown crime relates to child abuse, there is an obligation to report. This is succinctly phrased by one MHP, Participant I from French linguistic region: “The law of the canton actually obligates us to report all [cases of] child abuse.”

A few participants also stated spontaneously that they would disclose information without a patient’s consent if the crime has resulted in harm to or the imprisonment of an innocent person. One MHP, K from German linguistic region underscored, “If I don’t have to suppose that someone else [is] sitting innocently behind bars because of it [the crime revealed by the patient], then I don’t report it.” Another participant, L from the same region, similarly voiced his opinion as such: “But for me personally, I wouldn’t hesitate too much. It would be unbearable to keep something like that.”

*Other Crimes.* Crimes of a similar nature—those that are similar to the original crime—and minor crimes are grouped as “other crimes.” Participating MHPs disagreed on reporting less severe crimes or crimes of a similar nature for which a detainee was already in prison. In the case of crimes of a similar nature, many stated that they would only mention that a detainee showed progress because he talked about his weaknesses that could lead to understanding his prior actions. One MHP, M from German linguistic region, used the example of child abuse to explain:

I inform the client in advance. Suppose, I am treating a patient for child sexual abuse, and he eventually tells me that he killed someone, I would strongly advise him to report himself. If he does not want to do that, I would ask my colleagues as to how I should deal with the case. But if he told me that he has abused a child three years ago, we would globally make a note of it as dark figure of crime [that the client discussed his past crime].

One therapist—highly valuing confidentiality to ensure good therapeutic benefit for the patient—revealed that he would be against any disclosure. He stated he would even keep additional homicides to himself in a patient already convicted for homicide, because he judged the confidentiality in this case to take precedence over solving the crimes for the benefit of therapeutic progress:

I had a mistrustful patient, paranoiac, in jail since several years, particularly dangerous, that I worked with therapeutically, whom I clearly told that he

was in a privileged relationship of total confidentiality, who confessed four more murders to me, that I could never talk about in a substantial way with details. It was important for him to talk about it, it was important for his [therapeutic] process. And it does not change anything about whether he stays in prison or not. That depended upon other considerations, if he represented an additional danger if he was released. Else [without this strict confidentiality on my side] he would have never talked to me about it (Participant P from French linguistic region).

For minor crimes, some participants said they would try to motivate the patient to report him- or herself, if they have the impression that this would help the patient cope with it or others. Minor crimes would bother them less and in uncertain cases, they would ask their medical superiors for advice.

It is delicate because it depends on what it is about. If there were thefts, offenses that did not touch on another person's integrity, that would bother me less than if [the patient] hit or killed somebody. [...] If it refers to physical suffering, I would ask myself the question, I would ask [my superiors] if I need to do something (Participant N from French linguistic region).

MHPs were unsure as to when they should report the patient (when a patient refuses to consent to disclosure), but if they found that their patient was trivializing their past crimes, they were more likely to disclose the past crime.

I am not sure that I would report him. If he is absolutely not dangerous at the moment, if it is just about his past and if I realize that this person has learned something, that he has rebuilt his life and that, despite his crime, he has moved on, I do not see why his whole life should be destroyed. On the contrary, if it is a person that finds it completely normal and trivializes it, maybe there I would have more of a tendency to wanting to report it. It depends on the person and what he made from it, from his crime (Participant O from French linguistic region).

*Risk Evaluation*

For participants who said that they would report past crimes, the key point was whether those crimes change the future dangerousness of the patient. For instance, when revealed crimes have no effect on the evaluation of current levels of dangerousness, confidentiality is kept. One participant, H from German linguistic region, emphasized this as: “If it is a serious offense from the past, that was never solved [...] and it does not result in any immediate endangerment of third parties that would justify me to breach confidentiality, then I would say nothing.” Another participant, Q from the same region stated:

It is not about initiating a prosecution, but about danger for the future. It may be that someone has committed a serious crime, but everything related to the risk is already known. If it does not have extra value, it does not matter. In therapy, I would even say that he has disclosed his dark figure of crime [discussed this past crime], which is something positive. [...] But if I see that because of the serious crime, there is a risk of homicides that I was unaware of before, I must naturally take it into account [for the risk assessment].

Inversely, if upon risk assessment it is determined that the past crime changes the patient’s dangerousness, then information about the past crime is reported.

The question is what that means for the current risk assessment. Is it relevant? Is it nothing new or do I need to make a new risk assessment? Everything that is relevant to the risk must be properly mapped (Participant Q from German linguistic region).

And when asked the question-“If the crime that was confessed by the detainee influences the evaluation of danger, in this case, do you reveal it?”-another participant, P from French linguistic region emphasized, “Of course. That’s the paramount principle. One must not play any role in increasing the person’s dangerousness.”

It was also recognized by MHPs that risk assessment is not an easy task. Thus, the mapping of a patient’s risk may at times require the assistance of third persons, so that an unbiased opinion can be obtained as to whether the reporting should or should not be done.

It needs more than a suspicion and you have to keep your patient’s interest in mind, but you are by all means obliged to thoroughly evaluate the degree of dangerousness that a patient represents. And if you doubt your capacity to have a realistic perception of this dangerousness, which is difficult for a therapist, you need to talk about it with someone. It is always the same principle. And if this person said that you do not need to worry about it or, on

the contrary, said, “I also have a concern,” from this moment on it is out of your reach (Participant P from French linguistic region).

#### *Seek Advice from Colleagues and Superiors*

In addition to requesting support for the evaluation of dangerousness, MHPs also seek advice from peers and superiors with regard to whether or not they should disclose information about past crimes. This was primarily applicable in cases where MHPs were uncertain as to how they should solve a dilemma regarding disclosure of previously unknown information. For example, MHPs from both language regions of Switzerland stated they would refer to legal experts, colleagues, and the cantonal medical officer or responsible person at the state level. Advice would be sought regarding how to proceed in the face of difficult situations. An MHP, C from French linguistic region, stated: “I would need to talk about it with the team and my superior because it is extremely delicate.” The same participant also said that “[m]y answer is that I would not keep this to myself, I submit the case to the cantonal physician and if he authorizes me to disclose it, I do it.” Finally, participant, R from the same region, explained that such information about past crimes is disclosed by patients because they want to talk about it and it is an indirect way of them seeking help:

Even if the danger is averted, from a therapeutic perspective it is not by accident that the person tells us about it. If he talks to me about it then it is because it burdens him. Now, what do I do with that? I cannot be held hostage by this information. The action to be taken is therefore clear to me, to me and to us here. And I would tell him that I submit the question to the cantonal doctor [...] and then what will happen next will depend on the decision of the cantonal physician (Participant R from French linguistic region).

Also evident in the above quote is the uneasiness MHPs feel when they must refrain from disclosing a patient’s past crimes. Knowledge of the crime makes them feel hostage to the information.

#### *Encouraging Patients to Disclose*

As stated earlier, when minor crimes were discussed and when the crime does not change future dangerousness, participants would ask patients to report the crime themselves because this would be advantageous to them, as it may reduce punishment in most cases. Making the unknown crime known was deemed important by the MHPs in order to protect the victims. This was particularly true from the interviews conducted in the German linguistic region. However, there were MHPs from both regions who stated that they would maintain

confidentiality if patients refuse to report themselves. As one MHP, S from French linguistic region stated: “In this case, we would certainly try to make the patient report himself. [...] In case he refuses, I would possibly stop the treatment, but I would not necessarily denounce him.” Another participant, T from German linguistic region, echoed this sentiment: “I would advise the patient to turn himself in and apart from that let the matter rest, if it is clear that no consecutive crime will result from it.”

In cases where patients are hesitant about reporting themselves, many participants indicated they would continue the therapy and seek to gain the patient’s confidence, within the therapeutic encounter and using therapeutic means, so that they can convince the person to report. For example, Participant U from German linguistic region reported that he would discuss the situation with his patient and seek to motivate him: “The first thing I would do in this situation is to discuss it with the patient. I would try to motivate him to report himself.”

### **Discussion**

Limitations of the study design include a social desirability effect that is common to qualitative investigations and may be a concern here as we investigated a sensitive topic. Additionally, because this is a qualitative study of a small sample of participants working in correctional institutions in Switzerland, the findings are not generalizable to all professionals working in this setting or to other countries, due to differences in health care and penal systems and varying levels of physicians’ experiences. As a qualitative interview-based study, we sought to understand the attitudes of MHPs and their course of action when prisoner-patient discloses a past crime. This should not be confused with assessment of attitude, which would require a different study design and study goal. Although we cannot claim to predict future behaviour, we asked participants to report their approaches to cases they had faced in the past. We thus have good reason to believe that the attitudes they reported are close to reality and not only theories about how they think they should react. The limitations notwithstanding, the responses of our participants were open and diverse enough to identify key points for ethical reflection and to gain a comprehensive overview of confidentiality breaches in the revelation of past crimes in correctional settings, particularly in Switzerland. While the findings are unique to Switzerland, they contribute to a better understanding of similar incidences and how MHPs respond in the forensic setting in different countries.

From the study results, we conclude that most participants would make their decision to disclose and thus breach confidentiality depending on whether the patient might commit

further crimes in the future, that is, whether the patient poses a danger to third person or persons. Such situations could be seen as being similar to *Tarasoff* and *Tarasoff*-like cases, where future danger to an identifiable victim is evident (Melamed et al., 2011; Mills et al., 1987; Pinta, 2010). Conversely, if therapists consider that the risk of recidivism for the original crime is low and has not been altered by the additionally confessed crime, confidentiality is given more importance than the disclosure of past crimes. Such decisions by the therapist are based purely on their individual attitudes and judgment of the patient. This finding is consistent with other studies that also have found professionals' attitudes towards confidentiality disclosures to be case dependent and subjectively determined (Bruggen et al., 2012). Also, decisions to disclose past crimes could be influenced by existing cantonal laws. One Swiss canton's law on confidentiality disclosures (Gesundheitsgesetz Basel Stadt (GesG), 2012) is particularly interesting because it provides a list of crimes that a physician may report (e.g., murder, physical harm, danger to life, robbery, human trafficking, kidnapping, extortion, sexual abuse, spread of communicable diseases). The existence of this law clearly shows that this canton is making it somewhat easier for physicians to reveal past crimes or at least provides general authorization to breach confidentiality.

After analyzing participants' perceptions on disclosure of past crimes, risk assessment of dangerousness was one of the most important factor undergirding disclosures, taking into consideration both the type of therapy the patient was receiving and the type of crime involved. This is an important finding, as therapists must assess the risks posed to and by a patient in order to be certain that they are making the right decision regarding a disclosure. In the inverted *Tarasoff* case from Israel, it was concluded that the therapist made a poor risk assessment by calling upon his *Tarasoff*-like duties when not applicable (Margolin and Mester, 2007). Additionally, our finding is important because, despite cantonal differences in the organization of prison health care, dangerousness was the driving factor and not particular cantonal or general prison rules regarding disclosures. For instance, in cantons where the prison health care is under the justice department (i.e., mostly the German linguistic region), one might expect MHPs to be less respectful of confidentiality than those who were completely independent of the justice department and/or the prison system (i.e., most parts of the French linguistic region). However, even physicians from those cantons where MHPs were deemed "less independent" reported not revealing past crimes systematically to the authorities but marking the confession of the detainee only as a correction of the dark figure. An interesting finding relates to the feeling MHPs had of being held hostage by the revealed information, which might consequently "force" them to disclose the past crime. Although this

perception was not prevalent amongst many participants, it nevertheless deserves further consideration and exploration. In this situation, the decision of the therapist to disclose information because he or she is uneasy with the gained knowledge raises questions regarding whose interests are prioritized. Is it professionally acceptable for therapists to forgo confidentiality rules when they feel uncomfortable with the new information? It is understandable that therapists may also have the need to unload such information in order to be able to continue their professional roles. This could either be accomplished through seeking therapy or consulting with their colleagues about their possible course of action.

A few participants stated that they would stop therapy when patients refuse to report themselves or do not provide consent to the MHP to do so. That the therapists would rather stop therapy than breach confidentiality is a peculiar situation and also warrants further investigation as to why confidentiality is held as a higher good than continuation of therapy. The fact that participants would report their patients if they trivialize their crimes also presents another concern of moral judgment. Is not showing remorse a morally sufficient reason to disclose, while ceasing therapy in response to a refusal to self-report a reasonable distinction? This attitude of a therapist towards trivialization of crime on the part of the prisoner-patient is noteworthy because the nature of the crime has not changed, while the attitude of the patient toward the crime somehow alters the actions that MHPs would undertake. Such physician attitude may result in disclosure of confidentiality even when not necessary to protect third parties. This certainly raises questions regarding physician's legal and ethical obligations towards medical secrecy and beneficence of the patient. At the same time, MHPs seem to consider prisoner's own perceptions of their crimes to be an essential indication of whether the patient is actively engaging in therapy. An assessment that the patient is refractory to therapy on the basis of his or her attitude to past crimes may explain an MHP's judgment that discontinuation of therapy would be "normal" or acceptable.

An overarching concern that the study results reflect is the lack of consensus as to when and whether past crimes should be reported. This question underscores the dilemma faced by MHPs who may feel obligated to disclose such information if someone is in danger or when someone else is imprisoned for this crime. Here, as reported by the participants, seeking advice from superiors, lawyers, and colleagues may be a good option. It is not surprising, of course, that the attitudes of the MHPs in this study also varied; as other research has shown, attitudes of physicians with regard to confidentiality rules, when to breach confidentiality, and their duties to maintain confidentiality differ (Bruggen et al., 2012; Elger, 2005, 2009b,

2009a; Melamed et al., 2011). Two possible interventions that could help MHPs become more cognizant about confidentiality, its exceptions, and when and how they should act if faced with certain circumstances include greater and improved educational training and the development and availability of clear guidelines on this issue. If guidelines and educational training concerning confidentiality are put into place, the result could be better and more predictable outcomes on the part of therapists.

MHPs in correctional settings (as well as those in the community) can appropriately deal with difficult cases if the legal and ethical requirements concerning confidentiality are clear and known to them. Dilemmas associated with when to disclose past crimes could be resolved if existing guidelines better explained which types of crimes are protected by confidentiality rules and which are not. Furthermore, an indication of key factors related to the underlying ethical reasoning relating to disclosure of past crimes would also help MHPs in their judgment.

Our study findings presented risk assessment of dangerousness as an important guiding tool to determine whether confidentiality should be breached. However, such assessment is not straightforward and empirical evidence is needed as to how these assessments should be done and by whom and how results should be interpreted to ensure uniform application. We also saw hesitation of MHPs to disclose past crimes but a willingness to stop therapy. Such attitudes of MHPs could be due to unclear guidelines. This finding also poses questions in relation to what it is about the crime (and/or the patient or confidentiality itself) that makes MHPs uncomfortable breaching confidentiality but “justifies” an MHP to cease the therapeutic relationship with the patient. If guidelines were clear, MHPs may be more confident in their course of action and may be able to continue their therapeutic relationship with a patient, which is of utmost importance in light of their deontological duty of care. In addition, MHPs must have the opportunity to provide relevant details from their own experience, of which legal and ethical scholars may not be aware, to the tailoring of existing guidelines and the development of new laws and clinical tools. Given that such rules and regulations are often binding on MHPs, it is important that they reflect the realities of their practice.

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## **Vulnerabilities due to age and gender**

**Facing the challenges of an increasingly ageing prison population in Switzerland: In search of ethically acceptable solutions**

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***Abstract***

Prisons in Switzerland are facing challenges associated with growing numbers of ageing prisoners. This paper explores two health care related concerns linked to the changing demographic pattern and evaluates them using the principle of equivalence of care. The principle stipulates that health care received by prisoners and non-prisoners should be equivalent. Its implication for prison health care is analysed focusing on the declining abilities of older prisoners within the unsuitable physical environment of the prison. The equivalence principle is also used to address questions about adequate access to health care for older prisoners at the end-of-life. Health care services such as palliative or hospice care are explored along with other alternative solutions such as compassionate release. Finally, ethically acceptable solutions to prison medicine that adequately responds to the needs of ageing and dying prisoners are discussed with an emphasis on duties of health care providers and other stakeholders.

## **Introduction**

In both the community and in prisons<sup>10</sup>, the ageing of the population raises novel issues. Today, there are more older people than at any other point in history. This is due to several factors including decreasing fertility rates, better public health measures, and improvements made in the field of medicine (Anderson and Hussey, 2000). The growing older adult population impacts all facets of our lives, be it social, economic or political (United Nations - UN, 2009). For instance, greater numbers of older persons are additional strains on the already burdened health care systems of many nations. Anderson and Hussey reported that industrialized countries spent between one-third and one-half of their total health care expenditure on older patients (Anderson and Hussey, 2000).

The ageing of our society is mirrored in prison institutions, where prisoners over the age of 50 years are considered “old”<sup>11</sup> (Gallagher, 2001; Rikard and Rosenberg, 2007). In the general population, “older adult” usually refers to citizens who are 60 years and older. The lower age limit used to categorize older prisoners is due to their accelerated ageing: prisoners aged around 50 years suffer from similar health conditions as 60 year olds in the general population (Fazel et al., 2001b; Loeb et al., 2008). In Western countries, the number of ageing prisoners is rising (Fazel et al., 2001a; Tarbuck, 2001). In Switzerland for instance, prisons recorded a total of 8.206 prison admissions in 2010. Of these, 8.5% were above the age of 50 years representing 700 older prisoners (Bundesamt für Statistik, 2011). The proportion of older prisoners is relatively small considering that 17,2% of the general population are elders (over 65 years) in Switzerland (Bundesamt für Statistik, 2012b). However, the ageing prisoner population is expected to grow dramatically in the future due to trends toward longer sentences and more older adults entering the prison system (Loeb and Abudagga, 2006; Tarbuck, 2001). This signals that there will be more prisoners growing old and many of them will even die in prison.

In Switzerland, all 26 cantons have their own judicial authority and health related laws. The autonomy enjoyed by each canton leads to diverse prison systems and different prison health services. As of 2011, there are 113 institutions that incarcerate individuals in Switzerland. The total capacity of these institutions is 6.660 places and according to the latest data, 6.065 people are currently imprisoned (Bundesamt für Statistik, 2012a).

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<sup>10</sup> The term “prison” is used to include all types of detention facilities. By “prisoners” we mean persons detained in any of these facilities.

<sup>11</sup> In this article we use older, old, ageing and elderly as synonyms.

According to recommendations from the United Nations and the Council of Europe<sup>12</sup>, the quality of health care available to prisoners should be equivalent to that of any other person living in the community (Council of Europe - COE, 1998; Levy, 1997; Lines, 2006; Staub, 2008; Swiss Academy of Medical Sciences - SAMS, 2002; United Nations - UN, 1982, 1990). In this article, we address two health care related challenges faced by older prisoners and examine ethically acceptable solutions using the equivalence principle framework. We begin first by presenting the principle of equivalence of care, followed by an evaluation of the prison environment and its impact on the weakening physical health of older prisoners. We then analyse end-of-life care of dying older prisoners and conclude with a discussion of ethically satisfactory solutions, with a particular emphasis on the role of health care personnel working in prison and their obligations towards elderly prisoners.

*Equivalence of care – What does it mean in prison?*

The principle of equivalence<sup>13</sup> was first mentioned in the *Principles of Medical Ethics* in 1982 (United Nations - UN, 1982) and is also noted in various legal recommendations and guidelines. Abiding to the guidelines of this principle is predominantly a European<sup>14</sup> phenomenon (Elger, 2008; Friedman, 1992) because it incorporates a unique human rights framework with enforcement mechanisms through the European Court of Human Rights and the European Committee for the Prevention of Torture (CPT). The Swiss Academy of Medical Sciences (SAMS) refers to the principle and reports that imprisoned persons are entitled to receive equivalent medical treatment to that obtained by any individual in the general population. This entitlement for prisoners means not only access to preventive, diagnostic, therapeutic and nursing care, but also the right to self-determination, information and confidentiality (Swiss Academy of Medical Sciences - SAMS, 2012).

Although the SAMS guideline was issued 10 years ago, its implementation remains a challenge in Switzerland and in other countries. Prisons are fundamentally different from the

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<sup>12</sup> These recommendations from the UN or the Council of Europe are usually called “soft” law because they do not have binding character such as ratified conventions or treaties. They are nevertheless important regulatory documents to which the CPT or decisions of the ECHR refers to.

<sup>13</sup> Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (PME), 1982, Principle 1: “Health personnel, particularly physicians, charged with the medical care of prisoners and detainees, have a duty to provide them with protection of their physical and mental health and treatment of disease of the same quality and standard as is afforded to those who are not imprisoned or detained.”

<sup>14</sup> The *Australian* medical association also stresses “equal duties” (“The duty of medical practitioners to treat all patients professionally with respect for their human dignity and privacy applies equally to the care of those detained in prison”: <http://ama.com.au/node/503>), whereas the US does not use the principle of equivalence, but a standard called “cruel and unusual punishment” (20, 21).

community since they are an enclosed environment with distinctive rules (Birmingham et al., 2006; Exworthy et al., 2011). Ageing prisoners have unique health needs that must be specifically addressed to ensure that they obtain adequate health care access and appropriate treatment. Free choice of physicians is not guaranteed in prisons indicating that these prisoners are treated only by general practitioners or physicians working within the prison system. Visits to geriatricians or a second opinion, though recommended in international soft law (Council of Europe - COE, 1998), represent an extra burden and rarely occur. Birmingham and colleagues highlight the difficult situation that physicians face when seeking to offer equivalent medical attention to patients in a climate of cost restraints and lack of certain treatment options (Birmingham et al., 2006). Equivalent provision of health care is further complicated by the prison organisational and security aspects that directly impact provision of health care in prisons (Powell et al., 2010).

The difficulties associated with ensuring equivalent provision of care in the prison setting is compounded with the inconsistent interpretation of what the principle of equivalence exactly means? The ambiguity associated with its meaning make the implementation of the principle seemingly difficult. A clarification of the principle within the framework of health care for prisoners in general and ageing prisoners in particular is urgently needed. The essential question being: which characteristics must be fulfilled for a health care treatment to be considered equivalent for a person in prison?

A mechanism to conceptualize the intention of the principle of equivalence may be to not concentrate on “how” this principle should be interpreted in the prison context but “why” should we provide equivalent care to prisoners and “where” does this idea come from? Some people are opposed to the view that prisoners should receive this level of care as they might feel that prisoners must be punished and are therefore less deserving. Hence, establishing an ethical basis for the principle of equivalence is important and might also forward its application. The most important concept underlying the principle of equivalence is the abstention from inhuman and degrading treatment (Council of Europe - COE, 2010) which is ultimately based on respect for human dignity. However, the principle of human dignity has often been criticized to be a vague (Horton, 2004; Jacobson, 2007; Marmot, 2004) and even a meaningless concept (Macklin, 2003). In a Kantian sense (Gentzler, 2003; Mattson and Clark, 2011), it is our shared humanity that justifies the equivalent provision of health care for prisoners. Pointless suffering and an early death is not acceptable under these premises, if

we are able to prevent it (Cohn, 1999; Nordenfelt, 2003). Health is a right deriving from human dignity itself and not from any kind of authority.

Indeed, the principle of equivalence raises questions concerning the goals and justifications of incarceration. Is retribution achieved with prisoners' loss of freedom? Or should retribution also impact the provision of health care? Within the framework of inalienable human rights enshrined in international human rights law, punishment will not include lower standards of health care than outside prisons. As access to health care varies in different countries, it has to be considered first, that with the loss of freedom, the state renders a detainee unable to provide for his basic needs and thus has the responsibility to fulfil them, including health care (Cohn, 1999; Marmot, 2004). However, another question is, which level of care should be made available to prisoners, as discussions may arise, when we talk about scarce resources like organs for example (Kahn, 2003). There, the issue of just desserts becomes relevant (Cohn, 1999) and could be resolved if we accept that the punishment is the loss of freedom. Other than that, detainees are equal members of our society and must not suffer additional retribution (Cohn, 1999). Finally we should ask ourselves, what kind of society we want to be and what the denial of equivalent health care to prisoners would do it.

Last, but not least, if we accept that human dignity is inherent to all human beings, on a collective level, theories of justice, like for example Rawls "veil of ignorance" (Rawls, 1999) suggests that it would be fair to allow prisoners to have the same level of care as everyone else (Cohn, 1999). Ethical principles such as equality and social justice are even used to support the provision of health care as a human right, but this is still quite controversial (Smith, 2005).

Although the principle of equivalence grounded in ethical values like justice and equity, the concept is still vague and continues to be interpreted in various ways. For the sake of consistency, we use the equivalence of care for prisoners to mean the following: same quality and standard along with same outcomes for persons living in or outside prison. To elaborate, the principle of equivalence of care in prisons must be achieved in two steps. First, health care in prison should be of the same quality and standard like outside prison, i.e., the same preventive measures should be offered and the same treatments should be made available. But this is not enough in the case of imprisoned people and thus attention has to be paid to the results of the health care interventions. Charles and Harper stated that by achieving and measuring the equivalence of outcomes, the true spirit of the principle of equivalence is met (Charles and Draper, 2012).

Thus, it is not enough to just offer an older prisoner same treatments as that provided to an older person in the general population, because the older prisoners may need more or different interventions due accelerated ageing in prison. Treatments should therefore be administered according to need and not to provide equal services to individuals of the same age group.

Finally, equivalence of care for prisoners is a concept which is very difficult to implement in practice (Lines, 2006; Niveau, 2007) and physicians working in prison have to be aware of that. For the future and to ease this process, an assessment of health care treatments in prison is needed to be able to measure the outcomes, compare them with the general population and introduce a certain standard that would clarify the equivalent treatment for prisoners.

To ensure equivalence of care in prison, two major obstacles must be overcome: independence of prison health care and specifically trained prison health care personnel. The Council of Europe (Council of Europe - COE, 1998) and the CPT (European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2008) have specified that prison health care personnel must be independent from the prison administration and judicial authorities. Unfortunately, only a few countries have implemented this recommendation. For instance, in Germany, the Ministry of Justice and not the Ministry of Health is responsible for prisoner's health care. If prison health care and public health authorities are distinct, necessary cooperation cannot be assured (Hayton et al., 2010). Such "parallel system" functioning has been criticized (Keppler et al., 2010) since they are laden with inherent problems. In order to realize true independence of prison health professionals from correctional and judicial authorities, countries such as France, Norway, and some cantons in Switzerland shifted this responsibility of prisoners' health to the Ministry of Health (Keppler et al., 2010).

If health care is placed under the authority of prison administrations instead of health departments, a number of additional local factors may further impede equivalent care for prisoners. This includes professional isolation of prison physicians, especially in remote rural prisons, potential lack of specialized and continued education and training, and the possibility that prison administrations interfere with medical decision making (Hayton et al., 2010).

To address health care needs of ageing prisoners in an equivalent way, health care providers need to have special medical knowledge, realizable through regular geriatric training for

prison physicians. In addition, to satisfy the principle of equivalence, cantons should ensure that prisoners have access to geriatricians and other specialists (Collins and Bird, 2007).

#### *Accommodation of older prisoners*

Adaptation to the prison environment for ageing prisoners is a challenge in itself. Elderly prisoners face particular difficulties in this respect. Appropriate physical surroundings are necessary as they impact the physical health and well-being of an older person (Wahl et al., 2012). The current prison settings and its architecture were built to suit younger and able-bodied individuals, who continue to constitute the largest portion of the prison population (Neeley et al., 1997; Ornduff, 1996). Almost everything from prison clothing to daily prison schedule is primarily designed with younger adults in mind and thus is an impediment to older prisoners. Moreover, long corridors without places to rest, lacking handrails, stairs, noisy and crowded places make moving around the prison difficult. Thus, incarceration itself becomes an additional burden for the increasing number of ageing prisoners, who on a daily basis must confront with the prison environment.

Equivalent treatment for all prisoners would imply that changes must be made to the prison architecture so that it is “age friendly”. The goal of these changes is to ensure that the prison’s physical environment supports and even compensates for the declining competencies of its ageing members (Wahl et al., 2012). Prisons might need to be re-designed to reduce walking distances between a prisoner’s cell to dining, recreational, and health care areas; include handrails in corridors to provide support while walking; and built elevators so that older prisoners could avoid using stairs. In addition, specially adapted furniture like higher beds and chairs should be incorporated to reduce accidental falls and injuries.

Another solution could be to construct new prison facilities suited for older prisoners. In such cases, the location of these prisons is of particular importance. Specialised health care facilities need to be available in the immediate surroundings and accessible to older inmates. Close proximity to specialised facilities would imply that new correctional facilities must be built either in or near an urban area (Neeley et al., 1997).

However, within the correctional institutions, stakeholders do not agree on whether older prisoners should be grouped together in special housing areas or whether it is best to continue mixed accommodation with younger prisoners (Ornduff, 1996; Thivierge-Rikard and Thompson, 2007). The arguments in favour of separation revolve around the provision of adequate and specialised health care for older prisoners and protection from possible

violence. Examples of specialised health care could include on-site dialysis, counselling on death and dying as well as palliative and hospice services (Thivierge-Rikard and Thompson, 2007). On the other hand, mixed housing conditions are said to have beneficial effects on younger as well as older inmates. Younger prisoners are calmer in the presence of older inmates and may profit from the elderly prisoners' assistance in administrative work. Such co-residence allows older prisoners to build social networks consisting of both older and younger inmates. Furthermore, it is argued that segregation of prisoners by age might exclude ageing inmates from other prison services available to the general prison population (Aday, 2003; Ornduff, 1996).

Finally, older prisoners do not have the choice that their peers outside the prison have between selecting to stay where they are and thus "age in place" (Wahl et al., 2012) (i.e., the prison), or choosing to move to a nursing home, a retirement home or an assisted living facility. Although older prisoners' wish to stay in their familiar environment might be similar to their peers' in the general population, the realization of these wishes could be problematic. This is particularly the case when older prisoners have served many decades of sentence and have aged in prison. Since these prisoners lived most of their life in the correctional system, they may have come to consider it as their home. In such circumstances, they are likely to face great difficulties at the time of release. A proper process is needed that guides them gradually through this change. Conversely, an older person, who is a first-time offender, might not be able to adjust to the new and restrictive prison environment. Therefore, to avoid additional burden on ageing prisoners, it is necessary to create a system that is not only conducive to their health, but also receptive to new and flexible options. Older prisoners are not a homogenous group, their heterogeneity demands readiness to evaluate and evolve according to their individualized needs (Loeb and Abudagga, 2006; Neeley et al., 1997). However, costs for "age friendly" environments, and qualitatively and quantitatively different health care needs of elderly prisoners must be adequately considered.

#### *End-of-life care and death in prison*

With increasing numbers of older prisoners and many of them living to an advanced old age, the prison system faces challenges associated with end-of-life care and deaths of its ageing members (Gautier, 2011; Human Rights Watch, 2012). As discussed above, the prison environment is at present poorly adapted to the needs of its older population with deteriorating physical health. This exacerbates problems associated not only with ageing

prisoners' regular activities of daily living but also interferes with ethically appropriate end-of-life care.

In Switzerland, correctional institutions are not equipped with hospice or palliative facilities to respond to the needs of dying prisoners. Such services are available in a few correctional facilities in the US (Hoffman and Dickinson, 2011; Linder et al., 2002; Ratcliff and Craig, 2004). Studies evaluating prison palliative and hospice care have so far revealed their positive results (Bronstein and Wright, 2006; Linder and Meyers, 2007). Older dying prisoners, who benefit from these support programs, and younger prisoners, who volunteer as hospice service providers, reported positive outcomes (Bronstein and Wright, 2006; Linder et al., 2002). Although it is practical and cost effective that younger prisoners and prison guards provide informal help to ageing and dying prisoners, this nevertheless means that prisoners do not have access to trained personnel that would be available in similar settings outside prisons (Collins and Bird, 2007).

Within the framework of the principle of equivalence (Lines, 2006; Niveau, 2007), equivalent care must also be available to dying prisoners. Appropriate end-of-life care should incorporate not only help with activities of daily living, but also offer opportunities to bridge ties with family members, and psychological and spiritual counselling that would prepare dying prisoners to face their imminent death. Prison health services would need to adapt and revamp their health care structures by training their personnel in end-of-life care, hiring physicians mainly trained in prison and geriatric medicine, and ensuring that necessary tools are available to cater to the needs of severely ill and dying prisoners (Collins and Bird, 2007; Linder and Meyers, 2007).

The lack of suitable in-prison end-of-life care even in highly developed countries, where older inmates are dying within the system, has intensified the debate surrounding compassionate release (Gautier, 2011; O'Connor, 2004; Williams et al., 2011). This is a program designed to let terminally ill prisoners live the last days of their lives as free individuals. If prisoners still have ties to their families, this humanitarian measure allows them to spend their last days with family members. Unfortunately, in many countries it is a very seldom used program as the specified criteria are stringent and the process is arduous (Human Rights Watch, 2012; Williams et al., 2011). In the US, one of the requirements for compassionate release is that the prisoner must be diagnosed with an incurable illness whose prognosis is predictably terminal. This pre-requisite disqualifies many older prisoners who suffer from non-life threatening diseases such as Alzheimer's and other dementias. Although

these neurological conditions generally render older prisoners mentally and physically unable to harm another person or seek retribution when freed and permitted to live in the community, compassionate release is, in most cases, not permitted for this group of patients.

Compassionate release in case of fatal disease is strongly based on human dignity and the obligation to abstain from inhuman and degrading treatment. In the case of incapacitating diseases, it might also involve questions surrounding two other elements, namely the concept of personal identity and the justifications for punishment. Considering a Lockean view of the person defined using criteria such as consciousness, rationality and purposive agency (Gordijn, 1999; Kuhse, 1999), compassionate release for older prisoners suffering from dementia would be the most acceptable solution, as this person is arguably not the same person who committed the crime decades ago. Gordijn explains it as follows: “[...] corresponding to Locke’s definition of personal identity, when a man is no longer conscious of a certain past action, he is not the same person as the one who committed the action, although he has remained the same man” (Gordijn, 1999). The Lockean view of the person could be extended so far as to state that an individual with dementia is not a person anymore, as they lack those features that define a person and thus no longer retain the same rights and responsibilities as one (Hughes, 2001; Kuhse, 1999). Moreover, the four classic justifications for imprisonment, namely retribution, deterrence, incapacitation and rehabilitation (Dresser, 1990) that presuppose a rational and self-conscious person, could no longer be fulfilled. In the legal context also, individual accountability is based on similar considerations about the person. Other concepts of personal identity that claim it to be stable over time, such as the situated-embodied-agent (SEA)-model was described by Hughes (Hughes, 2001). This model views the person within a historical and cultural context and could be interpreted as being more problematic as the personal identity of the perpetrator and the demented person is the same. However, the loss of certain capacities would eliminate the justifications for punishment requires rationality, temporality and accountability. It is therefore important to ask, if the perpetrator’s mere embodiment of the person is sufficient to justify continued punishment for the purpose of retribution or whether declining mental capacities and their consequent loss of personhood should also be taken into account.

To comply with the principle of equivalence in Switzerland and other countries, greater support services are needed. The question remains who should be responsible to ensure and securing adequate medical and supportive care for older dying prisoners and how these services should be implemented. Furthermore, when compassionate release is obtained, steps

must be put in place to ascertain that these prisoners are properly cared for either by the family or by state agency.

### **Discussion**

Ethics in prison medicine is particular, in that the problem is not only interpreting what is ethically adequate, but how to act ethically in an environment that is not conducive to international ethical and legal requirements. Taking prison environment and details of medical care for older prisoners into consideration, prison health care personnel should seek support from public health authorities, cantonal health departments as well as from university and public health institutions to find individual solutions to each ageing prisoner's environmental needs as well as general solution to questions related to prison architecture and planning. Ethical and social responsibility in prison medicine implies not only engagement for the benefit of individual patients but also encouraging authorities to participate in search of adequate and timely solutions.

Given cantonal specificities, ethically acceptable outcomes may vary to achieve the common goal of equivalence of care. This implies that there is more than one outcome and therefore different solutions may be valid based on the circumstances. An ethically unsatisfactory solution arises if an immediate sufficient option does not exist, but a less optimal "better than nothing" alternative is available. This is the case where prison authorities engage younger prisoners to help with daily care needs of those who are older. This arrangement is certainly one that is better than none, but health professionals know the dangers of such arrangements since most of them have treated patients for physical or psychological abuse and exploitation by other inmates. Hence, the ethical duty of health professionals in these cases is to insist that such "solutions" are not in line with the principle of equivalence and that changes are very much needed and necessary. Health professionals may have, in many cases, significant authority to propose and implement ethically suitable solutions if they adamantly persist on refusing to comply with false "better than nothing" compromises.

Concerning ethical care for dying prisoners, health care professionals have obligations to inform authorities, with patients' consent, about medical prognosis as well as, if appropriate, medical arguments concerning diminished dangerousness. Indeed, the Council of Europe highlights that detainees should not die in prison but be granted humanitarian release. Truly equivalent end-of-life care might only be best obtained outside the prisons. Providing compassionate release is probably the less costly and more humane alternative.

As summarized above, a number of ethically acceptable solutions exist to implement equivalent health care for elderly prisoners (Birmingham et al., 2006; Linder and Meyers, 2007; Thivierge-Rikard and Thompson, 2007; Williams et al., 2011). Not all of them will result in increased costs to the prison system. For example, compassionate release of non-dangerous prisoners or transfer to palliative care structures is an ethical and a more cost effective measure than continuing to detain dying prisoners in very expensive acute care facilities.

The first ethical duty of prison health care providers is to describe problems adequately. Prison health professionals are best placed to collect data that are necessary to help cantonal and federal stakeholders to make evidence based decisions. Since physicians working in prisons lack necessary training in data collection and research, Swiss medical schools and public health institutions should support scientifically sound data collection in prison. Previous efforts in this matter include research projects financed by the Swiss Health Department on smoking in prison (Ritter and Elger, 2012) as well as a study on death in custody financed by the Swiss Network for International Studies (Elger et al., 2009).

The duty to describe implies informing cantonal health departments about current problems. This is also a responsibility of Swiss physician associations as they must identify gaps in services and approach relevant officials. They have the obligation to make cantons aware of deficiencies in systems where prison health care personnel is employed by prison administrations or the justice system, instead of departments of health. This could even go as far as the one put forth by the British Medical Association (British Medical Association, 1992, 2001), where they stress “cooperation between medical bodies, non-governmental organizations and others who recognize that political and social reform is the best medicine and [...] support systems for prison doctors” (Summerfield, 1993).

### **Conclusion**

The steady increase of ageing prisoners requires active search for ethically acceptable solutions, in line with the principle of equivalence of care. One of the ethical and practical challenges is the identification of solutions that might vary from canton to canton but that pursue the same goal. Indeed, health care personnel in prison have an ethical duty to provide time and resources to not only search for ad hoc solutions for their ageing patients, but also to stimulate a broader discussion and to collect needed data that will support ethically and scientifically sound evidence based decision making.

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**Easily forgotten: elderly female prisoners**

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**Abstract**

Women form a growing minority within the worldwide prison population and have special needs and distinct characteristics. Within this group exists a smaller sub-group: elderly female prisoners (EFPs) who require tailored social and health interventions that address their unique needs. Data collected from two prisons in Switzerland housing women prisoners were studied. Overall 26 medical records were analyzed, 13 from EFPs (50+ years) and for comparison 13 from young female prisoners (YFPs, 49 years and younger). Additionally, five semi-structured interviews were conducted with EFPs. Using the layer model of vulnerability, three layers of vulnerability were identified: the “prisoner” layer; followed by the layer of “woman”; both of which are encompassed by the layer of “old age”. The analysis of these layers resulted in three main areas where EFPs are particularly vulnerable: their status of “double-minority,” health and health-care access, and their social relations. Prison administration and policy-makers need to be more sensitive to gender and age related issues in order to remedy these vulnerabilities.

## **Introduction**

Female prisoners constitute between 2% and 9% of the total prison population in about 80% of prison systems worldwide (Walmsley, 2006). In Switzerland, females form 5.2% of the prison population (Bundesamt für Statistik, 2013b), which is comparable to the median level in Europe (4.4%) and lies between other western European countries such as Lichtenstein (0%) and The Netherlands (8.8%) (Walmsley, 2006). Despite being a minority among prisoners, their number is not only rising but rising at a greater rate than their male counterparts (van den Bergh et al., 2011). While countries and correctional systems in which female prisoners are detained may vary, their general characteristics described in the literature paint a distinct picture of the “typical” female prisoner (Fair, 2009). However, for the small sub-group of female prisoners, namely elderly female prisoners (EFPs)<sup>15</sup>, it is not known how age influences this picture and if they require different types of interventions.

### *The “typical” female prisoner*

The “typical” female prisoner is convicted for a non-violent crime, accordingly serves shorter sentences (van den Bergh et al., 2011), and is less likely to be a recidivist. Additionally, she usually hails from a socioeconomically disadvantaged background, often with no educational qualification, and belongs to a minority group (Lewis, 2006). It is likely that she has experienced physical and/or sexual abuse, has been a victim of exploitation, and suffers from drug and alcohol abuse. Compared to male prisoners and women living in the community, a typical female prisoner has higher rates of mental health problems, often meeting the diagnostic criteria for a lifetime mental disorder, as well as a greater prevalence of chronic diseases and worse physical health (Fair, 2009). Due to poor access to health-care prior to incarceration and risky lifestyle behaviors influenced by socioeconomic conditions (Harris et al., 2007), she is a high user of prison health-care services (WHO, 2009).

We also know that a female prisoner is often the sole carer for her children and other dependents (Fair, 2009). Therefore, her imprisonment can severely impact family structure. Finally, due to their small number, prisons designated for women are scarce and may be located in remote regions, thus adding another burden as she and her family would have fewer opportunities to remain in touch (Ginn, 2013; van den Bergh et al., 2011).

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<sup>15</sup> In this article we will use the following abbreviations: EFP for “elderly female prisoner” and YFP for “young female prisoner”

Institutional factors further deteriorate her position as a prisoner. First, female prisoners continue to be incarcerated in prisons designed for young male prisoners, who form the bulk of the prison population (Lewis, 2006; van den Bergh et al., 2011). This means that security standards are higher than necessary (Fair, 2009). Second, personnel working with female offenders are often not specifically trained to respond to the social and health needs of this population (Lewis, 2006). Third, how reproductive health concerns are addressed in these prisons varies significantly (van den Bergh et al., 2011). Simply put, the needs of female prisoners derived from the above description of the “typical” female prisoner are not taken into account in most of the current prison structures.

### *Elderly female prisoners*

Among female prisoners, elderly female prisoners (EFPs) deserve special attention due to their advanced age and the changes associated with it (Reviere and Young, 2004). They constitute a “minority within a minority” and while it is recognized that female prisoners and older prisoners have special needs, the combined needs of EFPs are rarely addressed (Leigey and Hodge, 2012). Only few studies are available on EFPs and even fewer from Europe. Views of EFPs on health-care and social relations in prison have been explored in three studies (Aday and Farney, 2014; Krabill and Aday, 2007; Wahidin, 2005). One quantitative study addresses the mental health of EFPs (Lindquist and Lindquist, 1997), and two others, respectively, functional impairment (Williams et al., 2006) and somatic health (Lindquist and Lindquist, 1999). A literature review on the health of EFPs underscores the necessity to better address health needs of EFPs (Reviere and Young, 2004). Two articles compare somatic and mental health between older male and female inmates (Kratcoski and Babb, 1990; Leigey and Hodge, 2012). As a result of the very limited existing knowledge on EFPs, programs and policies for this group are almost non-existent amounting to “malign neglect” (Leigey and Hodge, 2012).

Using data from Switzerland, this study highlights the vulnerabilities of EFPs in their current context of imprisonment. Demographically in Switzerland the proportion of female prisoners was 370 of a total number of 7,072 prisoners in 2013 (Bundesamt für Statistik, 2013b) and like their counterparts elsewhere, they are mainly sentenced for non-violent crimes (Bundesamt für Statistik, 2013a). To fill in the existing research gaps, this article explores why EFPs require specific social and health interventions based on an analysis of their layers of vulnerability (Luna, 2009) and suggests what can be done to address these vulnerabilities.

*Layers of vulnerability*

As a group, female prisoners are often deemed vulnerable (Ginn, 2013; Lindquist and Lindquist, 1997; Plugge et al., 2008). This vulnerability is mostly, if not all, derived from one or more of the features described above. However, the concept of vulnerability is used as a label for all female prisoners, without qualifying which specific features of being a prisoner and being a woman contribute to it. The layer model of vulnerability developed by Luna (2009) offers a better way to conceptualize different factors that make female prisoners in general and EFPs in particular vulnerable. Rather than simply stating that EFPs are vulnerable and thus considering it to be a permanent and categorical condition, identifying relevant features that add to the overall vulnerability better reflect the complexity of the issue and rightly considers the social circumstances that influence vulnerability (Luna and Vanderpoel, 2013). It is a flexible and dynamic model as it takes into account different dimensions of the problem, subdividing it into layers that can be tackled individually despite their interrelatedness.

The concept of vulnerability has predominantly been discussed in research ethics and is used as a label to mark an entire population's vulnerability, such as children in the 1978 Belmont report. In light of the criticism raised against this concept (Kipnis, 2001; Levine et al., 2004), this article chooses to forgo applying the adjectival label of "vulnerable" to this population to avoid engaging in paternalism or stereotyping. Rather, we consider an inclusive definition of vulnerability, namely EFP's risk of harm to multiple dimensions such as health and well-being where circumstances or the context "makes or renders someone vulnerable" (Luna, 2009). Models based on layers of vulnerability have proven useful in informing policies and regulations concerning migrant workers and vulnerable young people (Sargeant and Tucker, 2009; Victorian Government Department of Human Services, 2010). Thus, based on the goal of this study, we utilize this framework of layers of vulnerability to interpret our data.

**Method**

The data from a larger national project examining the health-care situation of older prisoners in Switzerland are used for this manuscript. This project collected both qualitative and quantitative data of older inmates and quantitative data of younger prisoners located in two of the three language regions of the country. Here, only data from female prisoners are presented.

*Setting*

In Switzerland, there are two prisons that house female prisoners with long-term sentences, one each in the German- and French-speaking regions. The total capacity of both prisons for female prisoners combined is 151 places. Ethics committee approval was sought and obtained for the study.

*Participants*

The two prisons housed a total of 19 EFPs (50+ years), of which 13 agreed to participate. The age of 50 years was chosen as a cut-off based on previous studies (Plugge et al., 2006) and in consideration of the existing knowledge that the age of prisoners in terms of health is 7-10 years greater than their actual age (Reviere and Young, 2004). Health data belonging to 26 female prisoners were collected, of which, 13 were EFPs and 13 YFPs (under 50 years). The YFPs were randomly selected by choosing those whose name came after the EFP on an alphabetical list provided by the prison health service. Of the 13 EFPs, five agreed to participate in a semi-structured interview.

*Data collection and analysis*

Extraction of health-related data from medical records took place using a tool developed by the research team. Medical records were made available by prison health services and data were anonymized using a code for each participant.

Basic data gathered included demographic and health information such as disease information, number of visits to nurses, general practitioners (GPs), and other health-care providers. To obtain an in-depth understanding of their health and health-care usage, for this study, we utilized information in relation to two aspects: (a) diseases diagnosed and (b) health-care accessed (nurses and GPs) in the last 6 months. Data were extracted by two research assistants and entered into an EpiData file and checked for errors. Descriptive analysis took place using IBM SPSS 21.0.

In order to understand how EFPs perceive their health and health-care, aging in general, their aging experiences, and the social circumstances in prison, face-to-face semi-structured interviews were conducted with five EFPs (56 - 70 years). The interviews included EFPs from both prisons and the language of communication was German or French based on the preference of the participants. YFPs were not interviewed because the national project was designed with a focus on elderly prisoners. On average the interviews lasted 91 minutes, they were tape recorded, transcribed verbatim, anonymized, and checked for errors. Additionally,

pseudonyms in the form of first names were attributed to every quote, rather than to the five interviewees to ensure maximum anonymity for this highly vulnerable group and small number of EFP interviewed. Major themes were identified in MAXQDA 11 using directed content analysis (Hsieh and Shannon, 2005). The analysis was done by three members of the research team to ensure consistency in coding and interpretation of the data. The principal analysis according to the three layers was carried out by VH. For reasons of validation, investigator triangulation was achieved through a second (WB) and third researcher (TW) coding the data according to the layers. Results were discussed within an interdisciplinary group and compared to those of an independent coder (BE). All coders have a background in Bioethics and TW also has a background in Gerontology. The discussion of independent coding by three researchers confirmed that similar themes were emerging and consensus on the attribution to the layers was reached. Afterwards, VH compared the coding schemes and all codes were combined in one comprehensive scheme that was approved by WB, TW and BE. Different coders and independent coding were used to ensure that no codes were missed and themes were attributed to the layers based on convincing grounds.

## **Results**

### *Health of the study participants*

From the 26 medical records, differences are evident in the demographic and incarceration information between the two age groups. Among the sample of YFPs 85% committed a non-violent crime, and the mean time spent in prison was 1.11 years. Among the EFPs only 46% committed a non-violent crime, and the mean time spent in prison was 3.6 years. The entire sample of female prisoners had a low educational level, with 61.1% having no qualifications (meaning no high school diploma). Of the 26 women, 38.5% were Swiss, while 61.5% were of foreign nationality. A total of 23.1% were married, 38.4% were either divorced, separated or widowed, and 38.5% were single or had never been married.

Concerning their health-related data, 65.4% (n=17) of the female prisoners had at least one mental health diagnosis. Female prisoners suffered from a number of somatic diseases. All disease types coded by ICD-10 classifications are presented in Table 1.

**Table 1:** *Somatic disease types according to ICD-10 in female prisoners by age groups.*

	Age (Years)	Number of diseases	Most frequent types of diseases (ICD-10)
Young Female Prisoners	30.5 (19 - 45)	3.5 (0 - 8)	<ol style="list-style-type: none"> <li>1. Endocrine, nutritional and metabolic disease <b>17.4%</b></li> <li>2. Disease of the musculoskeletal system and connective tissue <b>10.9%</b></li> <li>3. Disease of the respiratory system <b>10.9%</b></li> <li>4. Disease of the skin and subcutaneous tissue <b>10.9%</b></li> <li>5. Disease of the nervous system <b>8.7%</b></li> <li>6. Others <b>41.3%</b></li> </ol>
Elderly Female Prisoners	56.3 (51 - 70)	6.6 (1 - 17)	<ol style="list-style-type: none"> <li>1. Disease of the musculoskeletal system and connective tissue <b>19.8%</b></li> <li>2. Endocrine, nutritional and metabolic disease <b>12.8%</b></li> <li>3. Disease of the circulatory system <b>10.5%</b></li> <li>4. Disease of the respiratory system <b>9.3%</b></li> <li>5. Disease of the digestive system <b>8.1%</b></li> <li>6. Others <b>39.5%</b></li> </ol>

The average number of visits to nurses in the last 6 months was: 32.9 visits (range: 2 - 96) and 33.5 visits (range: 2 - 142) respectively for YFPs and EFPs. Visits to the GP are less frequent, with 2.3 (range: 0 - 4) visits for YFPs and 3.1 (range: 0 - 7) visits for EFPs.

### Vulnerabilities of being an EFP

#### *EFPs as prisoners*

This first layer of vulnerability incorporates two concerns related to EFPs' incarcerated status. The consequences of this physical confinement are: (a) poor quality of life in prison and (b) loss of autonomy in personal life.

*Poor quality of life in prison.* EFPs expressed poor quality of life in terms of the negative effects of imprisonment on their mental well-being. They reported that being imprisoned results in feelings of hopelessness, as Sara described: "My soul is broken. (...) My soul is completely corroded. Prison has really destroyed my soul."

Participants saw their life in prison as not worth living, Milena, in her late 50s, simply stated that "life in prison is not a life at all." This thought was exacerbated by their precarious health, either already present before imprisonment and/or worsened during incarceration, such as in Maria's case:

Walking, that's the worst for me (...), the physician says that I need surgery, but I'm very afraid. I never had one before, not even with my eyes and now I'm blind [in one eye]. That was before prison. I had surgery on my shoulder, that does not work well (...) My back, down here, that's a catastrophe. My intervertebral disk is completely broken (...). Now I don't know what to do (...) these people don't have a clue about sick people.

Environmental factors can create additional vulnerabilities. In one of the prisons, inmates, for example Catherina, complained about only having cold water in the cell and about generally inadequate room furnishings, making life in prison more burdensome:

The rooms are miserable. There is a small table, (...) a bed and a toilet, an open toilet, catastrophic (...). And cold water, no warm water (...). Three years I have been living here with my sick bones with cold water in the cell. Yes, that is terrible.

*Loss of autonomy.* The loss of autonomy in prison influences crucial parts of personal life such as not being able to choose health-care providers or health-care services, strict prison regulations, obligations to work, and privacy. These limitations mean changes to their health-

care, as compared to their health-care habits before imprisonment. Cynthia expressed the dissatisfaction and concern regarding the quality of health-care provider and standard of health-care in prison by describing her visit to the dentist:

There is a chair, probably from 1873. The equipment is not much newer. And then there was this young girl, about 20 years old who said that she is a dentist. Then she checked my teeth and said, yes, that's difficult. Well, great. After that I left. I said I would go [to the dentist] after my release.

Moreover, structural issues were mentioned, including difficulties accessing specialized or outpatient treatments and limited access to preventive measures in the same way as they were used to before imprisonment, as portrayed by Vera:

They wanted to send me sometime [to the ophthalmologist] because I said pretty please about ten times. (...) But now I won't go, I don't give a damn if I become blind or not, really. I don't rack my brain over it. Normally [outside the prison] I did a check-up for my eyes every three months, here once a year. What will be next? Three years - without treatment?

The quality of health-care services provided also was considered poor, making self-help necessary or requiring EFPs to be forceful in order to get the desired treatment that would otherwise be refused. Lena felt that "Health-care is really, really dreadful" and that one must be self-reliant, else, "If you can't help yourself, that's bad". Similarly, Amelia was able to receive necessary help after making a big deal, "I'm wearing lenses, so I already went there three times to get my contact lens solution, because now they order it for me after I caused a big ruckus".

Second, the possibility for these prisoners to make their own decisions is reduced by prison administrative processes. Multiple regulations exist in prison with which inmates must comply. These regulations are so ingrained in the system that interviewees felt that they were at the mercy of these regulations. As Lilian described: "You have no chance to wish for anything. This is a prison. What is done for one person is true for all others. You don't get any special treatment."

Our EFPs perceived these regulations as unjust and arbitrary as they were applied in changing ways. Marla reported her experience:

I have just learned - the more you try to fight in prison, against anything, if you ask for so-called justice: the more you will be put down. They like having people who cry

- who take medications to calm themselves down, and not the ones who hold their head high.

Exceptions to the rules are seen as rare and very special. Bernadette relayed her experience of being allowed to garden in an area of the prison where inmates are usually not permitted as a very emotional event:

And with Mrs. C [a prison officer, name removed] (...) who was absolutely exceptional because she had a lot of patience and in spite of my age, she accepted to have me at her side. It was something important because when I find myself in the courtyard...this is what the therapy is...they open the gate wide and the garden is on the side of the path of the officers' rounds. And there sometimes the officers pass by or the director with visitors but no one is allowed to go there (...). And when I open my cupboard, take my tools and cross the gate, I have the impression of finding myself as if I were almost free. I feel privileged (...)...maybe this seems stupid in your eyes (...)...but I feel like I am different from the others.

Private space is rare in prison as many aspects of inmates' lives are under scrutiny. As prison life means communal life, inmates face common problems associated with it and avoidance strategies are scarce. Carla, however, protected herself by sidestepping conflicting situations:

I believe, that it always depends on yourself (...), how I do it, simply withdrawing from everything and really avoiding every potential for conflict and also not becoming too close friends with anybody, then you don't run into danger (...). There are three women in our residential unit with whom I never exchange even a single word. They are 'air' to me, because they just represent a potential danger.

The most common approach among those interviewed was that of retreat and isolation. All interviewees kept their social relations inside prison superficial and to a minimum, while "exporting" it to the outside and stressing the importance of extra-mural contact. Alina revealed her strategy of keeping to herself as:

Due to the fact that I always occupied myself and I lived to the outside and not to the inside. I consciously kept myself apart, not only because of my age, but as a person. And I always had a computer in prison, right from the start. I always had contact with the outside world, much more than with the inside.

Inside prison they compensated this lack of social contact in various ways, even to the point of humanizing objects, like Astrid did: “I’m telling you: my friends are my books, my computer and my four walls.”

*EFPs as women*

The second layer of vulnerability is that of being a woman in prison. This layer included two specific issues: minority status of female prisoners and difficulties managing surrounding social relationships.

*Women as a minority.* Female prisoners only comprise a small proportion of the total number of inmates; as a consequence, there are only few places that detain them. Thus, sentences are executed in one place: open and closed regimes as well as detentions prior to deportation, determined by differences in the level of security in relation to the risk of escape. Carina mentioned being in an open regime but having to follow the same rules as those in a closed one, which greatly impacts her degree of freedom:

I am subject to the same regulations here like those who are in a closed regime. So, in an open regime I would have the right to use my cell-phone at certain times; I would have the right to use the internet at certain times. It doesn’t matter [in this prison] if you are from the high security section, if you are in an open regime, if you have an [indeterminate security] measure, here everybody is placed under the same umbrella.

This lack of differentiation by type of prison sentence presents potential for conflict, as Lina found:

We also have people, who already served one-sixth of their sentence, who can go outside [prison] accompanied. (...) This is a huge problem (...), when people are allowed to go outside and they are in the same place with people who are never allowed to go outside at all (...). That is a huge potential for conflicts and this you can see again and again, when the ones who are allowed to go outside - there are some who never say a word about it - but there are others who are close to hyperventilating, because they are trumpeting it around and they make a fuss and this of course is fuel for aggressions of the others.

Another issue specific to being a woman in prison was lack of gender-specific preventive measures such as mammography. Isabell mentioned barriers to breast cancer screening:

Also preventive measures, (...) I think this is just a gross negligence how it is done here (...). In another European country [name removed], women above the age of 50 get a mammography every two years. (...) Here, I have never seen a gynecologist. And in case you ask about mammography: ‘Do you have problems?’ and that is exactly the point: no, not yet! That is why one wants preventive measures.

*Social relations.* Vulnerabilities of being a female prisoner were evident in their social relationships. As prisons present unisexual environments that are not “naturally” found in society, the social relations within them will be influenced by it.

Relationships among inmates are seen as distrustful, begrudging, and dominated by intrigues and drugs. Verena outlined her tendencies to isolate herself from other inmates, thereby presenting the quality of social relationship among female prisoners.

Here in prison, these are all forced acquaintances. And every woman has another background (...). The atmosphere in prison is really strange, from the outside you think or I always imagined (...), that there would be a profound solidarity between the women, that they would help each other, because they share the same problem. At the moment, they are all in the same boat. This is not at all the case, rather the opposite. And it is extremely pervaded by envy, by jealousy, by resentment, and drugs infuse the whole thing as well. Then there are deals, when you ask for something then immediately you depend on others. (...), I get along well with the fellow inmates, but again, always keeping a certain distance.

With some prison staff, the participants perceived the connection rather positively. Sina admitted that “the environment here has always been very open”. This was because she found that the director “listens to the people”. Upon acknowledging that other inmates may not feel the same about prison personnel, Sina evaluated her positive experiences with prison personnel hinged on two characteristics: integrity and taking responsibility seriously:

Someone really extraordinary was the prison warden. He is a man who has integrity, is upright, if a crackdown is needed, he does it but if he needs to listen, he listens. And he knows when you need him, when you write to him; he is someone who responds.

The most important social relations for interviewees were contact with family and friends. EFPs were constantly thinking, worrying, and wishing to see and be with their family and friends. For Lea, whose family is located at a distance, her inability to visit them played a role in her deteriorating health:

I tell you quite honestly: I can't live without my family. This is why I'm having so many problems with my health. Because of my children and my family I have to cry so much sometimes. I'm so happy when I've seen my family, when they come and pick me up. I enjoy seeing my grandchildren and my daughter. My heart belongs to my children.

Not only was the physical location of the prison a problem in ensuring relationship with family members and friends, but also the actual prison structure with its high level of security checks. For instance, Valery, upon being concerned about the uncomfortable security checks that her aging parents would have to go through should they choose to visit her, she decided against their visits and stated, "I talk to my parents on the phone every day. I actually want to spare my parents the procedure here."

#### *EFPs as older persons*

The third layer of vulnerability is that of age and here, two sub-layers are identified: older prisoners as a minority among a minority and aging and its consequences.

*Older prisoners as a minority among a minority.* Again minority status is an issue for EFPs, as their small numbers mean that they have to adapt to circumstances dictated by the majority. Josephine indicating the difficulty of adjusting to a noisy environment noted her dissatisfaction: "Yes, the noise, a lot of noise, you never have a room (...), where it is calm, where there are only people of my age because we are only very few."

Upon comparing themselves to YFPs, the participants considered themselves quieter and as having other interests. Additionally, they sometimes felt ostracized by YFPs and found that free-time activities available in prison were not adapted to their age and needs. Hanna concluded how those who are older no longer fit "in" with younger prisoners as follows:

You are really on the edge. In prison A [name of prison removed], we were two women, I think the other was around 65 and we walked together and we really noticed: the other inmates don't accept us anymore, because we are the oldies, the mummies. You are really shoved away; (...) you can't participate in conversations anymore, because you're not 'in'. In sports you cannot take part; they don't want us, because with us they cannot win. You're simply shut out.

*Aging and its consequences.* Increasing age usually brings with it deteriorating health. Fulfilling prison duties such as cleaning one's cell or fulfilling work obligations become difficult. Ursa described the severe pain she is experiencing:

That's very bad and my cell, cleaning my cell, for me sometimes I'm cleaning with tears in my eyes. But what can I do? (...)

Q: You have so much pain that you have to cry?

Yes, there is no other way. And the social worker says that I have to be strong, that I have to clean. Then I say that I'll do it, what else can I do?

Workplaces also are not adapted to the health needs and physical abilities of EFPs. These work responsibilities even created new health problems such as shoulder pain. This is reported by Alma: "I think it is an imposition that (...) they actually force women around 50 to sit at a loom, that forces you to sit in an awkward position and I think it is a real disgrace and imposition. (...) And then I got (...) serious problems with my left shoulder."

Additionally, interviewees mentioned that nutritional needs change with age and that healthy food is difficult to obtain. Antonia, suffering from diabetes, pointed out: "They provide me with bad nutrition, a lot of salty food which is not good for sick people. What people eat here is not healthy food."

Prison officers and medical personnel were portrayed as largely being insensitive to age, with officers rarely considering the age differences between YFPs and EFPs. Manuela criticizing this stated: "For the officers, whether you're 20 or 50 years old, it is: like do or die basically." Patricia felt that male prison officers ignored EFPs because they were no longer sexually desirable: "The officers don't look at us [EFPs] a lot. They are usually men and they like to watch the young [women] and well, we are already old (...)." Finally, medical staff in one prison was even viewed as ridiculing EFPs and not taking their complaints seriously. Lara explained the treatment that she receives due to her age:

They have no idea; they don't tell me what kind of medication I'm taking. And when I say, please I would like to get a print-out, I would like to know my diagnosis, (...). Then they say, oh Mrs. X [name deleted] you don't understand and you're old. When I go there because I'm in pain, they give me a pill and I go to work with pain. I tell them that I cannot work, that I have severe pain then they say: 'Oh, what a shame, I cannot buy a new hand for you and I cannot buy a new life for you.' I tell them, I don't need a new hand and no new life; I need medication to reduce my pain.

### **Discussion**

The accounts of EFPs paint a picture of the different vulnerabilities associated with being a prisoner, a woman, and an older adult. Among the three identified layers of vulnerability, relations and synergies exist. These vulnerabilities arise from imprisonment and how gender and age is constructed in this closed environment. We identified three issues from the data that, when taken together, underscore the unique vulnerabilities of EFPs: their status as “double-minority”, vulnerabilities related to health and health-care access, and the social relations in- and outside prison.

#### *EFPs as a “double-minority”*

The prisoner-layer contains those vulnerabilities that are common to all prisoners such as low quality of life and loss of autonomy. They may seem to be gender neutral. However, Seymour (2003) described the “profoundly gendered nature of crime and punishment” as a display of masculinity. Indeed for EFPs as a “double-minority,” issues that arise are due to “standardizing” prisons with the image of a stereotypical young and able-bodied male prisoner in mind (Reviere and Young, 2004). This standardization leads to homogenizing the prison population without acknowledging and attending to inmates’ differences. The compliance to strict regulations and adherence to authority are markers of prisons as “violent organizations” where “difference attracts harassment and victimization” (Seymour, 2003) both by staff and other inmates. EFPs due to their age and gender display two distinct differences compared to “the common inmate”.

Due to their small number, female prisoners are incarcerated in mixed prison regimes, creating conflicts because of the variety in individuals’ degrees of freedom. The high administrative burden associated with managing varied prison regimes also results in ignoring some differences and privileges related to diverse regimes as mentioned by Carina. For male prisoners, institutions such as open and closed regimes are usually separated. In a given institution, male inmates have a similar degree of freedom. Similarly, when units for older prisoners are designed, they are commonly done so for older male prisoners (Codd, 1998) as they tend to be more populous than EFPs. In summary, their small number actually puts EFPs at a disadvantage as very limited resources are allocated to them and their uniqueness is mostly ignored.

In criminology, being female is often put on a par with the category of “victim” (Seymour, 2003). Women as offenders are therefore contrary to social constructions of gender. This is

especially true for women having committed violent crimes. From the quantitative data obtained from EFPs, we found that 56% were incarcerated for violent crimes and had lived in prison for several years, thereby presenting an unusual offender category. Furthermore, older female offenders violate traditional expectations and attitudes of society towards older women, such as their representation as “the benevolent grandmother” (Codd, 1998). As a result, they are ignored or rendered “invisible” (Codd, 1998). In the interviews, this ignorance of EFPs’ needs was underpinned through their experiences of injustice and arbitrariness when rules were applied that disregarded age- and gender-related circumstances, such as having to clean the cell under significant pain. In contrast, exceptions such as detailed by Bernadette (i.e. ability to garden) are highly valued.

The aging process that is already a period of adaptation and acceptance outside prison is all the more strenuous inside. While our sample of EFPs was still at the lower age range, they experienced restrictions due to declining physical abilities. The worsening of one’s health status was perceived to be in conflict with strict prison rules, mandatory work responsibilities, defined free-time and the confined environment. For instance, while old age in society is “the product of structural factors such as retirement and pensions rather than determined by physiology” (Twigg, 2004), this is not transferred to the prison context in Switzerland. Our participants reported the obligation to work despite their age. Hence, prison rules do not account for age. This is illustrated by Alma’s comment on the imposition of forcing women of a certain age to sit at a loom. Williams (2006) also found that EFPs are often assigned work that is too difficult for them to perform. The often negative judgment of aging bodies associated with decline is compounded by gender, as judgments concerning the body have a greater bearing on women, who become socially invisible (Twigg, 2004), as shown in Patricia’s comment referring to the male officers. Safeguarding possibilities for EFPs to remain active either through free-time-activities or adapted work places can however, prove crucial as productivity strongly impacts social worth in the elderly (Hurd, 2000).

#### *Health and health-care access*

Lindquist (1999) identified age and gender as “the most consistent demographic predictors of health status and medical care utilization, with females and older inmates reporting higher morbidity and concomitantly higher numbers of medical encounters” while EFPs combine these two predictors. The results from our quantitative data showed that EFP often use prison health-care services. Especially their mean visits to nurses in the last 6 months are higher compared to elderly male prisoners in Switzerland who on average visited nurses 9.0 times

(Wangmo et al., 2014). This higher number could possibly be related to the number of somatic diseases, with our sample of EFPs suffering from more diseases than older male prisoners in Switzerland, who on average have 4.3 diseases (Wangmo et al., 2012). These results are in accordance with comparative studies of older female and male prisoners' health (Kratcoski and Babb, 1990; Leigey and Hodge, 2012) that found higher numbers of chronic and mental health conditions.

Additionally, Williams (2006) found that high rates of functional impairment in geriatric female prisoners can be exacerbated by the prison environment. Such environmental factors mentioned by EFPs as not being conducive to health, were having cold water in the cell and a lack of access to healthy food as well as exercise opportunities. Indeed, Douglas (2009) and Deaton (2009) found that women prisoners felt that limitations associated with imprisonment, particularly poor diet and the inactivity, negatively affected their health and that their health had deteriorated over the time of incarceration.

Concerning prison health-care, EFPs' subjective feelings were that their needs were not adequately managed and that only forcefulness and determination helped them to cope with this situation. Based on our methodology we are not in a position to know whether this reflects insufficient care or different expectations based on high service use before imprisonment. Our participants frequently compared services offered in prison to what had been available outside, raising questions about the quality of the services provided and the competence of prison health-care staff. Similar comparisons are done by women prisoners participating in a study by Plugge (2008). The variability between cantons in Switzerland (some offering systematic breast cancer screening others not) might explain some unfulfilled expectations of the interviewees, but, it may nevertheless be in line with the standard of care offered routinely outside prison in the same canton. An additional constraint was the reduced possibilities for self-care and self-medication. The resulting sense of disempowerment is well-known among women prisoners (Douglas et al., 2009). Access to specialists and outside treatments was also described as difficult.

The health of EFPs in our sample is heterogeneous and they do not all suffer from bodily decline. However, some conditions are generally more frequent in women, such as osteoporosis or breast cancer and require proper diagnosis and treatment. Additionally, older female inmates suffer from more chronic physical health conditions than their male counterparts, while engaging less in physical activity (Leigey and Hodge, 2012). Coupled with the "feminization of old age" in society, meaning women living longer and suffering

more years of disability than men, this means that prison health-care services have to be adapted to deal with these demands and support healthy aging where possible. Additionally, health-care usage between men and women in the general population differs. Wang and colleagues (2013) showed that between the ages of 16 and 60 years women consult primary care services more often than men, while ages over 60 and similar conditions yield comparable patterns of health-care use. EFPs are high users of prison health services and show different patterns of health-care usage compared to aging male prisoners, thus availability of health services should be adapted. In old age, care needs will further increase especially social care for which prisons are currently not equipped.

### *Social relations*

Maintaining contacts with family and friends were described as extremely important to EFPs independent of family makeup. Interviewees occupied various roles as daughter, wife, mother, grandmother, and friend. These relationships existed outside the prison walls, making it difficult for EFPs to maintain them. The limited possibility of participating in the lives of their loved ones can be considered a great burden both for the persons detained and their family members (Krabill and Aday, 2007). Valery's quote highlighted how she put the trouble her parents would face in coming to visit her above her desire to meet them. Similar feelings were also displayed by our other interviewees and showed that choices they make concerning their contacts are influenced by the context (i.e. prison regulations for visits) and the needs of their family members (i.e. the burden of passing through security). Possibly, visitations of family could also be grievous (Krabill and Aday, 2007) or family members and others may be less likely to visit due to stigma associated with the incarceration itself since it goes against social expectations of older women as discussed above. In her comment, Lea strongly identifies with her role as a mother and by extension as a grandmother reflecting more traditional gender images concerning family. Fostering the maintenance of social relations for EFPs will require a broader view of possible roles that older women can occupy from the part of prison system. For instance, prisons have programs on family-related issues but these often focus on parenting (Morash and Robinson, 2002), thus concern younger women with under-age children. Other conceivable roles especially for EFPs as mothers of adult children, grandmothers or daughters of parents of an advanced age which we found in the interviews are usually not acknowledged reinforcing their "invisibility". This neglects realities of carework as gendered work (Twigg, 2004), that women often furnish throughout their lives as well as the overall diversity of women claimed by Michalsen and Flavin (2014).

From the five interviews with EFPs, different sources for isolation were prominent. All interviewees shared a general mistrust towards other inmates and only very selectively formed acquaintances. Contact and involvement were even described as dangerous, making it necessary to keep one's distance from others. The view of the social environment of the prison as "intensely isolating and intimidating" (Douglas et al., 2009) also came out in the voices of our participants. This depicts how the hierarchical prison environment shapes social relations due to "power"-based relations both between and among prisoners and staff (Seymour, 2003). Carla avoided certain women because they represented a threat of violence and Lina referred to violence caused by varying degrees of freedom provided to different prisoners based on their sentence and incarceration status (i.e. whether they are able to leave the prison for a visit or not). Violence is engrained in the prison system, among others, physicality, confrontation and danger "are unequivocally associated with credibility, respect and survival" in this context (Seymour, 2003). This holds true for relations with officers who were often perceived as insensitive to age. The relationship with other prison staff differed based on function. Inmates felt that attitudes of primary care staff were uncaring, disrespectful and unresponsive, similar to what is found in other studies (Harner et al., 2011; Plugge et al., 2008) and Lara suggested ageist attitudes and ignorance of her constant physical pain also reported in another study (Aday and Farney, 2014). With other staff members, EFPs described better relationships as they were seen as more understanding. This is illustrated by Sina who was very positive but nevertheless conveyed the hierarchical structure of prisons. This hierarchy shapes the relations between and among prisoners and officers creating "emotional and symbolic distances, enabling the 'us and them' of prison life." (Seymour, 2003)

This structural isolation is furthered by the isolation that increases within the age layer of vulnerability because EFPs are less likely to take part in free-time activities (Krabill and Aday, 2007). Hanna illustrated how "bodily signs of old age can serve as physical markers for those who will be excluded" (Calasanti, 2005) meaning that YFPs exclude EFPs from activities solely on grounds of their exterior markers of old age. Similar to another study (Lindquist and Lindquist, 1999), the participants noticed their changing needs with age. For example, a more peaceful and quiet environment and the need for more privacy was desired. Differently from our results, the only other study investigating social relations of EFPs, Krabill (2007) found that EFPs form friendships in prison for social support and to cope with

the hardships of prison. Although these were sometimes not very close relationships, the tendency of isolation was much greater in our interviewed sample.

However, the ability to isolate oneself from others was noted as difficult because of the lack of privacy inherent to the prison system (Wahidin, 2005). Forced communal life and its intrinsic problems were compensated for by using avoiding strategies. Trying to conserve islands of privacy and individuality, such as, their cell or ability to use their computers, became the main focus of EFPs' attention. This is contrary to traditional views of female prisoners as more sociable or more in need of relationships (Morash and Robinson, 2002). Verena revealed this social perception when she described her previous belief of solidarity among female prisoners because of their shared fate.

### *Limitations*

Only five EFPs were interviewed for this study. We acknowledge that this is a limited sample size for a qualitative study. Like every other qualitative study, the responses from our older female participants are not generalizable. Thus, it could be that older female offenders in other countries may have very different vulnerabilities than those mentioned in this study. Again, with regard to our EFPs, it is important to note that only those incarcerated in prisons included in the larger national project were interviewed. Only two female prisons were eligible for inclusion and from those, we requested interview permission from all 13 EFPs, whose medical record data were gathered. Five agreed, and the remaining mostly chose not to participate and for a few, interviewing was not possible due to language barriers. Because of language barrier, it is possible that we failed to capture the unique experiences of those EFP who may have social networks outside the country and whose social relation needs might be magnified. Additionally, the national project's qualitative component was limited to interviews with older prisoners. Finally, the EFPs who agreed to be interviewed may over represent the group of those who are not feeling well and would like to express their views. However, they also described positive elements, so we do not think that this bias is major.

Quantitative data obtained from the medical records are subject to limits of such sources including variation associated with recording of details based on health-care personnel and institutional standards. The sample size presented is very small and thus, the findings are not statistically significant and again, not generalizable. It is nevertheless clear that these are the best possible data available from Switzerland and allows for the presentation of the health and health-care access data for EFPs that often are neglected. Data on female prisoners, not to

mention EFPs, are extremely rare. Despite these limitations, our Swiss data contributes to the field of aging, prison studies, and minority aging. The Swiss prison setting has its own specificities, especially the obligation to work, which we were able to bring forth in our findings.

### **Conclusions**

The three issues that emerged from the layers of vulnerability of EFPs are those in need of special attention in order to remedy and improve the conditions of EFPs. Based on our analysis of vulnerabilities associated with being a woman and an older person in prison, following interventions are recommended that bear to address their social needs and health conditions. First, in light of the significance of social relationships, stronger emphasis on fostering social support networks for EFPs (Reviere and Young, 2004) should be put in place. This would mean reassessing prison rules regarding visiting hours, number of visits, and security checks imposed for the visitors, as many of them could be aging parents of these prisoners or even their young (grand)-children. Second, educating security and medical personnel about gender and age-specific needs of prisoners is an important measure to implement in prison as perspectives on gender are known to influence how these prison personnel care for those incarcerated. Such education may also help, for example, in making arrangements and family-related programming for female prisoners such as has been demonstrated for correctional administrators (Morash and Robinson, 2002). Third, to date, handbooks for prison staff and policymakers exist that are gender-sensitive and built on a human rights approach (Penal Reform International, 2013; WHO, 2011). Their aim is to protect female prisoners from harm and violence in prison. The consistent use of these handbooks should be encouraged so that they form a baseline marker to respond to the needs of female prisoners. When implementing this knowledge, the specificities of EFPs must also be addressed, as they have different needs from YFPs where the focus on substance abuse programs, for example, would be greater. Fourth, intervention is needed in the allocation of workplaces for EFPs that are age appropriate and sensitive to their health conditions. This might be a Swiss-specific intervention due to its work obligation irrespective of age. Fifth, an intervention of particular importance for EFPs is the quality of prison health-care and access to outside services that takes into account gender and age-related patterns of health-care usage and needs. Finally, female prisoners in general and EFPs in particular should not be further penalized for their small numbers by being incarcerated in structures that were not designed for them and not responding to their needs. More gender-centered approaches do

not necessarily increase economic costs. For example Fair (2009) pointed out that women are usually detained in higher than necessary security levels, which results in very high costs. Those funds could be allocated differently. Some issues identified for EFPs are also applicable to (elderly) male prisoners such as access to health-care and preventive measures as well as contact with family and friends. Therefore, rather than viewing prisoners as ungendered (Seymour, 2003) a stronger focus on gender and age issues could improve their condition substantially.

We set out to characterize the different layers of vulnerability of EFPs to show that the singular combination of vulnerabilities arising from their status as older women in prison requires tailored interventions. We saw that conceptions of gender and aging bodies play an important role in the experiences of EFPs as double-minority in prisons, such as in their relations and their health-care. Findings from the study call for particular attention to gender and age-specific concerns, which recognize not only the vulnerabilities of EFPs, but all prisoners.

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## **Chapter II: The impact of prisoners' vulnerabilities on end-of-life care**

End-of-life has been a much discussed topic in Bioethics, not least because of the right to die movement and continuing debates around assisted dying and the meaning of a good death and a death with dignity (Emanuel and Emanuel, 1998; Street and Kissane, 2001). This has led to great advances in end-of-life care such as the hospice movement and the development of palliative care. Yet in prisons, end-of-life care is not available in most cases raising serious issues. In the United States, 2,975 state prisoners died due to illness in 2011, cancer and heart disease being the leading causes of death (Noonan and Ginder, 2013). In England and Wales, the Prisons and Probation Ombudsman investigated 647 natural deaths between 2007 and 2012, of which he classified 214 as foreseeable (Prisons and Probation Ombudsman for England and Wales, 2013). Switzerland handles comparably small numbers with 7.4 deaths that have been recorded on average per year between 2006 and 2011 and that were not due to suicide (Bundesamt für Statistik, 2012). While under the principle of equivalence, the access of prisoners to end-of-life care is imperative, it is often neither provided in prison nor as so-called "palliative care in-reach" (Stone et al., 2012). This means that prisoners often die under precarious conditions such as lacking adequate pain medication (Byock, 2002; Maschi et al., 2014). Accordingly, fears of prisoners to die in prison are common, however, not only because of lacking care but also because of the stigma associated with it and the impossibility to have family and loved-ones around (Aday, 2006; Deaton et al., 2009). In this chapter I will first investigate the views of aging prisoners in Swiss corrections about the possible prospect of dying in prison. This will contribute to investigating their vulnerabilities, as multiple sources of harm arising due to the prison environment in the connection with death will be identified. Second, to shed light on vulnerabilities arising due to violations of the principle of equivalence, I will discuss the sensitive issue of assisted dying for older prisoners. This will raise questions about the right to self-determination of prisoners, who are limited in many choices due to the restrictive environment.

An often cited alternative is the early release of seriously ill and elderly prisoners grounded on humanitarian and medical criteria (Beck, 1999; Williams et al., 2011). Legal provisions for this type of release, also known as compassionate release, have been developed in most countries. Yet, all of them are rarely used (Beck, 1999; Chiu, 2010; Williams et al., 2011). Reasons for this are lengthy and complicated procedures and flawed medical criteria.

However, the large body of literature on this topic exclusively stems from the United States and the United Kingdom and examines this issue from a theoretical perspective. Lacking end-of-life care combined with non-functioning release provisions increase the overall vulnerability of this population. Drawing on a theory of punishment, I will describe the opinions of older prisoners concerning compassionate release, as their views on this topic have not been investigated so far. I will also give voice to the other side, namely stakeholders. It will be an investigation on how vulnerabilities of prisoners at the end-of-life are addressed on a policy level. A possible solution to the identified hurdles to early release of seriously ill and aging prisoners will be discussed.

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**Vulnerabilities of aging prisoners at the end-of-life**

**Concerns and questions at the end-of-life**

***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 75 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 attitudes towards 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.

### **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 et al, 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 et al., 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 et al, 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 et al, 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 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 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 could 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 (ethics committee of both Basel-Stadt and Basel-Landschaft), 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 75 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 et al, 2009).

Another common criticism was the handling of deaths by prison personnel and administration who addressed 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, 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 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, ehm, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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 et al, 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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***Will I stay or can I go? Assisted suicide in prison***

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So far, the availability of “assisted dying”, which encompasses physician assisted suicide (PAS) and euthanasia for prisoners in those countries where it is decriminalized, has not been discussed. The criteria for assisted dying usually include a hopeless prognosis and unbearable suffering, the informed, voluntary, and constant choice of a competent person and a lack of reasonable alternatives (Rietjens et al., 2009; Ziegler and Bosshard, 2007). We will investigate these criteria for prisoners.

A strong objection against the provision of assisted dying in prison is the question whether a free and informed choice can be made in an environment with reduced autonomy and options. Conversely, excluding prisoners from such options at the end of life raises questions about justice, fairness, and the limits of punishment: What is the difference between choices in end-of-life care and rights or provisions that prisoners are stripped of, such as the right to vote or the choice of physician for example? If we agree that end-of-life care should be available to everyone, because of its existential nature, should PAS and euthanasia be viewed as a mere choice among different treatment options at the end-of-life (Onwuteaka-Philipsen et al., 2003)? And if PAS and euthanasia should be provided to prisoners, then under what conditions? Is “prison tedium” (Handtke and Wangmo, 2014) for prisoners in life-long or preventive detention a strong enough “unbearable suffering” (Rietjens et al., 2009)?

Choices at the end-of-life are special by way of their finality (Byock, 2002). And while autonomy in prison is limited concerning certain choices and rights, this should not impede on the most existential ones including prisoners right to stay on hunger-strike, issue advance-directives and do not resuscitate orders, and refuse life-saving treatments (World Medical Association (WMA), 1991). Because the State has the duty to care for those it incarcerates, this duty of protection should not override the explicit wishes and the exercise of individual rights where they do not harm others (Greenberg, 1982). Therefore, prisoners retain the ability to make informed and voluntary health care choices.

Considering the legal basis for the provision of assisted dying to prisoners, distinct situations present themselves due to how PAS and euthanasia are embedded in the legislation and health care systems of the different countries and what role the physician plays as he is an important actor in the process. Switzerland works with non-profit right-to-die organizations in the provision of PAS. However, the legal situation is such that assisted suicide is not prosecuted if it is not performed out of selfish motives (Art. 115 Swiss Criminal Code (SCC)) and thus, does not clearly locate PAS within health care, meaning that the principle of

equivalence, which Switzerland adheres to (Swiss Academy of Medical Sciences - SAMS, 2002), does not directly apply. However, Switzerland follows the principle of normality, stating that “Their [prisoners] rights may only be limited to the extent that that [sic] is required for the deprivation of their liberty and their co-existence in the penal institution.” (Art. 74 SCC) Thus, general access to assisted dying should be guaranteed for prisoners as a treatment alternative at the end-of-life.

Inmates suffering from terminal diseases can fulfil the necessary criteria for assisted dying, and could thus, in theory, be eligible for it. Moreover, one special group of prisoners, namely those in life-long detention, could also claim that a life without the prospect of release amounts to “unbearable suffering”, a concept whose boundaries are much debated (Rietjens et al., 2009). Discussions about being “tired of life” or “suffering through living” as a valid reason for euthanasia in the Netherlands exist (Pike, 2010; Sheldon, 2005). Possibly, “prison tedium” (Handtke and Wangmo, 2014) could be added as reason for assisted dying, as it is a singular situation those prisoners find themselves in, as most of them have served their sentence, but remain in prison as they are considered “dangerous”, often with no prospect of being released at all. Those prisoners might perceive the lack of perspective and alternatives, reduced quality of life and deprivation of liberty as “unbearable suffering”.

Finally, alternatives to assisted dying, such as end-of-life care should be made available to prisoners, either in prison or as so-called palliative or hospice care “in reach” (Stone et al., 2012). Compassionate release is certainly another very humane option that is not yet fully exploited. It could present prisoners suffering from a terminal disease with an alternative, as it refers to the early release to allow an ill inmate to die outside. Nevertheless, it is marked by lengthy bureaucratic and judicial processes, based on “clinically flawed and procedural barriers”, e.g. a definite prognosis (Williams et al., 2011). In reality, only very few prisoners ever receive such release, while many do not live to see the decision. But while it is important to provide these options, some inmates might still prefer assisted dying similar to many individuals in the community who opt for euthanasia or PAS. This means that those countries where forms of assisted dying are decriminalized, should make them available to prisoners and pay special attention to the possible reasons and the practical challenges associated with this population.

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**Blessing or curse? The case of compassionate release**

***The collision of care and punishment: ageing prisoners' view on compassionate release***

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**Abstract**

Most prisoners wish to spend their last days outside prison. Early release of seriously ill and ageing prisoners, commonly termed compassionate release, can be granted based on legal regulations but is rarely successful. The aim of this paper is to present the views of ageing prisoners on compassionate release using qualitative interviews. Participants argued for compassionate release on the grounds of illness and old age, citing respect for human dignity. Their hopes of an early release however often contradicted their actual experiences. Framing these results within Garland's depiction of the criminology of the self and the criminology of the other, it is evident that in reality, the punitive strategy prevails. This strategy explains the rare use of compassionate release and how it negatively impacts prisoners' access to end-of-life care. A possible solution is the welfarist criminology, strongly supported by a human rights approach. Awareness of the dominance of the punitive strategy is crucial for medical personnel as they are best placed to ensure access to end-of-life care for prisoners through compassionate release.

## **Introduction**

Prisoners at the end-of-life often wish to spend their last days in the community (Linder and Meyers, 2007; Byock, 2002). For seriously ill and ageing prisoners<sup>1</sup>, legal regulations are in place to interrupt their sentence or to release them early from prison<sup>2</sup> (Russell, 1993; Chiu, 2010). These regulations were founded on a humanitarian concern for the dying and for practical reasons such as high costs or the inability to care adequately for such persons in prison (Dubler, 1998). Despite the availability of legal provisions that support the expressed wishes of prisoners to die outside prison, inmates at the end-of-life are rarely released (Beck, 1999; Williams et al., 2011).

The failure to implement compassionate release policies could further influence the current shift in prison demographics. First, the number of prisoners likely to die during the course of their sentence, such as prisoners with life or indeterminate sentences, is rising (Prison Reform Trust, 2013; Schneeberger Georgescu, 2009). This is especially true in the European context because of the abolishment of the death penalty (Newcomen, 2005). And second, the proportion of ageing prisoners is increasing at such a rate, it has prompted researchers in the United States to call it an 'aging crisis' (Williams et al., 2012; Maschi et al., 2013). Similarly in England and Wales, prisoners aged 60 years and over are the fastest growing group, doubling in size from 2002 to 2011 (Prison Reform Trust, 2013). With the proportion of prisoners aged 50 years and older increasing 5.2% in one year alone to now representing around 12% of the prison population (Berman and Dar, 2013). In Switzerland, the number of prisoners aged 50 years and older has more than doubled from 2003 (n = 296) to 2014 (n = 664) (Bundesamt für Statistik, 2014). Schneeberger (2009) found that this increase was due to a rise in the number of prisoners serving indeterminate sentences and ageing in prison rather than an increase in ageing persons committing criminal offences.

Studies of prisoners' views about death and dying in prison have commonly found that prisoners are fearful of dying in prison (Aday, 2006; Deaton et al., 2009; Loeb et al., 2014; Linder and Meyers, 2007). Concerns related to inadequate care at the end-of-life, regrets about the inability to see their family and loved-ones, and the perception that dying in prison has a stigma attached to it, not only for them but also for their family. Taken together, the research showed that it was the place of death that was important to the prisoners. The significance of not wanting to die in prison was underscored by the finding that a greater

proportion of prisoners would be more likely to accept life-prolonging treatment if they would receive parole (Phillips et al., 2011).

Prison is generally deemed unsuitable for compassionate end-of-life care due to its punitive nature (Mahon, 1999). The prison environment is viewed as a major stressor for older adults (Maschi et al., 2015), making the fear of dying there more prominent. While end-of-life care exists in some prisons, it is not standard clinical care (Williams et al., 2011). Even if the prison successfully provides this care, it is not without its own challenges (Dubler, 1998). Indeed, end-of-life care for prisoners is often rendered difficult by the restrictive environment and opposing goals of providing care versus ensuring security (Mahon, 1999). Finally, the provision of end-of-life care in prisons and compassionate release are not mutually exclusive. That is, even if end-of-life care is provided, compassionate release should still be regarded as an alternative, possibly even as a human rights based obligation, to grant a death with dignity (Newcomen, 2005). Accordingly, the need for release processes that facilitate end-of-life prisoner care have been highlighted by investigators (Granse, 2003; Dubler, 1998; Williams et al., 2011).

The wishes of prisoners to be released at the end-of-life are often not respected because they appear at odds with the goals of punishment (Berry III, 2009). However, the release of prisoners towards the end of their lives could offset the high costs incurred when caring for the dying within the ill equipped prison system (Dubler, 1998; Berry III, 2009; Elger et al., 2002). Currently, few seriously ill or ageing prisoners have been considered for early release on compassionate grounds contained within their legislative provisions (Williams et al., 2011; Beck, 1999; Reimeringer and Gautier, 2012). Reasons include the lengthy and complicated administrative process, flaws in the medical criteria (Williams et al., 2011; Chiu, 2010), the influence of negative public opinion and the political climate (O'Meara, 2010; Greifinger, 1999). Despite these challenges the Council of Europe supports the wide application of early release for seriously ill, aged prisoners on compassionate grounds except in cases where the prisoner still represents a substantial risk for society (Council of Europe, 1982).

### **Study purpose**

While prisoners' wishes might often be to die outside prison, their views and expectations in relation to compassionate release provisions available to them in the legislation have not been investigated. It may be that a particular group of prisoners might wish to die in prison if they

consider it their home and fellow inmates and staff as their family (Ginn, 2012), suggesting the need to carefully evaluate a prisoner's expressed wishes on a case by case basis. Central to this debate are the views of the ageing prisoners. To date, no study has investigated the question of compassionate release from the perspective of older prisoners. The goals of this study were threefold: a) to present the opinions of ageing prisoners in Switzerland on compassionate release; b) to frame their arguments for and against the topic using Garland's (1996) two criminologies of the self and the other, notable as it underpins the low uptake of compassionate release provisions, and c) to propose a middle-way solution based on Garland's *welfarist criminology* supported by European human rights.

### **Garland's strategies of crime control**

Garland's (1996) *criminology of the self* and *criminology of the other* makes a distinction between two types of crime control: the preventive strategy and the punitive strategy. He describes the punitive strategy as prevailing, which is supported by penal populism. This may provide some explanation for the recent mass incarcerations occurring particularly in the United Kingdom and the United States (Garland, 2001; Garland, 1996). The influence of rising penal populism has been criticised by other researchers (Lacey, 2008; Tonry, 2007). While Garland acknowledges that the United States is disproportionately affected by such a punitive model (Garland, 2013), there have been descriptions of these trends in European jurisdictions (Downes and Van Swaaningen, 2007; Wacquant, 2001). An example of this could be the restricted use of compassionate release (Reimeringer and Gautier, 2012; Prisons and Probation Ombudsman for England and Wales, 2013; Williams et al., 2011). While Garland explains penal populism as an attempt to reassert sovereign power, Wacquant presents a more comprehensive view (Wacquant, 2009a). For him, the penal state is mostly the result of economic deregulation mandated by neoliberalism with an emphasis on "individual responsibility". At the same time social welfare is reduced and subsequently solidarity is diminished. This creates social insecurity that disproportionately affects the poor and the marginalized, whose infractions are harshly punished as an attempt to restore at least a sense of physical and criminal security. And while the United States was identified as the source of this trend, it was noted that European countries are adopting similar strategies.

According to Garland (1996), the preventive strategy of crime control normalises crime and considers it a part of our society. Thus crime cannot be 'eradicated' by the sovereign state and can only be controlled by promoting preventive action against crime and allaying heightened fear of it. This strategy is accompanied by the *criminology of the self*, where

offenders are 'rational consumers' (Garland, 1996: 461) who are not much different from their victims. Hence, imprisonment is a means by which the offenders are punished and rendered incapacitated to commit further crime. The second crime control mechanism is the punitive strategy which builds on emotions of fear and insecurity. Harsh sentences are used to display the power of the sovereign state. This *criminology of the other* pictures the offender as an alien, a 'different species of threatening, violent individuals for whom we can have no sympathy' (Garland, 1996: 461), and who is profoundly different from 'us'.

In addition to these two strategies, Garland (1996) recommended a middle-way solution described as the 'once-dominant welfarist criminology' that portrayed offenders as 'disadvantaged or poorly socialized' (Garland, 1996: 462). In doing so, they become the responsibility of the state and 'social steps of a remedial kind' (Garland, 1996: 462) are required. In circumstances where end-of-life care is considered, the 'welfarist criminology' strategy promotes compassionate release as a means to support the human dignity of prisoners.

### **Methods**

In order to investigate the views of ageing prisoners on early release for seriously ill and ageing prisoners, we conducted qualitative interviews as part of a larger Swiss-wide study on the topic of ageing in prison. For that, 26 out of 109 prisons were selected in the French- and German-speaking parts of Switzerland because they : (a) were meant for prisoners serving long-term imprisonments, (b) had more than 20 places for inmates, and (c) were housing older prisoners at the time of request. This excluded prisons that dealt with short-term imprisonments, custody prior to deportation, those that had fewer than 20 places, and those that were not housing any older prisoners at the time of request. All 26 prisons were contacted and 12 agreed to participate in the study for qualitative data collection.

From the 12 prisons, 35 interviews with ageing inmates between the ages of 51 - 75 years were conducted (Table 1). Participant recruitment at each prison was aimed at interviewing the oldest inmates in a given institution. For this study, an older prisoner was defined as someone who is 50 years and older (Loeb et al., 2008). A semi-structured interview guide that covered various themes was used. Relevant to this article, participants were asked whether they thought a seriously ill and ageing prisoner should be released from prison and corresponding reasons were inquired.

**Table 1.** Participants' characteristics of ageing prisoners.

<b>Participants</b>	
<b>Mean age in years (Range)</b>	61 (51 - 75)
<b>Gender</b>	85.7% male
<b>Average time incarcerated</b>	6.13 years (4 months - 25 years)
<b>Type of prison regime</b>	18 closed regime 17 open regime

The first interview was conducted in November 2012 and the last interview was completed in October 2013. VH and WB conducted all interviews in either German or French. Excluded from participation were those who did not speak German, French, or English; were deemed physically or mentally incapable of participating, and were judged too dangerous by the prison health service. Participants received study information ahead of time and again on the day of the interview. Informed consent was obtained from the participants and ethics committee approval was first gained from the competent leading ethics committee (EKBB ethics committee of both Basel-Stadt and Basel-Landschaft), followed by nine other cantonal ethics committees, in line with requirements of Swiss law. The prison health services or administration arranged a separate room for the interviews. On average, the interviews were 96 minutes long, audio-recorded, transcribed verbatim, and anonymised by independent assistants. To ensure anonymity, we use a pseudonym for each of our participants.

For analysis, interviews were first read and relevant parts were extracted and copied into one document. Using the qualitative analysis software MAXQDA 11, the document was coded using thematic analysis (Braun & Clarke, 2006). Three members of the research team performed thematic analysis independently: VH, WB, and TW. Afterwards, we checked if similar themes were recorded by each and agreed on main themes and structure. After discussion, the team agreed on three major themes surrounding older prisoners' perspective on compassionate release: a) change in circumstances due to illness and old age, b) shared humanity, and c) clash of beliefs and reality. Results were compared to those of a fourth coder (BE). VH put together the agreed upon themes and sub-themes into one coding scheme that was checked for consistency by WB and TW. Quotes were translated from French and German into English by bilinguals in the two languages and checked for errors.

## **Results**

### *Change in circumstances due to illness and old age*

The majority of prisoners interviewed described how their advancing age and proximity to death changed how they viewed the circumstances of their sentences. They frequently favoured a transfer to a nursing home or the provisions under an early release program for the infirmed prisoner. Only one prisoner, Marc (65 years), stated that neither advanced age or terminal illness was a sufficient enough reason for ending a sentence early: 'Someone who has committed something bad, "deserves" to be here [in prison] all of his life. It's not because he is old or ill that he should be released.' Participants described the changes associated with ageing and illness in a custodial setting that made the early release of this group of prisoners necessary. These included: a) the prison environment being no longer suitable, b) reduced dangerousness, and c) dying in prison is not part of the punishment.

*Unsuitable prison environment.* The difficulties of coping with the prison environment in old age and declining health was emphasized by the participants. Reto (60 years) stated that 'it is quite hard here.' He expressed the view that the older prisoners were left 'to look after themselves' which led him to believe that 'someone with crutches or unable to walk belongs in a retirement or nursing home but not here.' Some participants described that for someone who is seriously ill and old, the prison environment might be too loud. Richard (65 years) stated: 'Imagine he is here and right opposite he has a young [prisoner] who wants to listen to his hip-hop and then he has to endure this music.'

A further issue of importance to the participants was the availability of medical care in prison. Christian (53 years) stressed that 'there is no possibility in prison to care for someone [at the end-of-life],' making the release of such prisoners necessary. Similarly, Richard described: 'Someone who has cancer (...) has to be released from prison. Or that there is, which we do not have here [in this prison], such an [end-of-life] unit.'

*Reduced dangerousness.* A further change associated with old age or serious illness in a custodial setting was that these prisoners are no longer dangerous according to most of the participants. They believed these prisoners were unlikely to pose a risk to society if they were released. Rudolf (60 years) and Erika (58 years) considered this was a sufficient enough reason for early release:

I think that if someone is seriously ill, what is the use of this idiotic life without parole, (...) someone like this certainly [does] not have the desire to commit an offence, such as to rob a bank or something.

Imprisonment as a punishment is put in place to protect society from these people, right? The society consists of these people too. They come from the society and not the other way round. So a person who is sick and is old, how can he harm society? He cannot harm anymore.

Some ageing prisoners believed that dangerousness remained in a few cases. For example, Gerold (61 years) said 'also an old man can suddenly attack with a knife' or Andreas (62 years), who described a relationship between recidivism and dangerousness:

For me the decision would be case specific. One would have to see what offence he had committed, how often he had re-offended, and is he a repeat-offender at all? In case he is not, then the discussion can begin. If he is a repeat-offender, there, I would have certain doubts (...).

*Dying in prison is not part of the punishment.* The final theme of the participants was that death in prison was not part of their sentence, therefore the impending death of a prisoner should prompt their release. Richard explained: 'I think we have already atoned [for our crimes] enough here [in prison] (...), you don't need to die here as well.' On a similar note referring to punishment, Martin (57 years) stated: 'You know, whatever crap someone has done, after a certain amount of time humanity has to accept that he has been punished enough.' For Claude (67 years), not releasing a prisoner at the end-of-life amounted to a death penalty:

These guys who will finish their days in prison with a terminal illness, I find that worse than a death sentence. (...) It is a death penalty, indirectly. (...) He will die in prison so he is sentenced [to death]. He is sentenced twice, it's a double sentence. He is sentenced, and then he is sentenced again by the illness.

Finally, participants suggested that there were alternative forms of sentencing and that those could be further explored instead of releasing prisoners without any form of supervision or control. Gérard (71 years) said: 'You don't have to keep a person in prison. I think there are enough means now to [supervise them] - for example an ankle bracelet - I think that a person has the right to finish her days at home.' This would also mean less spending due to savings in the care of seriously ill and ageing prisoners for the sake of keeping them in prison, as stated by Martin:

For example, if the person is in a poor mental state or is physically weak, so to speak, incapacitated, then, why should the State pay more than 300, 500 bucks per day for him? He can also lie at home in bed, or not?

*Shared humanity*

Referring to the finality of death, some participants expressed the view that seriously ill and ageing prisoners are also fellow humans and on that basis, they should have the chance for an early release. For instance, Bert (70 years) reported: 'We are still humans (...) we just made a mistake.' There was an appeal from the majority of participants to: a) recognise their dignity in death and b) respect their last wishes at the end-of-life.

*Dying with dignity.* The right to die with dignity was described by participants with reference to particular situations where they voiced concern their dignity might be lost. These views were based on the belief that end-of-life care was frequently seen as inadequate in prison. Moreover, the prison environment was considered to be an undignified setting at the end-of-life. Richard explained: 'The Lighthouse [hospice] for example, so that (...) he can die with dignity, because here he cannot die with dignity.' Erika explained how dignity should be safeguarded independent of the fact that the person committed a crime, suggesting that this was something that could be taken away as part of their punishment: 'One should leave people their dignity, even if they have committed a crime. [Arrangements should be made] that they can either die [outside of the prison] or are cared for properly [in prison] and not let them waste away like it is the case today.'

*Last wishes.* A limited number of participants mentioned the significance of celebrating life and fulfilling last wishes. They considered the last months of a person's life as important for realising wishes that were not possible in prison. Felix (67 years) expressed the view:

I agree that when you have done some kind of crap, you need to pay for that. But at one point, let's say, at 60 years and it is clear that you are suffering from heart disease and diabetes (...) that you have cancer or devil knows what and you only have a year left, then outside it is. He should enjoy this last time.

More concretely referring to the idea of last wishes, Gert (58 years) talked about a fellow inmate who had died while in prison: 'His wish had actually been to die in [his home country], where he had lived before. And [I think] such wishes [should be fulfilled].' René (56 years) described this idea in greater detail:

These last moments of life (...), that they can - I don't know - go and see the sea for example, if that is their dream (...). If the doctors say "He only has six months left to live", that he can leave during his last three months and realise a last wish, a last desire: see the mountains, go fish in a river. We are humans, we are not only there to punish. We are also here to celebrate life.

*A clash of beliefs and reality*

*Expectations vs. experiences.* From the accounts of the participants, it was evident that their expectations concerning the early release of seriously ill and ageing prisoners were based on their assumptions about the system they were in. Rudolf and Alain (56 years) believed that they would be released in the case that they each approached death. Alain stating: 'I still think they allow prisoners to die outside. Well...I think, I cannot really say for sure.' And Rudolf:

I know a person here who has cancer and he actually copes really well with it. And once I asked him, where he would like to die? He said that there is no question because two or three days before you notice that your life is coming to an end, they [prison administration] release you. Then the whole sentence is over. Even if, he then goes on to live for two, three, four or five more years, they release him to his family to die. I find that a nice gesture.

Very different from the expectations of early release, the actual experience described by participants stands in a stark contrast. Bert (70 years) criticised such a case he observed:

If it is evident, that this is the end, that it is an incurable cancer. That would be the moment to say, [from the part of] prison administration, it is a terminal case, we could see if we can place him somewhere outside [where he can die]. And not that they [wait until the last moment at which they] have to organise an emergency transport to the hospital where the prisoner dies the next day. That is simply, that [shows] little respect.

*Law and public oppose early release.* Some participants gave reasons, which explained the contrasting experiences between beliefs and reality. Klaus (59 years) claimed that Swiss legislation opposes his release and that there is even an intention to let prisoners die in prison: 'In my state, I do not belong here [in prison] but Swiss legislation is such that you have to die here. I know already three who have died here.' Others were aware of the role of public opinion for decisions on early release for seriously ill and ageing prisoners. René (56 years) cautioned against populism in law and its influence over justice stating that even if 'people from the street may not agree with legal decisions, [but] this is none of their business', fearing that allowing a greater involvement of the public in such decisions would mean that society will become a 'total jungle.'

### **Discussion**

From the 35 interviews, three main themes related to the early release of seriously ill and ageing prisoners emerged: a) change in circumstances due to illness and old age, b) shared humanity, and c) a clash of beliefs and reality. The majority of participants interviewed

supported compassionate release but gave various reasons. Framing them into Garland's (1996) criminology of the self and criminology of the other, we found that participants' reasoning for compassionate release on account of changed circumstances due to illness adheres to the criminology of the self (Reasoning 1). And participants' appealing to shared humanity responds to the criminology of the other (Reasoning 2). The difference between beliefs and reality demonstrated that the punitive strategy (i.e., criminology of the other) is closer to the actual use of compassionate release provisions. This finding corroborates what is known, that is, in most countries such decisions are rarely positive (Williams et al., 2011; Beck, 1999; Reimeringer and Gautier, 2012; Prisons and Probation Ombudsman for England and Wales, 2013). Reasons for the limited number of successful compassionate release requests include the lengthy and cumbersome administrative processes, narrow interpretations of law, and flawed medical criteria restricting its applicability (Williams et al., 2011; Beck, 1999; Reimeringer and Gautier, 2012). Additionally, the prevailing view of punitive strategies and the inadequate adoption of human rights guidelines for the legal and administrative processes associated with early release on compassionate grounds may be further reasons why this type of release is rarely sought or granted. Given these difficulties, Garland's welfarist criminology strategy, that promotes a human rights approach and with a strong hold in the European context, may represent the best approach by promoting a middle ground for compassionate release.

#### The criminology of the self (Reasoning 1)

The criminology of the self portrays offenders as being like one of us (Garland, 1996) and in turn promotes the discussion of compassionate release based on more factual, rather than emotional, arguments. This is because what is true about people in society stands for those in prison. We recognise them as our own and that the crime committed does not change this basic similarity. To illustrate, a seriously ill and ageing person outside of the prison is deemed to be less dangerous or less capable of committing a crime than a younger person. Consequently, the same logic should apply to prisoners who are seriously ill and old. This reasoning was precisely what our older prisoner participants claimed should facilitate an early release. They stated that dangerousness is significantly reduced in the case of ageing and seriously ill prisoners and that imprisonment, with the goal of containment, was no longer valid as these individuals were not in a position to harm others. This has been further evidenced by the decline in recidivism that has been found with increasing age (Fazel et al., 2006). One of the goals of the preventive strategy is to apply punishments in a 'just, efficient

and cost-effective way' (Garland, 1996: 459). Participants who supported alternative sentencing with electronic monitoring as a means of reducing the high costs associated with caring for seriously ill and ageing prisoners were in line with this strategy. The criminology of the self, with its underlying preventive strategy of crime control, appeared to support compassionate release provisions.

#### The criminology of the other (Reasoning 2)

Those participants who expressed themes of a shared humanity and a prisoners' inherent dignity despite the crime committed, epitomised how the prisoners believed they are viewed as a 'different species' or as Granse put it: 'something of a non-entity' (2003: 361). The criminology of the other differentiates between a person who has committed a crime and one who has not, denoting the former as an 'other'. With this other, the latter does not share any humanity and hence the other's dignity is no longer recognised. Our participants attempted to argue against this logic.

Translating this into end-of-life care, Granse (2003) described how only the recognition of a dying prisoner's shared humanity and vigilance that the prisoner is not treated punitively in a disproportionate way allows for compassionate care. The feeling of the other shows that respect for their humanity and dignity is somehow lost with their incarceration, creating a rift between them and 'us'. This rift was what participants hoped to bridge at the end of their lives at the very least through the fulfilment of their last wishes.

Granting and fulfilling the last wishes of ageing and seriously ill prisoners has two symbolic meanings, recognising that prisoners are fellow humans and acknowledging that the prospect of imminent death changes the importance of continuing the sentence. Yet the experiences of our participants showed the attitudes of the public towards early release were largely negative in their view. This explanation is similar to what Garland (1996) states in the punitive strategy, that harsh sentences entailing a lack of sympathy are largely supported by the public. The caution that one participant raised against such influences of 'populism in justice' has been echoed by O'Meara (2010). Thus, the criminology of the other and its punitive strategy are less supportive of compassionate release.

#### Finding a middle-ground: the welfarist criminology and human rights

When the criminology of the self and the criminology of the other strategies attempt to address the issue of compassionate release there is a 'clash of beliefs and reality,' the third theme to emerge from the study findings. In the experiences of older prisoner participants, the

criminology of the other was adopted when they were convinced that it was highly unlikely for a prisoner to receive an early release even if that prisoner was seriously ill and old. On the contrary, positive expectations were expressed by a few participants in relation to their own particular circumstances when they reported they were hopeful about the possibility of being released due to their ill health and old age. To them, the preventive strategy of crime control is possible since compassionate release mechanisms are in place. This is in accordance with Garland's framework (1996) describing how outcomes of the punitive strategy contradict preventive strategies of crime control, in this case, compassionate release.

To avoid the adverse impact of the punitive strategy and respond to the shortcomings of the preventive strategy, a solution is to adopt a middle-ground criminology: the welfarist criminology (Garland, 1996). Garland states that prevailing criminological views depend on 'our social and cultural configuration' (1996; 462) which is difficult to change. However, there are other support mechanisms that impact strategies of crime control such as the human rights approach. This is particularly true in the European context where human rights are strongly upheld by the European Court of Human Rights.

Participants adopted the welfarist criminology when they acknowledged that the dangerousness of the offender has to be considered and evaluated for his or her release. This reflects the middle way where the offender is viewed neither as someone who can only be locked away nor as someone who is a mere opportunist. This is in line with human rights guidelines which considers the seriousness of the offence, the time served in prison, as well as whether the offender still poses a risk to society (Council of Europe, 1982). This risk must be carefully managed however utilising evidence-based techniques (Newcomen, 2005).

Furthermore, these guidelines underscore the importance of a death with dignity, referring to end-of-life care outside prison (Council of Europe, 1998; European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Revised 2015). The prisoner participants supported this view when referring to their inherent human dignity. Conversely, participants described dying in prison as an additional hardship in the sense that it can be considered incommensurate punishment, even amounting to a form of capital punishment. Similarly, Dubler (1998) stated that dying and suffering are not part of a prisoners' punishment. Likewise, Adams (1994) argued that age is a determining factor in sentencing where a sentence can easily become a life-sentence for ageing prisoners. Participants described the incompatibility between the prison environment and the health status of seriously ill and ageing prisoners and felt that it led to an additional punishment,

especially when appropriate care is lacking. Indeed, human rights recommendations for ageing prisoners clarify that the prison administration must make necessary changes to maintain older prisoners' physical and mental health (Council of Europe, 2003). If these adaptations cannot be made, releasing the prisoner to an outside care institution should be considered so that no violations occur in relation to Article 3 on inhumane and degrading treatment of the European Convention of Human Rights as described in cases such as Papon vs. France or Farbthus vs. Latvia.

Attempts should be made to use compassionate release provisions more efficiently and successfully. This would necessitate changes in its application and design. In cases where an offender retains a level of dangerousness incompatible with his or her release, alternatives like electronic monitoring as mentioned by participants can be considered. While practical considerations such as cost-effectiveness are the main focus for the criminology of the self, adopting the welfarist criminology strategy will allow for the balancing of the rights of the offender to die with dignity with societal welfare. Accordingly, this position is more closely aligned with the goals of a 'human rights' approach. As Garland (2013) noted, it remains of paramount importance that human rights guidelines concerning compassionate release are incorporated into domestic laws and supported by administrative force to have a true impact on the penal reality against punitive tendencies.

### *Limitations*

The current findings based on qualitative interviews of 35 older prisoners in Switzerland are not generalizable to other cohorts of older or ill prisoners. Older prisoners from other countries may feel very differently about this topic. The Swiss context, which displays more comprehensive social safety nets than other nations, might have also influenced the participants' views. This is because limited social welfare creates social insecurity that cumulates in more punitive tendencies which disadvantage the poor (Wacquant, 2001; Wacquant, 2009b; Wacquant, 2009a). Therefore, Switzerland which has a long tradition as a social welfare state, similar to other European countries, might have more possibilities to care for released prisoners within its social system and likewise be able to support families that accommodate them as opposed to other countries such as the United States. In countries with lesser social safety nets, additional measures might have to be taken to ensure that compassionate release really serves its goal. A further limitation was that social desirability could have played a role in the answers participants gave to depict a more socially desirable

portrayal of themselves to the researchers. Irrespective of the limitations inherent to the methodology used, this study provides a valuable insight into the subjective opinions of ageing prisoners.

### **Conclusion**

The study aimed to investigate the attitudes of older prisoners towards early release of seriously ill and ageing prisoners. It was found that the majority of older prisoners interviewed expressed the view that early release should be possible due to illness, old age and human dignity. However the older prisoner's expectations were different to what they had experienced, revealing that in reality the punitive strategy dominates. The welfarist approach supported by European human rights framework is a possible middle-way solution between the two conflicting goals of ensuring human dignity and societal safety.

Although compassionate release is for the most part a purely legal process, it also has a medical component (Beck, 1999; Williams et al., 2011). Based on recommendations from the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (2002, Revised 2015), it is the duty of the health care professional to request compassionate release where applicable. The punitive strategy can be at odds with goals such as the need to provide equivalent care as stipulated by national and international guidelines (Lines, 2006; Council of Europe, 1998). To date though, the punitive strategy and limited application of human rights recommendations has had a negative impact on the delivery of necessary care, exemplified by the lack of access to end-of-life care both in and outside of prison (Maschi et al., 2014). This lack of access to clinical care is in violation of codes of ethics, ethical professional guidelines and human rights resolutions (Bretschneider et al., 2012; Swiss Academy of Medical Sciences - SAMS, 2012; Council of Europe, 1998).

It is important for professional groups to adhere to ethical guidelines, especially the medical personnel, so as to remain aware of the role played by punitive strategies when decisions relating to compassionate release are considered. A lack of awareness could mean that these decision-makers are equally affected by the emotions of fear and insecurity that this strategy incites. Constant vigilance that prisoners are not treated punitively would be necessary to avoid violations of their ethical codes. Further education of prison health personnel and prison administrations on human rights regulations for prisoners is necessary. This can prevent future reports of seriously ill and ageing prisoners dying under precarious conditions where they have supposedly lacked access to adequate pain management (Maschi et al., 2014). Taken together, these findings demonstrate the increasing need to provide adequate

solutions to the ethical dilemmas posed by end-of-life care in prisons where compassionate release provisions require improving upon, despite the dominance of the punitive strategy.

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***New Guidance for an Old Problem: Early Release for Seriously Ill and Elderly Prisoners in Europe***

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***Abstract***

Early release of seriously ill and elderly prisoners is possible in several countries but only few prisoners gain such exemption. We identified hurdles to the implementation of early release laws in Europe, by analyzing legal requirements for such release and qualitative interviews with 40 stakeholders. Provisions are based on the health status of prisoners and the ability to care for them in prison. Interviews revealed three barriers: practical hurdles, penological goals and multiple interests. Finally, early release is obstructed because three justifications are often confounded: compassion, the principle of equivalence and practical reasons, such as costs and overcrowding.

Legal regulations for the early release of seriously ill and elderly inmates<sup>16</sup> exist in a number of countries. Such provisions, often termed compassionate release, are based on a humanitarian concern for the dying (Beck, 1999) and high financial cost associated with end-of-life care (Maschi et al., 2013). Interests such as upholding penological claims, often work against the release of seriously ill and elderly prisoners on compassionate grounds (Reimeringer and Gautier, 2012; Williams et al., 2011).

Early release for these prisoners is generally based on medical criteria such as a terminal illness, debilitating conditions or the impossibility of providing adequate care in prison. Programs differ according to national and state level jurisdictions. In some jurisdictions, such release is not limited to medical reasons and may occur in light of a prisoner's old age, coupled with time spent in prison, severity of the crime committed (Reimeringer and Gautier, 2012) or "other extraordinary and compelling reasons" (Berry III, 2009: 850). Hinging on these criteria, different terminologies are used including medical parole or geriatric release to indicate early release of these prisoners, but refer to slightly different practices. In this article, we will use early release to encompass all these different programs: compassionate release, medical parole, and geriatric release.

The low number of prisoners receiving release based on such provisions indicates that seriously ill and elderly prisoners continue to die in prisons. This raises concerns because end-of-life care in prison is yet to be established in most countries and difficult to implement by nature of the environment (Wright and Bronstein, 2007). In the United States (US), where there is a longer tradition of providing end-of-life care in prison, such care is not widely available (Williams et al., 2011). As such, prisoners neither receive adequate end-of-life care inside prison nor can they access these medical services in the community due to lack of functioning release provisions in place. However, prisoners should receive end-of-life care equivalent to the standard available in the community (Council of Europe, 1998; Lines, 2006), even if the full application of international human rights law is sometimes limited by other factors (Easton, 2013). For example, the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) notes that detainees "who are the subject of a short-term fatal prognosis, who are suffering from a serious disease which cannot be properly treated in prison conditions, who are severely handicapped or of

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<sup>16</sup> In this paper we choose to consistently refer to two categories of prisoners eligible for early release: those who are seriously ill and those who are old. However, we do not exclude the possibility that someone can fit both the categories.

advanced age” require humanitarian assistance because the “continued detention of such persons in a prison environment can create an intolerable situation” (CPT, 1992: section III, e.iv). Given the rising numbers of elderly prisoners, a trend, sometimes termed the “aging crisis” (Maschi et al., 2013: 543; Williams et al., 2012: 1150) the topic of care for dying and fragile elderly detainees needs to be urgently addressed.

In Europe, the number of elderly prisoners is also on the rise. For example, in England and Wales, prisoners aged 60 and older are the fastest growing age group in prison, between 2002 and 2011 it rose by 103% (Prison Reform Trust, 2013). Based on numbers provided by SPACE I Annual Penal Statistics, between 2007 and 2012, the number of prisoners aged 50 years and over has increased from 7,713 to 8,600 in France and during the same period, in Germany, the number has risen from 7,078 to 7,378 (Aebi and Delgrande, 2009, 2014). In Spain, the proportion of prisoners of 60 years and older has risen from 443 in 2000 to 1,740 in 2012 (Instituto Nacional de Estadística, 2014). The increasing older prisoner population also means that natural deaths in prison are likely to become more frequent (Glamser and Cabana, 2003).

Available studies on the release of seriously ill and elderly prisoners are mainly from the US. The Human Rights Watch (2012) reported that of the 444 requests made for compassionate release by prisoners in the US (representing pre-approved requests by wardens and regional directors between 2000 and 2011), only 266 were approved. Considering the 6,629 deaths occurring in prison due to illness during a similar time period (2000-2012) (US Department of Justice - Bureau of Justice Statistics, 2014), this small number of prisoners receiving release begs the question: What are the hurdles that make these releases practically difficult?

Obstacles that hinder early release at the end-of-life are: (a) a lengthy and cumbersome process, (b) restrictive and unsound medical criteria and (c) narrow interpretations of legislations (Beck, 1999; Reimeringer and Gautier, 2012; Williams et al., 2011). The application process for release varies and can impact the time it takes to receive the permission for release. Possibilities for undergoing this process include a request that can be made by the prisoner on his own behalf or by the treating physician, which can delay the process (e.g. if the prisoner is too sick or has difficulty filling out legal forms) or that those who are seriously ill should be considered automatically for early release, which would save time and ensure more widespread use (Beck, 1999). Finally, in cases where release is granted, the prison must address another critical issue, namely, where to transfer the prisoner (Adams Jr, 1994; Groupe de travail Santé Justice, 2013).

In addition to the practical barriers, there are problems with the justifications for this practice, which go against the goals of imprisonment. Policies for the release of seriously ill and elderly prisoners were developed upon the premise that changes in health status of prisoners can impact the four justifications for imprisonment (Williams et al., 2011): retribution, deterrence, incapacitation, and rehabilitation (Berry III, 2009). Illness and old age can influence these justifications. For example, prisoners suffering from dementia may no longer be aware that they are being punished for a crime, thus, undermining retribution. Berry (2009) argues that the purposes of punishment even in light of changes due to debilitating mental and physical health are not sufficient justification for early release. Rather, other interests of the state have to outweigh “the penological benefit sacrificed by the corresponding sentence reduction” (Berry III, 2009: 882). Such state interests are often financial ones (Berry III, 2009). The costs for keeping seriously ill and elderly prisoners incarcerated are high (Williams et al., 2011) and it is estimated that 10% of the total direct prison costs of care in the US are associated with serious/terminal illness and disabilities (Maschi et al., 2013). Finally, other interests could also be humanitarian considerations, such as compassion or dying with dignity. In spite of the often used terminology of “compassionate release”, such considerations are seldom explicitly mentioned.

Despite the aging prisoner population across Europe, so far, no studies have assessed the different criteria for the release of seriously ill and elderly prisoners across countries or barriers to the implementation of related laws and regulations. Therefore, the goal of this paper is to first identify and analyze relevant legislations in five different European countries. Second, we present findings from qualitative interviews with 40 stakeholders across three European countries who described different hurdles to the implementation of early release laws and processes. Finally, we propose a solution for meaningful and functional legal provisions for the release of seriously ill and elderly inmates.

## **Methods**

### *Legal Analysis of Compassionate Release Provisions in Europe*

For legal analysis we first chose five western European countries with the highest prison population according to the World Prison Population List (Walmsley, 2013). These five countries included: England and Wales<sup>17</sup>, Spain, France, and Germany. We additionally decided to include Switzerland in our analysis since the research team is conducting a larger

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<sup>17</sup> England and Wales follow one legal system and are therefore counted as one country in this paper.

study on aging prisoners. We searched for legal provisions relevant to the release of seriously ill and elderly prisoners for each country, such as compassionate release or medical parole. The analysis consisted of classifying the type of law or regulation and identifying the criteria necessary to obtain release. Where available, we listed the proportion of prisoners having received early release in those countries.

### *Stakeholder Interviews*

As part of a larger study investigating the health care for elderly prisoners, interviews were conducted with stakeholders to seek opinions about the legal, prison and health care systems that affect older prisoners. They were recruited via purposive and convenience sampling from three Western European countries. Ethics committee approval was sought and obtained from all three countries.

Semi-structured interviews were carried out with 40 experts who were categorized into 3 groups as presented in Table 1. Four researchers conducted the interviews in French, German or English. The interview-guide contained one relevant question about what minimal criteria are considered for early release of a prisoner at the end-of-life as well as a vignette on this topic. Interviews were on average 70 minutes long and were either conducted face-to-face, via Skype or telephone. The recorded interviews were transcribed verbatim, anonymized and checked by independent assistants. All stakeholders had several years of experience working in the field. On average, they were 49.5 years old (32 – 69 years), and 13 of them were female. For more details see reference (blinded for review). In the results stakeholders are coded by a number, country id and their category.

**Table 1:** Stakeholder categories by countries

<b>Country id</b>	<b>HCP<sup>a</sup></b>	<b>NGO/IO/Omb<sup>b</sup></b>	<b>PA<sup>c</sup></b>	<b>Total</b>
<b>Country 1 (C1)</b>	7	4	13	<b>24</b>
<b>Country 2 (C2)</b>	5	2	1	<b>7</b>
<b>Country 3 (C3)</b>	6	0	2	<b>9</b>
<b>Total</b>	<b>18</b>	<b>6</b>	<b>16</b>	<b>40</b>

<sup>a</sup>HCP: Physicians, health care professionals and researchers

<sup>b</sup>NGO/IO/Omb: Work for international organization, NGO, or NGO-like institution

<sup>c</sup>PA: Prison administration (directors, personnel responsible for probation or social reintegration) and policy makers

*Analysis.* Interviews were coded using the qualitative analysis software MAXQDA 11. The interviews were first read followed by extraction of relevant passages of the interviews into one document. This document was then coded thematically (Braun and Clarke, 2006). This thematic analysis was performed by three members of the research team, VH, TW, and WB, independently to check if similar themes were recorded by each. Agreement on themes and structure was reached through discussion among these three coders. Results were compared to those of an independent coder (BE). VH drafted the final coding scheme and WB as well as TW checked it for consistency. Quotes were translated from French and German into English by bilinguals in the two languages and checked for errors.

## **Results**

### *Legal Analysis in Europe*

We found that the criteria for early release of seriously ill and elderly prisoners vary across the countries included in the analysis: England and Wales, Spain, France, Germany, and Switzerland (see Table 2 for details). Most notable is that only England and Wales mention compassion explicitly in their Prison Service Orders. They are the only ones with a provision permitting release rather than an interruption of the sentence. Spain and France have a provision with a predefined age as a criterion. All countries rely on health reasons mostly compounded by availability of care in prison. Numbers concerning the different provisions, i.e. how many prisoners had applied and which proportion had been granted release were often not available. This means in none of the countries it is clearly and regularly documented.

### *Experts' Perspective on Hurdles to the Release of Seriously Ill and Elderly Prisoners*

Stakeholders commented on the process of release based on their involvement in those requests and/or general experience as well as their knowledge on the topic. From their responses we identified three barriers to the provision of early release.

*Practical and organizational hurdles.* The practical and organizational hurdles evident from the interviews revolved around four issues: a) process of release for seriously ill and elderly prisoners being lengthy and complicated, b) difficulty of providing a definitive prognosis, c) finding an institution when release is granted, and (d) improvement of care available in prison.

Lengthy and complicated process. The overall process of release for seriously ill prisoners was described as arduous. Participant (27 C2, NGO/IO/Omb) stated: "It's really unlikely [that

compassionate release is granted]. (...) It takes quite a long time to make the decision. And often somebody applies for compassionate release but may have died before the decision is made.”

Additionally, a few participants pointed out that the procedure had become very complicated over the years because many people were involved in the decision making process (such as prison administrators, medical doctors, lawyers, governors) and pressure from the public had increased.

Well, people [in the community] want to have these people [prisoners] locked up. This is regrettable, really, because previously there were more possibilities, but today, there isn't (...). There are so many people who want to have a say that it has become difficult. And probably it will not become easier. (4 C1, HCP)

Difficulty of providing a definitive prognosis. While medical eligibility criteria require the presence of a terminal illness, this is often not sufficient, as a prognosis as to when the death of the patient is likely to occur needs to be provided. Indeed, some stakeholders pointed to this problem that physicians face in giving a definitive prognosis:

And the other thing is sometimes (...) doctors say, although we know this person is going to die, we can't be specific about when they're going to die. (...) So doctors sometimes say we can't give a diagnosis that clear. So it's very difficult, it's a very difficult situation. (27 C2, NGO/IO/Omb)

The challenging condition of prisoners who do not have a terminal disease but a debilitating illness was also discussed. Considering an example of an older prisoner with dementia, a participant relayed his disagreement on how these decisions are made:

[I would find it good] if somehow the authority could be side-stepped a bit and [we can] simply say, okay, this man or this woman has dementia or is old and sick and simply not accountable for what happened 30 years ago. But I think it needs a change in ideology in these expert commissions (...). I mean for this woman [with dementia] they re-evaluated her prison sentence [indeterminate sentence] (...) and said: 'This has to be kept that way.' Well, from a medical point of view, it's utter nonsense. (6 C1, PA)

Problem of finding an institution after release. Stakeholders pointed out that even if compassionate release is granted, it may not happen, if there is no institution willing to accommodate the prisoner: “I think the issue that is the most difficult to resolve is: Where would these people go? It's the question of who would be willing to accommodate them

outside. If that is not taken care of, these people remain in prison.” (37 C3, HCP). One participant (6 C1, PA) described the case of an ill inmate who was released early to his country of origin and the “logistical problems” such as “organizing who can pick him where and where does he even go, is there a pharmacy close by” because they needed “to get all these things sorted out.”. Moreover, institutions in the community are often reluctant to accept to accommodate prisoners “because they have no obligation to do so” (18 C1, PA).

Improvement of care available in prison. Stakeholders agreed that prisoners should receive the same level of care as the general population. When care can be provided, release of seriously ill and elderly prisoners is no longer necessary and vice-versa. Highlighting this situation a participant reported: “Everything that is necessary [in terms of health care] has to be guaranteed. If the structure of the prison cannot guarantee this, you have to interrupt the execution of the sentence.” (17 C1, HCP). However, another participant stated the consequence: “[Today], we can treat and provide care for almost any illness within the system and this is why there are no releases anymore” (12 C1, BA).

*Penological goals trump.* The justifications for imprisonment (deterrence, retribution, incapacitation, and rehabilitation) were used to argue against the practice of releasing seriously ill and elderly prisoners. Arguments in its support included claims that justifications must change considering the current condition of the prisoner (old age and illness) and humanitarian concepts such as dignity of the dying individual.

Retribution. For most participants, retribution was not a factor to oppose releasing prisoners at the end of life. Some even questioned the goal of punishment: “You release them [seriously ill and elderly prisoners] outside. But you cannot have somebody who is 65 years old, who is completely unable to walk, and tell me, you are punishing him, he’s already being punished.” (9 C1, NGO/IO/Omb).

Few underscored that the crime committed should be an underlying factor for early release decisions. The seriousness of the crime determined these decisions:

I think, it [release of seriously ill and elderly] depends very much on the type of offence [someone has committed]. One, who has murdered ten children, well he will die in prison or in a prison hospital. I don’t know anybody [like him] who would be released easily. (5 C1, PA)

The sentence as just desert for the crime committed is relevant in some legislations where there is the possibility to recall a prisoner to continue their sentence, in cases where they have gained temporary release. That is, if the prisoner's condition improves, he/she could be recalled: "So when the person gets better, they are re-incarcerated into prison and they continue their sentence." (35 C3, HCP)

Incapacitation. Public safety was an overriding concern in the early release of seriously ill and elderly prisoners. The potential risk of prisoners re-offending when released was presented as substantial, making incapacitation and therefore continued detention necessary to protect society: "I have to say it like this; even in a case like this [terminal illness] you probably cannot release a dangerous offender, because everyone can handle a gun, even shortly before dying." (10 C1, PA). However, some stakeholders also pointed out that due to criteria such as dangerousness and crime those offenders most in need of legal provisions are not eligible. This situation was exemplified by participant (29 C2, NGO/IO/Omb) as such:

In reality the situation is that these individuals [sex offenders or other serious crimes] can hardly demonstrate that they are no risk and... [...] that they could be released. The risk of public confidence [in the justice system] being damaged if people who have relatively recently been sentenced [because of a historic offence] if it's a late and life sentence or [if they] have very long sentences, releasing them is a difficult judgment.

Humanity and dignity were used as supporting arguments to argue for the release of seriously ill and elderly prisoners. Stakeholder (28 C2, HCP) stated:

What you see is that some prison administrators (...) really push to have their terminally ill offenders released. Because, you know, it's to do with dignity and, you know, all of those kind of issues associated with coming to the end of your life whatever you've done, you know, you're no longer a risk to society.

Another participant (38 C3, PA) pointed out that dignity and humanity were the basis of the legal provisions in his/her country, but this focus became diluted with the addition of practical and medical criteria:

So [release for seriously ill and elderly prisoners] is actually underused because when it is accorded it is really so that the person dies 15 days later or when they are already hospitalized. So they just do it in a way that the person is no longer in custody and these deaths are not counted in the prison statistic anymore (...). At the outset we had a humanitarian law but the intention of these laws (...) is not respected and moreover

they have narrowed it. (...) So they have redefined that law, these humanitarian criteria and have added criteria like non-adherence to rules and regulations and serious risk of re-offending.

*Conflicting and multiple interests.* Another important hurdle for the provision of release for seriously ill and elderly prisoners was difficulties in the decision making process and that the decisions were made considering different interest groups. First, release decisions were made by an entity consisting of different professions with varying interests and opinions. This meant that the process was often complex. Some stakeholders described it as shifting the responsibility for the decision between the parties involved due to fear of a possible wrong decision and accountability of its negative outcomes.

That is the crazy thing. Medicine and law try to pass the buck. (...) It is not a medical problem in that sense, but in the end it will probably be a legal problem. And the term 'incompatibility with detention' is not defined. Also here, it would be important to have clarity - a definition, a standard – would be essential. (8 C1, PA)

Highlighting accountability as a possible reason for this complicated process, another participant (20 C1, NGO/IO/Omb) described the possible consequence of such decisions:

Because they [prisoners] are people who still have criminal capacity and if the judge says, well this is an 85 year old elderly gentleman. And once he is outside, [if] he starts to sexually abuse children again, then the judge will have to suffer the consequences, especially the public will be very dissatisfied. So it is a very delicate subject.

Second, as evident in the quote above, the interests of different groups such as the public opinion are highly valued. Participants discussed interest groups in favor of and against the release of seriously ill and elderly prisoners such as the prison administration, the victim, the state, the public, and prisoners themselves. Participants reported that prison administration pushed for release because the death of an inmate in custody is not desired: "End-of-life equals outside. So there, the prison administration helps us, because they absolutely don't want any deaths in their statistics. Deaths in prison don't look nice." (32 C3, HCP). A few times, participants mentioned what releasing someone means to the victim. For example, one admitted: "You see I'm kind of, I'm in two minds about this because you do have to think about the victims of the crime that [the prisoner] committed as well." (31 C2, HCP)

An interest group with the power to make decisions for and against early release for seriously ill and elderly prisoners was the authorities and the state. Participant (18 C1, PA) reported

clearly that ill health is no reason for the state to give up its penalty claim if care can be provided in prison:

That was the big discussion between the clinic director and us [the authority] and I said: 'I don't see why, if medical care can be provided [inside prison], why should we renounce to the state's claim for punishment.' This is an ethical dispute between physicians and penal authorities. And there I said, 'No, I cannot, I have no legal basis to release him early'.

In line with this comment, another participant highlighted that for some prisoners, the authorities insist that these prisoners are not released until they die: "Once we had a patient where the authorities firmly said that he would not get out until he dies." (6 C1, PA) Society, as a whole, has a strong influence on these decisions. However, participant (29 C2, NGO/IO/Omb) actually stated that society needs to make a conscious choice about death in prison:

I also think that it's something that society needs to confront as we have more and more old people [in prisons]. Whether society wishes prisons to become as they increasingly have to be, places of death, where people will die in custody and then manage something, I think, society has not actually debated but I think there is little evidence available that compassionate release is granted with any or regarded with any great sympathy certainly by politicians but also by the public as a whole.

Finally, stakeholders argued that sometimes prisoners themselves refuse to be released on two grounds: quality of end-of-life care is perceived to be better in prison and the lack of relations outside prison to accompany them at the end-of-life.

One final footnote is that longer sentence prisoners, institutionalized prisoners, prisoners who have no family, perhaps because of their offence and because of their past, may often ask to die in prison. So, it is not easy, it's not an easy equation (...). But there are a lot of other issues, moral, political, practical and humane where the individual says: well, I have nobody on the outside, please let me die inside. (29 C2, NGO/IO/Omb)

### **Discussion**

In the interviews, we underlined the following obstacles for the release of seriously ill and elderly prisoners: practical and organizational hurdles, weighing penological versus humanitarian goals, and balancing of interests and responsibilities. These three concerns

share a common feature, namely, an inherent tension stemming from conflicting justifications for early release of seriously ill and elderly prisoners. A similar tension is evident in the legal provisions. Based on our results, we will first describe this tension in order to underscore its centrality in obstructing the early release process. Second, we will propose a solution to resolve this conflict by developing a guideline for drafting and/or analyzing release provisions for seriously ill and elderly prisoners.

*Obstructions in the Early Release Process: Tensions between Justifications*

Often, there is a confusion surrounding release on humanitarian grounds such as compassion and the principle of equivalence of care (Lines, 2006) both in the interviews and in the legal regulations. If compassion is the central element of a legal provision for early release of a seriously ill or elderly prisoner, it then should not be based on practical criteria like the availability of end-of-life care in prison. Provision of care should not depend on compassion. It is a duty in accordance with the principle of equivalence of care, which is the guiding principle in the health care for prisoners in Europe (Lines, 2006). Non-adherence to this principle and by extension non-functioning legal regulations for release without providing appropriate end-of-life care in prison can present serious human rights violations (CPT, 1992).

If the terminology compassionate release is taken in its literal sense, “compassion” emphasizes the need to acknowledge the suffering of a dying prisoner as “deprived of freedom” rather than “deprived of appropriate end-of-life care”. This was expressed by stakeholders who felt that the repressive, and often violent (Liebling and Arnold, 2012), prison environment does not provide the conditions for a death with dignity in spite of availability of end-of-life care and that dying in freedom is important. This is also often voiced by prisoners (Linder and Meyers, 2007) and in literature (Russell, 1993; WHO, 2007). A problem arises when confounding compassion with the principle of equivalence. A legal regulation for release based on compassion is permanently applicable and independent from the provision of health care. However, release provisions built on the principle of equivalence are mandatory if end-of-life care is not provided in prison and place the availability and accessibility of health care at the center. Thus, they are only applicable as long as end-of-life care is not available in prison. This trend was mentioned by participants stating, much as Beck (1999) that with improvements made in end-of-life care for prisoners, it is less likely that release for seriously ill and elderly prisoners is requested. Most legal regulations (see Table 2) are based on the criterion that release is granted for the prisoner to seek care not

available in prison rather than explicitly stating any goals related to compassion. Only England and Wales have provisions, based on compassion but combine them with criteria relating to the principle of equivalence. New legal regulations should make a distinction between humanitarian and health care criteria for early release. Such a regulation should also mirror its terminology, i.e., only those provisions based on true compassionate grounds should be called compassionate release.

The lack of clarity concerning these different justifications is reflected in the legal regulations but this impedes on the application. In the interviews, humanitarian grounds like compassion were overruled by penological goals but intermingled with positive duties like the principle of equivalence. Two penological goals took precedence over early release in the legal requirements as well as in the interviews: retribution and incapacitation. Retribution encompassed three considerations: the exclusion of certain crimes, the minimum time served and the possibility of re-incarceration. These three variables in early release decisions compromise the extensive application of release for seriously ill and elderly prisoners. As pointed out by one stakeholder, the exclusion of certain types of crime might exclude those who are most in need of the provision, because these are crimes that warrant particularly long or even indeterminate sentences. The minimum time served as criterion, in US legislations (Chiu, 2010), illustrates how retribution can trump humanitarian goals. Finally, the possibility of recall (Russell, 1993; Williams et al., 2011) has its basis in retribution, as prisoners should serve the maximum of their sentences. Additionally, it also has its grounding in incapacitation, as prisoners can be re-incarcerated if they reoffend. This element is very prominent in the legal provisions as all but one referred only to an interruption of the sentence. Incapacitation to protect society from further crimes seems to overrule all other considerations in the interviews. However, it must be substantiated with regularly collected and updated statistical evidence on criminal offences perpetrated by elderly and terminally ill prisoners after gaining release. There is a need for a decision on how much risk a society is willing to accept balancing it against humanitarian grounds such as compassion. This should ideally happen before drafting a legal provision. One participant actually pointed out how a humanitarian regulation can become obstructed by retrospectively adding criteria based on penological goals.

Early release decisions for seriously ill and elderly prisoners are dependent on two elements: medical eligibility and authorization by a legal entity (Beck, 1999; Williams et al., 2011). However, more than just medical and legal personnel are involved in the decision making

process, thereby adding to the overall complexity. Prison administration can play a decisive role and the concerns of the victims are sometimes given special weight (O'Meara, 2010). Evident from our results is the political dimension of the decision (Beck, 1999; Russell, 1993) related to concerns of authorities about bad press or to be perceived as being soft on crime (Human Rights Watch, 2012; Ornduff, 1996). One participant illustrated this by describing the consequences of a decision that, retrospectively, turned out to be "wrong". Protecting public interest is central to such decisions (Mancini and Mears, 2010; Payne et al., 2004) and this interest is usually portrayed as very retributivist. Hence, public opinion and politics can be an obstacle for early release decisions (Chiu, 2010). Our participants also assumed that the public would be opposed to such release. The lack of information on this subject given the influence public opinion has, should be further investigated, such as has been attempted by Boothby and Overduin (2007) who found that undergraduate students had negative attitudes towards compassionate release. Roberts (1992) found that the public has misconceptions about crime and the criminal justice system and generally knows little about it while Payne and colleagues (2004) found that the public needs to be made aware of some decisive issues, such as the role of deterrence or their ability to influence the development of policy. As decisions on the release of seriously ill and elderly prisoners continue to be influenced by public opinion, a participant alluded that the public has responsibility. It is important to place the discussion within the context of statistical risks to innocent victims that society accepts in general (e.g. deaths from traffic accidents) and put it in perspective with the consequences of a penal system which tries to guarantee zero risks. Indeed, the consequences of the greater call for public safety with longer and harsher sentences and increasing use of indeterminate or life-sentences (Prison Reform Trust, 2013) are not raised in public discourse.

If this involvement of different interests is not resolved when drafting legal requirements for the release of seriously ill and elderly prisoners, it is likely that the decision-making process will continue to remain obstructed. Therefore, the general acceptability of such a law as well as questions about responsibility and accountability must be resolved at the outset. When drafting a provision - including the definition of medical and legal criteria - for such release, the different professions concerned - lawyers, doctors, social workers and prison directors - need to be involved in its design. For example, clear medical criteria, such as which diseases to include or the problems with prognosis could be clarified by physicians. Otherwise, they will continue to exclude those most in need of it, such as prisoners with indeterminate

security measures or those considered dangerous and remain vague on decisive criteria, such as the diagnosis and prognosis.

*Clarification of Release Provisions for Seriously Ill and Elderly Prisoners*

Based on our findings we propose a guideline to clarify and/or direct the drafting of legal regulations for seriously ill and elderly prisoners. This guideline contains two levels of decision-making. First, at the societal level, the grounds on which early release for seriously ill and elderly prisoners will be based upon must be resolved. Two justifications can be identified in our results: compassion and the principle of equivalence. A third justification is found in literature, namely practical reasons such as costs, which in the US, has been the impetus for many release legislations, together with finding possible solutions to reduce overcrowding (Chiu, 2010; O'Meara, 2010; Ornduff, 1996). Elderly prisoners suffer from more diseases than younger prisoners and use health care services more often (Lindquist and Lindquist, 1999). End-of-life care is known to cause significant costs (Emanuel and Emanuel, 1994). The wish to reduce the strain on prison budgets is therefore a key factor.

It is important to distinguish these three justifications and to be aware of the fact that they will have different implications concerning their introduction and application. A legal regulation based on compassion will overwhelmingly take precedence over penological goals and thus will be least restrictive. It is also the only reason whose application is permanently valid as it is not based on criteria in the process of change. However, the introduction of such a regulation is optional because they are exclusively based on humanitarian grounds and no other obligations towards prisoners. Without a doubt, compassion needs the greatest commitment if translated into law and also requires a broad support from the society. If legal regulations are to be based on the principle of equivalence of care, this means assurance that seriously ill and elderly prisoners will have access to care that is not available in prison, such as social or end-of-life care, like every other person who is not incarcerated. If legal regulations are based solely on the principle of equivalence, early release of seriously ill and elderly prisoners must only be ensured when the necessary care is not available within prisons. Thus, its introduction is mandatory if the principle of equivalence is respected while its application can be transitory, that is, when prisons have the means to provide such care, early release regulation will have no utility. The same is true for legal regulations based on practical issues, such as costs and overcrowding. The difference is that implementations of this kind of legal regulations are not mandatory when other solutions are available to address these issues.

Second, if a decision has been taken to translate one or more of these justifications into law, several different regulations are a possibility, which can address and the practical problems that we identified. Comparing our findings to the literature, mostly from the US, practical problems concerning the release of seriously ill and elderly prisoners seem to be similar. The length and complexity of the process of applying for and gaining early release has been criticized by our study participants, as well as other scholars (Beck, 1999; Chiu, 2010; Williams et al., 2011). Possible solutions have been proposed to change the process like forgoing second opinions of physicians for instance in France, allowing any person to apply for early release for seriously ill and elderly prisoner or simplifying the entire procedure (Chiu, 2010; Reimeringer and Gautier, 2012; Russell, 1993). Difficulties associated with providing a definitive prognosis and the problems of prisoners with slow progressing debilitating diseases mentioned by stakeholders have also been discussed in the literature (Williams et al., 2011). Estimates of the time to live should not enter into the decision-making process since such predictions are extremely difficult to establish (Williams et al., 2011) and physicians might be held accountable if prisoners live longer than predicted. The problem of where to release a prisoner has been stressed by participants. Certainly, if no concrete plans after release are in place, the prisoner remains incarcerated. For elderly long-term prisoners, the difficulty is often that they may no longer have family anymore (Ginn, 2012). This means that institutions such as hospices or nursing homes must be willing to accept them. To materialize such possibilities, stronger relations should be built between prisons and outside institutions. Additionally, lack of obligation on the part of outside institutions to take on prisoners makes placement extremely difficult. One could think of creating financial incentives for these institutions or other inducements such as increased staffing and/or staff training. These issues should also be addressed in the legislation in order for the regulation to be both meaningful and practical.

Finally, for those prisoners who consider prison as a home (Ginn, 2012), for whom prison staff is the closest to a family and who do not wish for an early release, the situation is more complicated, as highlighted by a study participant. Those prisoners might find that to die in a familiar environment as dignified. Finding a solution for these persons will depend on our understanding of compassion and test the flexibility of legal regulations based on that concept.

### *Limitations*

It was not possible to be exhaustive in the legal analysis. We only mapped those legal provisions in a given country which either explicitly mention age or health status as criteria for release or where it was documented that they had been used for such reasons. As a qualitative study, our findings are not generalizable and give an insight into subjective opinions of the participants. This means that stakeholders from other countries could have other point of views. Social desirability could have played a role in the answers as well. Participants were working for different institutions or organizations, which is why their responses could have been biased by their policies rather than reflecting their personal opinions.

### **Conclusion**

We set out to describe the status quo of early release legislations for seriously ill and elderly prisoners in five European countries and to identify the barriers for the use of such provisions by drawing on stakeholder interviews from three European countries. We conclude that legal provisions for the release of seriously ill and elderly prisoners should focus on only one justification at a time, either compassion or the principle of equivalence or practical reasons such as costs and overcrowding. Each justification has a special characteristic which needs to be reflected in the legal regulation. The introduction of a legal provision based on compassion is optional but once instated, it is permanently applicable. In a different vein, those based on the principle of equivalence, although, mandatory in their introduction are only transitory in their application, and those based on practical solutions are both optional in their introduction and transitory in their application. Practical hurdles associated with the early release of seriously ill and elderly prisoners, need to be addressed in drafting such regulations and should involve all relevant stakeholders. Finally, it has to be stressed that legal regulations based on the principle of equivalence can amount to serious human rights violations if they do not function correctly and at the same time end-of-life care is not provided in prison. Using a concept such as compassion concerning seriously ill and elderly prisoners will require a solid understanding of its limits and implications to be fully applicable in law.

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**Table 2:** Legal provisions for early release in five European countries.

Country	Legal regulation(s)	Title	Criteria	Numbers
England and Wales	Prison Service Order 6000	Parole release and recall	Permanent release of determinate sentence prisoners, early release on health grounds and on compassionate grounds	Of 214 deaths (of 647 natural deaths) classified as foreseeable by the prisons and probations ombudsmen, 78 were considered for compassionate release, 13 were granted compassionate release and 26 were still awaiting the decision at the time of death (647 is the number of deaths investigated by the Ombudsmen between 2007 and 2012) (Prisons and Probation Ombudsman for England and Wales, 2013)
	Prison Service Order 6300	Release on temporary license (ROTL)	Release on temporary license only for precisely defined and specific activities, which cannot be provided in establishments (medical out-patient appointments, or in patient requirements)	ROTL was requested in 58 cases (from 214 mentioned above), of which 30 were granted and 8 died while awaiting the decision. (Prisons and Probation Ombudsman for England and Wales, 2013)
Spain	Art. 92 Spanish Criminal Code (SpanCC)	Probation	Probation on age grounds (above the age of 70) and for health reasons (seriously ill with an incurable disease), independent of time served	No data available according to the Spanish Federal Statistical Office

France	Art. 720-1-1 Code of Criminal Procedure	Suspension	Release on temporary license for health reasons (short term fatal illness or state incompatible with continued detention)	In 2012: 296 requests of which 253 were granted. 16 were rejected because the health status was judged compatible with continued detention, for 8 there was no terminal prognosis, in 5 cases the two medical expertises did not coincide, 2 were judged too dangerous and 1 had no place to go to. (Groupe de travail Santé Justice, 2013)
	Art. 729 Code of Criminal Procedure	Parole	Parole on age grounds (above the age of 70). Independent of time served but has to have a place to go to. Probation to seek medical care outside	In 2012: 464 persons aged 70 years and over. 177 have been released on probation (Groupe de travail Santé Justice, 2013). No data on number of persons seeking medical care outside
Germany	Section 455, para. 4 German Code of Criminal Procedure	Postponement of Execution of a Prison Sentence	Release on temporary license for health reasons to seek care not available in prison	No data available according to the German Federal Statistical Office
Switzerland	Art. 92 Swiss Criminal Code (SCC)	Interruption of execution	Interruption of the sentence for good cause. (Such as to seek care not available in prison)	Between 1995-2004 2.0- 3.4% of prisoners per year were granted intermission of sentence (Baechtold, 2009) No other data available according to the Swiss Federal Statistical Office
	Art. 80 para. 1, letter a SCC	Other forms of sentence execution	Possibility of transfer to another institution for health reasons	No data available according to the Swiss Federal Statistical Office

Baechtold A. (2009) Strafvollzug: Straf-und Massnahmenvollzug an Erwachsenen in der Schweiz, Bern: Stämpfli.

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## Discussion

This thesis presents an overview of the obligations arising in the care for aging prisoners, specifically end-of-life care. It does so by identifying their vulnerabilities, which paves the way to design tailored interventions and policies based on aging prisoners' needs. Based on Luna's layer-model of vulnerability (2009), I will distinguish between vulnerabilities arising from their status of prisoner and those attributable to their old age. Luna's model (2009) will further serve to identify vulnerabilities that influence the health of aging prisoners. Hurst's definition of vulnerability (2008) will be used for evaluating whether aging prisoners' health care claims are fulfilled using the principle of equivalence as a standard. Possible solutions for the health care of aging prisoners will be outlined in order to satisfy duties arising from these vulnerabilities. The vulnerabilities identified in the first part will then be discussed in relation to the end-of-life period and implications for the care of dying prisoners will be highlighted.

### Vulnerability of aging prisoners

Prison, like other highly organized hierarchical structures leaves little room for differences (Crawley and Sparks, 2005). Yet, every individual prisoner has several characteristics or layers that render them particularly vulnerable if they are not taken into account in his or her detention. Luna's definition of vulnerability (2009) is useful to characterize such layers and delineate them from others. The prisoner status as well as being old are such layers of vulnerability (Handtke et al., 2015a). Old age requires special consideration much as we consider young age to be necessitating such (Muncie, 2008). These two layers of vulnerability will be investigated separately and only be brought together to highlight possible interactions between the two. Generally, the layers have a specific order: the age-layer builds on the prisoner-layer, meaning that every vulnerability identified for prisoners will also be a vulnerability of aging prisoners while not all vulnerabilities of older prisoners are shared by prisoners in general.

Vulnerabilities will be those features that represent a risk of harm to the health of prisoners (Luna, 2009) and those related to the fulfilment of their health care claims based on Hurst's definition (2008). The latter definition makes it possible to see if older prisoners are at increased risk of being wronged in their claim to health care (Hurst, 2008). This claim to health care is the principle of equivalence (European Committee for the Prevention of Torture

and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Rev. 2015; United Nations, 1982). According to its requirements for health care in general, such as confidentiality, self-determination, and access to care, have to be fulfilled for prisoners as well and at the same level as any person would receive in the community. Thus, the two definitions of Luna and Hurst complement each other in compiling vulnerabilities of aging prisoners.

### **Vulnerabilities of being a prisoner**

Prisoners are often considered vulnerable as a group (Moser et al., 2004; Schüklenk, 2000). This vulnerability originates from the punishment inflicted on them which is the deprivation of freedom. This deprivation is achieved through imprisonment where offenders can also be contained to protect society, making security a prevailing issue in prisons. This function is represented in the regime and architecture of prisons, which together with its social functioning creates psychological pressures on the inmates. The negative influence these structural determinants have on the health of prisoners have prompted some researchers to speak of “unhealthy prisons” (De Viggiani, 2007). From the Agequake-project some features that can impact the health of prisoners negatively were identified (Handtke et al., 2015a; Handtke et al., 2016): their ability to consent might be compromised by the loss of autonomy and put them at risk of coercion, social isolation renders prisoners vulnerable as it impacts their mental health negatively, and the possible loss of dignity in combination with the former two features leads to psychological suffering of prisoners. Additionally, the delivery of health care is impeded by the prison environment so that community standards, according to the principle of equivalence, are not achieved.

### **Negative influences on prisoners' health**

*Loss of autonomy and risk of coercion.* Control of inmates in prison as a means to safeguard security is achieved by establishing strict rules and regulations whose infractions are punished and by creating an environment where choices are severely limited. This goes at the expense of a prisoners' autonomy (Handtke et al., 2015a). For health care, the threat of punishment can make prisoners susceptible to coercion hindering them to act in their own best interest. Loss of autonomy raises questions about their ability to give valid informed consent. Both points have been raised in research ethics (Moser et al., 2004; Schüklenk, 2000) but are adaptable to health care in general. This institutional control of prisoners' behaviors through adherence to clearly defined rules and doling out punishment when

breaches occur, are part of their institutionalization (Haney, 2003). The limitation in choice, such as food, clothing, and the time schedule is often difficult for prisoners to adjust to, as a consequence “muting self-initiative and independence” (Haney, 2003: 7). Both the loss of control over day-to-day decisions and the external constraints set by rules whose violations are punished lead to an adaptation in prisoners that makes them increasingly dependent on such external control mechanisms (Haney, 2003), thus compromising their ability to make independent choices.

*Social isolation.* The upkeep of the social network was experienced as problematic by prisoner-participants (Handtke et al., 2015a; Handtke and Wangmo, 2014). Attendance of family events, even funerals, is rarely possible (Handtke and Wangmo, 2014; Krabill and Aday, 2007). Social contact to outside relations has been described as a determinant of health, a lack of it leading to adverse health outcomes (De Viggiani, 2006), which one prisoner-participant referred to (Handtke et al., 2015a). The estrangement from family outside is often accompanied by social isolation within prison. Prison relationships are governed by interpersonal distrust and suspicion (Harner et al., 2011), related to fear of violence (Haney, 2003) and resulting in prisoners distancing themselves from others.

*Psychological suffering.* Participants of the Agequake-study experienced the deprivations and external control as burdensome (Handtke et al., 2015a; Handtke and Wangmo, 2014). In the worst case, the prisoner-layer overshadows all other aspects of the person, so that prisoners are no longer viewed as persons but only as criminals. This is in line with what Garland (1996) described as the “criminology of the other”, when emotions of fear lead to dehumanized perceptions of offenders. This is the greatest vulnerability that can arise out of this layer: the annihilation of all other dimensions of a person including human dignity. As a consequence all our obligations deriving from the respect of human dignity of prisoners are endangered. In combination with loss of autonomy and social isolation the emphasis on being treated like a criminal first and person second, leads to psychological suffering and negatively impacts mental health of prisoners (De Viggiani, 2007; Smith, 2000).

### ***Vulnerability of prisoners in health care***

In light of Hurst’s model of vulnerability (2008), two healthcare challenges facing prisoners will be discussed: concerns that arise from violations of the principle of equivalence in the doctor-patient relationship and prisoners’ access to health care.

### Vulnerability in the doctor-patient relationship

*Dual-loyalty.* In prison, health care personnel occupy different roles than in the community making it more challenging to adhere to the principle of equivalence (European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Rev. 2015). Physicians especially, can be involved in legal processes, lending their medical expertise to the prison administration and other judicial or state bodies. For example, they can be requested to do psychiatric assessments, obtain blood or urine samples to test for substance use, or to lend their expertise to the application of punishment (Pont et al., 2012). This can create vulnerabilities if prisoners are not first and foremost seen as patients or if physicians are not transparent about the different roles they occupy and what they entail, so-called dual-loyalty.

Dual-loyalty is a conflict of interest that arises for a health care professional between their medical duties towards a patient and other obligations, be them explicit or implicit, towards third parties, such as the State, the prison administration, or society as a whole (Konrad, 2010; Pont et al., 2012). There is a need for a clear separation between tasks that are in the interest of the prisoner-patient and those that are not (United Nations, 1982). The latter should not be performed by professionals responsible for the health care of prisoners (Pont et al., 2012). Dual loyalty is often encountered when making legal assessment of prisoner's health or dangerousness. In cases where information is transferred to third parties without the patient's consent, confidentiality in the doctor-patient relationship, which is seen as paramount and considered an ethical requirement in care (Hurst, 2008), is violated. In some instances however, confidentiality can be breached, such as in situations where there is imminent risk of harm to identified third persons (Felthous, 2006). Our Confidentiality-study found that confidentiality was violated in instances not mandated by law and that prisoners were often not informed of it (Elger et al., 2015a; Elger et al., 2015b; Wangmo et al., 2014a). Reasons for such breaches were related to dual-loyalty due to precedence of interests of third parties over those of prisoners, the dual role of mental health professionals, and when prisoners were treated as offenders and not as patients. This way confidentiality cannot be safeguarded which is detrimental to the trust in the doctor-patient relationship in prison (European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Rev. 2015). This makes prisoners vulnerable as they are at increased risk of having their confidential information disclosed and thus their privacy

violated to safeguard institutional and societal safety while not being able to seek health care elsewhere (Pont et al., 2012).

*Paternalism.* Due to the deprivation of liberty and the environment, other duties arise for the State, such as the duty of protection. The duty of protection is enshrined in the Swiss Criminal Code (art. 75 para. 2 SCC) and recognizes the vulnerable status arising with imprisonment. It is the duty to protect prisoners in their vulnerability against harm, such as described by the European Court of Human Rights in *Edward vs. United Kingdom* (Reports 2002-II):

In the context of prisoners, the Court has had previous occasion to emphasize that persons in custody are in a vulnerable position and that the authorities are under a duty to protect them. It is incumbent on the State to account for any injuries suffered in custody

In health care, there is a heightened risk that this protection shifts to paternalism, if medical professionals do not seek the informed consent of their competent patients but act in what they consider to be their best interest (Elger and Harding, 2004). This shift to paternalism in mental health professionals was identified in the Confidentiality-study (Elger et al., 2015b; Wangmo et al., 2014a). Even if prisoners make decisions that are potentially harmful for them, such as not disclosing abuse, this has to be respected by mental health professionals (Wangmo et al., 2014a).

#### Vulnerability due to limited access to care

Access to health care for prisoners as mandated by the principle of equivalence is often restricted (Exworthy et al., 2012). This creates severe vulnerabilities when their health is negatively affected by it. Access to care is a much researched area in health care and health policy and described as consisting of several components: availability, accessibility, accommodation, affordability, and acceptability (Pechansky and Thomas, 1981). These can be used to identify barriers to care (Thorpe et al., 2011). Several concerns about access to care were raised by participants of the Agequake-study (Handtke et al., 2015a). For example, they felt restricted in their self-care and self-medication (Handtke et al., 2015a), leading to a sense of disempowerment (Douglas et al., 2009). Self-care is defined as first-level health care, consisting of self-evaluation of illness, self-decisions regarding reactions to it and self-medication (Dean, 1981). Another type of care that was limited, was access to specialized care as it usually requires prisoners to be transported outside (Handtke et al., 2015a). This is

difficult because of budgetary and organizational constraints (Brunicardi, 1998). Generally, participants were dissatisfied with the health care services they were offered in prison as compared to what they had been able to receive outside (Handtke et al., 2015a).

### **Vulnerabilities due to old age**

The age-layer contains vulnerabilities associated with advancing age. These vulnerabilities arise out of declining health. As an older person in prison, vulnerabilities due to their status of prisoner are reinforced as a result of this age dimension, as layers can be interrelated and interactive (Luna, 2009; Luna and Vanderpoel, 2013). Such vulnerabilities that are emphasized by old age are the social support which further deteriorates and health care limitations are exacerbated because of aging prisoners' increased and complex health care needs. Concerns specific to older prisoners are the poor prison environment, which worsens their health and places them at increased risk of harm; as well as the greater uncertainty about the future in light of their prison sentence.

### **Vulnerabilities reinforced by old age**

#### **Exacerbation of social isolation**

Social isolation identified for prisoners in general is exacerbated with old age due to their exclusion by younger prisoners (Handtke et al., 2015a). Free-time activities are rarely designed for older inmates so that they often cannot take part in them (Crawley and Sparks, 2005). Similarly, Hayes (2013) found that aging prisoners have problems in socializing with younger prisoners. At the same time, they are situated far away from family and friends outside, who are themselves older, making it more difficult for these family members to travel long distances. This is because prisons are often situated in remote regions, are difficult to access, and visitation hours are very restrictive. Therefore, older and long-term prisoners are more likely to lose touch with the outside (Crawley and Sparks, 2005; Ginn, 2012). This can present a vulnerability, as social contact with family and friends is in itself a factor positively influencing health, for example Condon and colleagues (2008) found that prisoners find it easier to maintain good mental health if they have regular contact with them. For aging prisoners, the care aspect of social relationships also becomes more important: for example one participant of the Agequake-study described how he was not able to care for his dying father (Handtke and Wangmo, 2014). This shows that roles that we occupy with an advanced age, such as caring for our aging and frail parents, are no longer possible with imprisonment, placing a burden on the prisoner and the parent (Handtke et al., 2015a). Similarly, aging

prisoners can also not receive care by family members, depriving them of this possibility for social care, whose access is already severely limited in prison (Williams, 2013).

### Aging prisoners' greater limitations in health care

A trusting doctor-patient relationship and access to care are undoubtedly important aspects in the care for all prisoners, as described in the first part. However, for aging prisoners both issues become more relevant and can therefore be greater sources of vulnerability. This is related to their health status. The health of aging prisoners is worse than younger prisoners' and worse than that of the general population (Fazel et al., 2001b). As a result of a high number of chronic diseases they have increased health care needs (Aday, 2003; Wangmo et al., 2014b). This makes aging prisoners the most frequent users of prison health services (Lindquist and Lindquist, 1999; Williams et al., 2012). As a consequence, breaches of confidentiality become more likely as well as the consequent loss of trust in prison health care providers. This is especially true for mental health services, that were investigated in the Confidentiality-study as aging prisoners suffer from increased psychiatric morbidity (Fazel et al., 2001a), therefore relying more heavily on these services. The high somatic and psychiatric morbidity means that the health care needs of older prisoners are also more complex rendering access to different types of care more important. The impossibility of self-care, identified for prisoners, can have particularly negative consequences for older prisoners, for example those suffering from incontinence, as aging prisoners frequently do (Williams and Abraldes, 2007), and who feel it is too stigmatizing to disclose this information to health care staff (Drennan et al., 2010). Other barriers such as the access to specialists mentioned by elderly female prisoners in the Agequake-study (Handtke et al., 2015a) limits access to geriatric care and management of chronic conditions.

Finally, some types of care are specific to an advanced age, such as preventive medicine. Preventive medicine specifically for older people aims at the preservation of function and quality of life by reducing premature morbidity and mortality (Goldberg and Chavin, 1997). Normally, screenings and preventive examinations should be offered "to the individuals at highest risk of important problems such as cardiovascular diseases, malignancies, infectious and endocrine diseases, and other important threats to function in older people" (Goldberg and Chavin, 1997). This is why preventive medicine is of increased importance for the health care of aging prisoners who are a high risk group. However, access to preventive measures, such as a mammography was experienced as difficult by elderly female prisoners (Handtke et al., 2015a). This is in part contextual as Switzerland does not routinely offer and therefore

cover all types preventive examinations or screenings (Egger et al., 2013). In terms of equivalence of standards, it does not necessarily involve a violation of the principle if such preventive measures are not routinely offered to the general public. However, two issues should be considered: first, accessibility to these services should be guaranteed, much as in the community. Second, affordability as part of access to care (Pechansky and Thomas, 1981) has to be discussed as older prisoners might not have the resources to pay for the examinations and screenings because of their incarcerated status and resulting lack of income (Handtke et al., 2015a). Reasonings based on equivalent access could therefore include financial support by the State for such instances to abide by the principle of equivalence in terms of outcomes.

### ***Vulnerabilities specific to old age***

*Worsened health status in an unsuitable environment.* Age-associated declining functional abilities are worsened by the prison environment if no adaptations are made to it that address the physical capabilities of aging prisoners. Environment in this context is referred to broadly as including structural and organizational determinants of prisons. Prisoners in Switzerland are under the obligation to work independent of age as per the Swiss Federal Court ruling in 2013 (BGE 139 I 180), yet workplaces are seldom adapted to old age (Handtke et al., 2015a). Another example from the Agequake-study refers to the stringent prison rules elderly female prisoners talked about (Handtke et al., 2015a). One woman prisoner fulfilled the prison duty of cleaning her cell even under severe pain. This shows that someone who is already physically unhealthy still has to follow the same rules as anyone else for fear of reprimands, possibly worsening his or her health condition. No adaptations to the rules are made based on a prisoners' health status. This is why exceptions from these rules were viewed as special by participants (Handtke et al., 2015a) and not as natural adaptations to distinct needs. Other issues that are routinely described are problems navigating the prison environment, climbing stairs and adhering to the prison schedule (Crawley and Sparks, 2005; Handtke et al., 2012). If no adaptations to the prison environment are made, such as creating a specific unit or installing hand-rails and appropriate furniture (Handtke et al., 2012), older prisoners continue to be exposed to additional harm, or what Crawley and Sparks (2005) call "hidden injuries" due to "institutional thoughtlessness".

It is a possibility to release aging prisoners to an institution apt to care for their needs, so-called geriatric release, that is however rarely used (Chiu, 2010). Low use of such release is troubling because some legislations (e.g. France) have procedure whereby a prisoner can be

released if his or her health status is incompatible with continued detention (Handtke et al., accepted). That is, imprisonment that does not consider the poor health of the prisoners constitutes inhuman or degrading treatment (see *Papon vs. France* or *Farbtuhs vs. Latvia*). Engaging younger prisoners to help older ones with their daily activities, can be a risk for aging prisoners, when young prisoners are not trained and exploit the unequal power-relationship (Handtke et al., 2012). This is why for prison hospice programs, for example, younger volunteers are carefully selected and trained (Linder and Meyers, 2007; Stone et al., 2012).

*Uncertainty and lack of perspective for indeterminate sentences.* Protecting society is intrinsically linked to prolonging sentences based on assessments of dangerousness (Janus, 2004). This leads to vulnerabilities because of the uncertainty about the future in case of indeterminate sentences. As prisoners with such sentences represent the largest portion of aging prisoners in Switzerland (Schneeberger Georgescu, 2009), it is part of the age-layer in this context. In cases of indeterminate sentences, the sentence is re-evaluated regularly, but often results in continued incarceration. The absence of a release date and therefore uncertainty about the future is problematic. The impossibility of planning one's future is difficult for prisoners, thereby impacting their overall well-being (MacLeod and Conway, 2005). In our Agequake-study, planning exclusively referred to the time after release, for example positive steps like gaining closure by mending family ties (Handtke and Wangmo, 2014). Lack of planning and orientation towards the future could negatively impact the health of aging prisoners when it hinders them to make meaningful health choices, like adopting healthy behaviors supported by prison health promotion programs.

### **Obligations in the health care of aging prisoners**

From Hurst's definition of vulnerability in health care (2008) flows the obligation that the wrong older prisoners incur by being denied equivalent care must be remedied. Thus, a duty exists to increase the effort of providing such care to them even when faced with difficulties. The only limitation to these efforts are the claims of others (Daniels, 1994). This means that ultimately claims of older prisoners have to be balanced against those of other groups of society, for example in terms of costs and other limited resources. Based on the vulnerabilities identified in this part, three obligations for the health care for aging prisoners arise: avoiding dual-loyalty and paternalism in the doctor-patient-relationship; adapting the environment to the health needs of older prisoners; and finally, facilitating access to all types of care also available to older adults in the community.

***Strengthen medical ethics in the doctor-patient relationship***

Solutions that are proposed to resolve issues of dual-loyalty are to make the health services in prisons independent from the prison administration and the justice system, which so far has only been achieved in three Swiss cantons: Geneva, Vaud, and Valais (Council of Europe, 1998; European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Rev. 2015; Pont et al., 2012). It has also been suggested that health care personnel should work both in prison and the community at the same time in order to make the adherence to the principle of equivalence, including avoiding paternalism easier and more seamless (Pont et al., 2012). This represents a better integration of prison health care into public health care, which can be reinforced by a stronger cooperation and integration with community services. Many human rights guidelines support counteracting dual-loyalty and paternalism (Council of Europe, 1998; European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Rev. 2015). Medical Associations are called upon to take a greater interest in prison health care and are in a position to sanction human rights violations of their members (Pont et al., 2012). Training about human rights guidelines, especially ethical obligations of health care personnel has to be offered to the latter but also to prison administrations and criminal justice experts (Elger et al., 2015a; Elger et al., 2015b). Finally, involvement of independent bodies for inspection can provide an additional mechanism ensuring adherence to guidelines (Pont et al., 2012).

***Adapt the prison environment to the health needs of aging prisoners***

Aging prisoners in Switzerland are mostly a result of growing numbers of offenders sentenced to indeterminate sentences (Schneeberger Georgescu, 2009). In turn, these life- and long-term sentences are a consequence of the abolition of the death penalty in Europe (Newcomen, 2005). Points that were mourned by participants of the Agequake-study, mostly representing long-term prisoners, such as work, free-time activities and medical services should be better adapted to aging prisoners. There are recommendations supporting such measures (Council of Europe, 2003; United Nations, 2006). Specifically, there are guidelines advocating the adaptation of the accommodation so that aging prisoners with functional and cognitive impairments do not carry an undue burden (United Nations, 2006). Structural changes have to be accompanied by organizational changes, meaning adjustments of prison rules. Such organizational changes could include aspects experienced by our interviewees, such as the “breakdown of family ties” that should actually be prevented through flexible

visitation schemes and closeness to family (Council of Europe, 2003). This can fall in the realm of medical personnel (European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment - CPT, 2002, Rev. 2015). Models of visitation schemes and adaptations responding to the needs of older, long-term prisoners and their (aging) relations have been developed and can be used as models for implementation (Maschi and Aday, 2014). There also exists the possibility of transfer to an appropriate institution or of release. Thus, guidelines exist, but are not fully translated into practice. Nevertheless, awareness about such human rights guidelines has to be raised and cost-effective alternatives looked for.

### ***Improving access to care – equivalence of care***

Solutions to the rarely achieved equivalent access to care for older prisoners are to develop specific guidelines for them. For instance, the WHO has included a chapter detailing the specific needs of aging prisoners in their guidebook on prison and health (WHO, 2014). That way, health needs such as chronic diseases and functional and cognitive decline can be addressed, for example based on geriatric models of care in the community (Williams et al., 2012) by adapting them to the prison environment. This would help aging prisoners as prison administration and health services might not be aware of all these types of care and models of implementation. Additionally, it is not always clear if access should be guaranteed in prison, or whether outside services should be made more easily available to prisoners. The former would require all or most services to be available in-house at the same standard as outside and the latter demands facilitating transport to outside institutions or building stronger cooperations with outside services to come inside prison. This would entail making prisons more “permeable”, as they would have to simplify access to outside personnel coming to prison. Which model is chosen ultimately depends on the organization of the prison health system. Modern techniques have also been investigated, such as telemedicine which has shown some advantages and success, such as lower costs while maintaining the same level of care (Brunicardi, 1998).

### **End-of-life care for prisoners: vulnerabilities and obligations**

Vulnerabilities identified in the first part are equally relevant to the end-of-life period of seriously ill and aging prisoners. By discussing these vulnerabilities in the end-of-life context, two issues arise: the importance of access to end-of-life care including assisted dying and complications for a death with dignity in prison.

### Access to end-of-life care

The vulnerability identified in the first part that is most prominent in literature on end-of-life in prison is the lack of access to end-of-life care for seriously ill and aging prisoners (Maschi et al., 2014; Stone et al., 2012). The most common type of end-of-life care is palliative care. This interdisciplinary medical practice refers to the provision of pain and symptom management for patients suffering from life-threatening illnesses, as well as assistance to family (WHO, 2015). Symptom management includes addressing psychological and spiritual needs of patients. Hospice care is another type of end-of-life care sometimes not clearly delineated from palliative care (Hui et al., 2013). However, hospice care is reserved for the dying while palliative care is available to all seriously ill individuals independent of prognosis (WHO, 2014). One integral part of end-of-life care is advance care planning, which has been shown to improve care as well as patient and family satisfaction (Detering et al., 2010). For prisoners, access to such care in or outside prison is still rare. This is described by prisoner-participants in our Agequake-study (Handtke and Wangmo, 2014; Handtke et al., accepted). Interviews with stakeholders in three European countries revealed that access to care outside by using early release mechanisms is equally difficult (Handtke et al., accepted). Lack of end-of-life care means that terminally ill prisoners die under severe pain, far away from family and under undignified conditions (Granse, 2003; Maschi et al., 2014). The restricted contact with social relations outside denies prisoners at the end-of-life the possibility for closure (Handtke and Wangmo, 2014). However, inside prison, social support for dying inmates can be fostered, when they receive care from co-inmates. For example, end-of-life studies from the United States routinely report the success of hospice volunteer-programs, where younger prisoners care for a dying co-inmate (Evans et al., 2002; Loeb et al., 2013). Finally, access to all aspects of end-of-life care should be granted if equivalence of care is the standard for prisoners. The neglect to provide end-of-life care renders prisoners at the end-of-life particularly vulnerable.

Another question is the access to assisted dying for prisoners, which was raised by our study participants (Handtke and Wangmo, 2014) based on the principle of equivalence of care. In Switzerland, assisted dying is only possible through physician assisted suicide, not euthanasia and the question is more difficult to resolve than in other countries, as assisted dying is not considered a medical treatment by Swiss law or practice, as opposed to Belgium or the Netherlands (Onwuteaka-Philipsen et al., 2003). Physicians are not the main actors in providing assistance to dying in Switzerland but rather right-to-die organizations fulfil a

central role (Hurst and Mauron, 2003). This means that the principle of equivalence is not directly applicable as assisted dying is not part of health care. So, it does not necessarily present a vulnerability according to Hurst's definition (2008). However, other principles such as the principle of normality in prison (Art. 74 SCC), stating that prisoners' rights should only be limited to the extent required for their incarceration, could grant them access to these services (Handtke and Bretschneider, 2015b). The question of assisted dying also raises questions about autonomy. Based on the respect for autonomy, prisoners should be allowed to make their own end-of-life decisions including assisted dying and the duty of protection, identified as possible risk for paternalism, should not overrule their informed wishes (Handtke and Bretschneider, 2015b). Indeed, in Belgium, euthanasia requests from competent prisoners suffering from a fatal illness have been granted (Snacken et al., in press). Additionally, the expression of prisoners' self-determination through the use of advance directives has been supported (Andorno et al., 2015). However, the issue of possible coercion discussed in the prisoner-layer requires great attention concerning the evaluation of the voluntariness and informed choice of prisoner-patients.

Concerning assisted dying, another issue is whether "prison tedium" (Handtke and Wangmo, 2014: 379) qualifies as unbearable suffering that would allow for assisted dying or rather necessitates other State-action to remedy circumstances that lead to this kind of suffering. Some participants of the Agequake-study with indeterminate sentences who had already spent a considerable amount of time incarcerated mentioned "prison tedium" as a reason for wishing to seek assisted suicide (Handtke and Wangmo, 2014). By this they referred to difficult prison conditions that can make the prospect of being incarcerated for the rest on one's life unbearable (Handtke and Bretschneider, 2015b). Thus, psychological suffering identified in the prisoner-layer is particularly relevant for prisoners with indeterminate or long-term sentences and raises questions about assisted dying for reasons other than terminal illness and ultimately about the consequences of prolonged imprisonment.

### **Dying with dignity**

A death with dignity or rather a "death without indignities" (Allmark, 2002) is denied to terminally ill and aging prisoners if autonomy is not fostered and barriers fail to be removed. Fostering autonomy in seriously ill and aging prisoners encompasses reducing fear of death, preparing for it, and including them in treatment decisions (Handtke and Wangmo, 2014). Barriers for a death without indignities are when deaths of inmates due to natural causes are not handled differently than other types of deaths in prison (Handtke and Wangmo, 2014),

such as suicide and if dignity is lost because the prisoner-layer has overshadowed all other aspects of a person (Handtke et al., 2016). The latter view was expressed by our prisoner-participants who appealed to our shared humanity for compassionate release decisions (Handtke et al., 2016). When dignity is lost, humanitarian measures such as compassionate release or access to end-of-life care become obstructed. The former, meaning the need to treat natural death as a life event that needs to be acknowledged results out of the demographic shift in the prison population towards old age which brings with it a shift in the causes of death. This is characterized by rising numbers of deaths due to natural causes, for example, cancer and heart disease were the leading causes of death in state prisons in the United States in 2011 (Noonan and Ginder, 2013). Until now, the most common cause for death in prison was suicide (Wobeser et al., 2002). Suicides in prison are a direct reflection of the prison conditions, such as deprivation and overcrowding (Huey and McNulty, 2005) and expose the failure of prisons to prevent them (Daniel, 2006). Deaths due to natural causes, be it old age or illness, should not be treated in the same way as suicides by the prison administration and staff, namely as neglect entailing negative consequences if discovered, but rather as a natural event occurring in every life course. Prisoners remarked how callously deaths in prison were treated and both, prisoners and stakeholders, explained that they are a taboo (Handtke and Wangmo, 2014; Handtke et al., accepted). Not openly addressing the possibility of dying of natural causes, creates vulnerabilities for older prisoners as only few participants in our study reported having made arrangements for their death and some refused even thinking about the possibility of dying in prison obstructing advance care planning and preparation (Handtke and Wangmo, 2014). Additionally, bereavement did not take place and deaths of co-inmates were not properly acknowledged, leading to negative experiences of death in prison which possibly increases aging prisoners' fear of it.

### **Obligations in providing end-of-life care for prisoners**

End-of-life care faces the same problem as other types of specialized care in terms of access for prisoners. In the United States the model of providing hospice-care within prison is dominating, while in the United Kingdom the practice of compassionate release or transfers to hospitals or hospices is preferred (Stone et al., 2012). This includes so-called "community-based working in prison" services (WHO, 2014). The outcome of the latter has not yet been investigated (Stone et al., 2012). Allowing prisoners' access to end-of-life care outside, includes compassionate release provisions. This is similarly described in human rights guidelines (European Committee for the Prevention of Torture and Inhuman or Degrading

Treatment or Punishment - CPT, 2002, Rev. 2015). These guidelines usually emphasize the role of the physician in determining when appropriate measures have to be taken to determine at what point the health status of the prisoner is no longer compatible with detention. For that, it is necessary that physicians examining this are knowledgeable about the prison environment and available health care resources to make an informed judgment. However, the compassionate release process always involves a second legal step that approves the relocation or release of the terminally ill prisoner (Williams et al., 2011). It is often at the intersection of these two steps that problems arise. First, if medical criteria as to what constitutes a health status incompatible with detention are defined by legal professionals without consulting physicians, this can lead to poorly chosen medical criteria that hinge on conditions that are not aligned with medical practice, such as a definite prognosis or the ability to walk (Greifinger, 1999; Williams et al., 2011). Second, because this process consists of two distinct steps, it is vital that roles and responsibilities of the two professions are clearly defined (Handtke et al., accepted) and that cooperation between them is ensured. This is important because it facilitates finding solutions, especially for difficult cases. For example, if a physician defines the status of a given prisoner as incompatible with continued detention, he or she transmits this information to the authorities, fulfilling his or her role. This role has to be clear for physicians as well as the human rights obligations it is based upon (Handtke et al., 2016). In the second step, legal authorities have to comment on the risk that the prisoner poses to society. The risk has to be investigated by another physician to avoid dual-loyalty conflicts. In the simplest case, the prisoner can be released because he or she is too ill to be detained further and does not present any danger to society. In more difficult cases, a prisoner can no longer be kept in prison due to his or her health status, but still presents a danger to society, so that middle-way solutions have to be found. Such a solution could be the transfer to a different institution with a secure unit allowing for a higher security level, or his or her movements can be monitored using an electronic bracelet (Handtke et al., 2016). Another solution is a secure hospital unit able and willing to provide the appropriate level of care in case there is no such care available in prison. In any case, the response has to be proportional to the threat posed by the prisoner. Such balancing between human rights and public interests is often employed to resolve conflicts of interests (Tsakyrakis, 2009). Finding such middle-way solutions requires coordinated communication between the two professions. What has to be recognized is that finding a viable solution that ensures appropriate care for these fatally ill or older prisoners is not optional, but warranted by the principle of equivalence (Handtke et al., accepted). Solutions based on the principle of equivalence must

be differentiated from decisions based on more than health care, namely those based on compassion, meaning a sympathetic emotion towards the plight of dying prisoners or practical reasons, such as costs and overcrowding (Handtke et al., accepted).

Another possibility of granting access to end-of-life care is to provide it in prison, which is the dominant model in the United States. Problems with this strategy are first, the general tension between providing care in an environment designed for punishment and incapacitation (Granse, 2003), focused on the person as prisoner rather than as patient. Often the adequate provision of pain medication is an issue as prisoners are considered to be abusers of analgesics such as morphine (Stone et al., 2012). Second, providing such care in prison is complex due to high security requirements, which limits the number of prisons it is available in. However, the existing programs have been shown to be cost-effective (WHO, 2014). Making end-of-life care available in every single institution is highly unlikely, especially in a country like Switzerland with low numbers of prisoners and small institutions that often struggle to even fully provide primary care. Of course, there is the possibility to make centralized facilities, where all prisoners at the end-of-life in a given country could be transported. This can be difficult for prisoners to maintain contact with family and allow for visitation of family members. In Switzerland, there is the additional barrier of several language regions that needs to be considered. Models in the United Kingdom and United States however, often strongly collaborate with community services. If such community services are available country-wide, a possibility could be to have end-of-life care delivered through such services to prisoners. In Switzerland, there are for example general practitioners delivering end-of-life care to their patients (Otte et al., 2015). Such models could function if these community services have easy access to their patients in prison and if prisoners can be provided with the necessary equipment in prison or conversely, if community services are able to offer secure units within their institutions. This model is facilitated in countries where prison health care is part of public health care, such as the United Kingdom, where providing palliative care in prison is part of the national strategy (Department of Health, 2008). This preserves the independence of these services and assures the same level of care as in the community. To date, such solutions have not been investigated, which could be a point of future research.

## Implications for future research and practice

From the results of this research several points could be identified that need to be investigated in future research and translated into practice:

- A more inclusive definition of vulnerability that adequately addresses the vulnerable situations of older prisoners and like minority groups.
- The identification of other defining aspects of care necessary for the fulfilment of equivalence of care for aging prisoners.
- Concerning the doctor-patient-relationship, programs could be designed for physicians working in prison and then validated by research to improve confidentiality and respect for autonomy of prisoner-patients.
- In terms of environmental changes, interdisciplinary research has to investigate appropriate and cost-effective solutions for prisons to adapt to aging prisoners' needs or seek alternatives.
- Programs for older prisoners and their relations to renew or stay in contact have to be devised.
- Measure outcomes of different prison health systems (models of providing care in prison vs letting community carers inside) to find the golden standard based on evidence.
- Solutions to access end-of-life care need to be investigated and their efficiency as well as efficacy must be explored to develop viable models that are widely applicable.
- Early release mechanisms need to be better monitored to measure obstructions or improvement of the legal processes. Specifically refusals of early release requests should be documented and analyzed.

## Conclusion

In this thesis, I set out to identify vulnerabilities of aging prisoners in order to delineate what obligations exist to improve their health care, including end-of-life care. For that, two definitions of vulnerability were used: Luna's layer-model and Hurst's claim-based model. The first served to separate vulnerabilities arising from a persons' status of prisoner from those associated with old age. Additionally, the layer-model allowed the identification of

vulnerabilities of aging prisoners that have a negative impact on health. The second definition made it possible to isolate vulnerabilities that arise because of older prisoners' claim to equivalent health care remains unfulfilled. From the combination of the vulnerabilities compiled by using the two definitions, obligations for the care of aging prisoners were derived.

Vulnerabilities of all prisoners comprised loss of autonomy, social isolation, and psychological suffering, which negatively impacted their health. Health care of prisoners was not up to the standard set by the principle of equivalence as the doctor-patient relationship was compromised by dual-loyalty and paternalism, as well as due to restricted access to care. Some of these vulnerabilities were exacerbated by the age-layer. For example, social isolation worsened in old age, and similarly, the concerns with dual-loyalty, paternalism and access to care deepened. This was due to aging prisoners' increased and complex health needs. Furthermore, aging prisoners' health suffered from an environment that was not adapted to their needs and those having indeterminate sentences experienced uncertainty and lack of perspective.

All these vulnerabilities lead to obligations in the care for aging prisoners, namely strengthening the doctor-patient relationship, adapting the environment, and improving access to care based on needs. To achieve greater equivalence in the doctor-patient relationship, the independence of health care personnel has to be achieved and in case they are involved in legal processes their role needs to be precisely delineated. This includes the greater engagement of medical associations, who are well positioned to monitor violations of ethical codes. For housing, there is a high need for structural adaptations to the needs of aging prisoners that must be accompanied by organizational changes. Access to care, being of heightened importance for older prisoners because of their high health care needs, depends on the prison health system and its connection with services in the community.

End-of-life care has to confront the same vulnerabilities and currently faces challenges in granting access for seriously ill and elderly prisoners and allowing for a dignified death. Solutions include providing end-of-life care by a within-prison model or as an in-reach model. One part of the in-reach model is compassionate release, which is obstructed in a number of countries due to poorly functioning and legally obstructed compassionate release processes. To remedy this, greater cooperation between legal and medical professionals in the design and application of the legal processes is necessary.

In sum, in this thesis, I was able to draw a picture of the situation of aging prisoners in Switzerland and compare it with results from other countries, which has not been done so far. While equivalence of care has been discussed in literature, an approach using the concept of vulnerability is singular. Basing aging prisoners' claims on vulnerability gives them a strong moral force in addition to their foundation in human rights. Additionally, equivalence of care remains unexplored for older prisoners, who by way of their high health care needs represent a special population among prisoners. Finally, it is clear that Switzerland has several challenges to face in providing end-of-life care to prisoners because of its different language regions, its fragmented prison health care system, and its abundance of small institutions. To provide equivalent access to care and specifically to end-of-life care, Switzerland will have to improve its prison health systems and better connect them with the one available in the community.

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## Appendix

### Prisoner Interviews

#### French Interview-guide

Remarque:

Cher Monsieur / chère Madame ..., tout d'abord je souhaite vous remercier de participer à cette étude et pour cela de nous avoir autorisé l'accès à votre dossier médical. Les informations que nous en avons extraites nous ont été très utiles. Lors de cet entretien, je vais vous poser des questions sur votre santé, sur votre qualité de vie et sur votre opinion à propos du vieillissement en prison. Le but de l'entretien est d'obtenir des informations qui ne ressortent pas de votre dossier médical. Comme cela a été indiqué dans les formulaires d'information et de consentement, soyez assuré que vos réponses seront traitées de manière confidentielle et anonyme.

1. Sexe:

J'aimerais commencer l'entretien par quelques questions introductives:

2. Quel âge avez-vous?

3. Quelle(s) langue(s) parlez-vous?

4. Quelle est votre formation professionnelle?

5. Quel était votre métier avant d'arriver en prison?

6. Quelle fonction ou activité exercez-vous désormais/en prison?

7. Qui dans votre vie compte parmi votre famille?

✓ Qu'en est-il de votre état civil?

✓ Avez-vous des enfants et petits-enfants?

i. Si oui, combien en avez-vous et quel âge ont-ils?

✓ Avez-vous des frères et sœurs?

i. Si oui, combien en avez-vous et quel âge ont-ils?

8. Combien d'amis avez-vous en-dehors de la prison?

9. Combien de visites de votre famille ou de vos amis avez-vous reçu au cours du mois dernier?
10. Combien de coups de fils avez-vous passé ou reçu, ou encore combien d'emails/lettres de leur part avez-vous écrit ou reçu au cours du mois dernier?
11. Combien de fois par mois aimeriez-vous recevoir de la visite?
12. Y a-t-il une limite du nombre de visites et/ou de coups de fils que vous êtes autorisé à recevoir?
13. Combien d'amis avez-vous au sein de la prison?
14. Quelles sont vos conditions de vie ici en prison?
  - ✓ Vivez-vous seul dans votre cellule ou la partagez-vous? (Cellule individuelle avec ou sans espaces communs, cellule à plusieurs, etc.)?
15. Combien de fois êtes-vous déjà allé en prison (séjours différents)?
  - ✓ Si vous êtes déjà allé plusieurs fois en prison, avez-vous toujours été dans la même prison ou dans des prisons différentes?
16. Depuis combien de temps (pour cette fois) êtes-vous en prison?

**Maintenant je vais vous poser quelques questions sur vos diagnostics avant l'incarcération**

17. Avez-vous déjà souffert d'une ou de plusieurs maladie(s) avant votre incarcération?
  - ✓ Pouvez-vous s'il-vous-plaît les énumérer?
18. Avez-vous reçu des médicaments pour cette (ces) maladie(s)?
19. Le traitement a-t-il été poursuivi en prison après que vous ayez été incarcéré ?
  - ✓ Expliquez s'il-vous-plaît.
20. Recevez-vous les mêmes médicaments qu'avant l'incarcération ou recevez-vous des génériques (médicaments de principe actif identique)?
21. Comment ressentez-vous le fait qu'on vous donne des génériques et non des médicaments princeps?
  - ✓ Pensez-vous qu'ils agissent de la même manière ?
22. À quel moment prenez-vous vos médicaments normalement?

23. Êtes-vous satisfait des horaires de prise de médicaments?

✓ Si ce n'est pas le cas, veuillez nous expliquer brièvement pourquoi.

24. Qui vous donne les médicaments?

**Diagnostics après l'incarcération :**

25. Avez-vous subi un examen médical d'entrée à votre arrivée en prison?

26. De nouvelles maladies ont-elles été diagnostiquées après l'incarcération?

✓ Pouvez-vous s'il-vous-plaît me les nommer?

27. Recevez-vous des médicaments pour cette (ces) nouvelle(s) maladie(s) établie(s)?

✓ Veuillez indiquer précisément lequel et justifiez.

28. Prenez-vous régulièrement les médicaments prescrits ou plutôt les médicaments prescrits vous sont-ils administrés régulièrement?

✓ Si ce n'est pas le cas, décrivez-nous les difficultés.

**Je voudrais désormais vous poser quelques questions sur votre état de santé et sur l'accès aux soins:**

29. De quels services médicaux avez-vous bénéficié dans le courant des 6 derniers mois?

✓ Médecins généralistes/médecins de famille

✓ Ophtalmologue

✓ Dentiste

✓ Spécialistes

✓ Ergo- et/ou physiothérapie

30. Quel état de santé et quels symptômes ont été la raison de la consultation et quels ont été les conséquences et résultats?

✓ Veuillez expliquer.

31. Avez-vous déjà été examiné par un spécialiste pour des problèmes psychiques?

✓ Si oui, quel diagnostic a-t-il posé?

✓ Comment le vivez-vous?

32. Avez-vous séjourné à l'hôpital ou en maison médicalisée ces 6 derniers mois?

- ✓ Combien de temps ces séjours à l'hôpital ou en maison médicalisée ont-ils duré?
- ✓ Pour quelles raisons ont-ils eu lieu?

33. Êtes-vous tombé lors de ces 6 derniers mois?

- ✓ Si oui, combien de fois et quelles circonstances ont conduit à cette chute?
- ✓ Quelles ont été les conséquences de la chute? (Avez-vous par exemple informé un médecin ou l'administration pénitentiaire de votre chute, avez-vous reçu de l'aide pour éviter de futures chutes, avez-vous peur de retomber encore?)

34. Avez-vous eu des troubles du sommeil ces 6 derniers mois, par exemple des difficultés pour s'endormir, se réveiller pendant la nuit et/ou ne plus être capable de dormir plusieurs heures à la suite, et/ou avez-vous été fatigué lorsque vous étiez éveillé?

35. Avez-vous déjà eu des problèmes pour bénéficier de prestations de santé en prison?

- ✓ Veuillez expliquer ces problèmes.

36. Avez-vous eu des difficultés pour obtenir les médicaments dont vous avez besoin?

- ✓ Veuillez les décrire.

**Avec les trois questions suivantes j'aimerais en savoir plus sur votre consommation de tabac et d'alcool. Êtes-vous d'accord avec cela?**

37. Êtes-vous fumeur?

- ✓ Si oui, combien de cigarettes fumez-vous par jour?

38. Avez-vous ou avez-vous eu une dépendance à l'alcool?

- ✓ Veuillez expliquer.

39. Avez-vous déjà consommé des drogues illicites comme des dopants, des calmants, des opiacés, de la marijuana (cannabis) ou des drogues hallucinogènes?

- ✓ Veuillez indiquer lesquelles vous avez déjà prises et pendant combien de temps.

40. Avez-vous eu pendant les 6 derniers mois un ou plusieurs de ces troubles?

- ✓ Douleurs dans les jambes, les épaules, les bras ou les mains
- ✓ Mal de dos ou de poitrine, essoufflement pendant le sport
- ✓ Toux persistante
- ✓ Jambes gonflées
- ✓ Sensations de vertige ou troubles de l'équilibre
- ✓ Problèmes de peau (par exemple psoriasis)
- ✓ Problèmes de ventre ou de digestion (diarrhée, constipation)

**Maintenant j'aimerais vous poser quelques questions sur la santé et la qualité de vie:**

41. Votre cellule/chambre est-elle adaptée à vos besoins de santé et/ou a-t-elle une configuration particulière (par exemple un lit particulier, une chaise plus haute, un meilleur éclairage etc)?
42. Avez-vous des difficultés avec la configuration de la prison?
- ✓ Expliquez brièvement, par exemple trop d'escaliers, trop de bruit, pas de poignées auxquelles se tenir sous la douche ou en sortant ou rentrant dans la baignoire, le chemin jusqu'à la pièce avec la télévision...)
43. Quelles manœuvres utilisez-vous pour faire face à ces problèmes résultant de la configuration de la prison?
- ✓ Quels moyens d'assistance utilisez-vous?
44. Avez-vous la possibilité de faire du sport?
- ✓ Si oui, quels types de sports pratiquez-vous?
  - ✓ Combien de fois par semaine faites-vous du sport?
45. Avez-vous à votre disposition des appareils médicalement recommandés comme des fauteuils roulants, déambulateurs et/ou des bandes de gymnastiques (Thera-Band) et êtes-vous autorisé(e) à les utiliser dans la prison?
- ✓ Si non pourquoi?
46. Bénéficiez-vous de certificats médicaux de la part de votre médecin en raison de votre âge avancé afin de réduire vos tâches en prison?

47. Y a-t-il dans votre environnement quelque chose par exemple des bancs ou des espaces de détente que vous pouvez utiliser pour faire une pause pendant votre travail ou pendant la promenade?
48. Les détenus qui sont âgés de plus de 65 ans ont-ils le droit d'aller en retraite comme les autres adultes du même âge?
- ✓ Si oui, quelles sont vos possibilités d'aménagement du temps libre?
49. Qu'aimeriez-vous faire durant ce temps?
- ✓ Quelles activités trouveriez-vous utiles ou sensées pendant votre temps libre et/ou votre temps de travail obligatoire?
50. Recevez-vous un salaire pour votre travail et/ou recevez-vous une pension de retraite?
- ✓ Si oui, combien par jour/ par heure?
  - ✓ Pouvez-vous utiliser ce salaire en prison?
51. Recevez-vous, si nécessaire, le soutien financier de quelqu'un?
- ✓ Si oui, veuillez expliquer.
52. Y a-t-il des problèmes qui sont liés au vieillissement en prison?
- ✓ Si oui, lesquels sont-ils?
53. Quelles solutions proposeriez-vous pour réduire les problèmes des détenus âgés?
54. Pensez-vous que vous êtes plus susceptible d'être victime de maltraitements physiques et/ou violences que les détenus plus jeunes?
- ✓ Veuillez expliquer brièvement.

**Dans la prochaine partie, je vais vous poser des questions relatives à la spiritualité/la foi et la mort: Nous posons ces questions par routine et non car nous pensons que vous allez bientôt mourir.**

55. Êtes-vous croyant?
- ✓ De quelle confession êtes-vous?
56. Avez-vous l'accès aux offices religieux dans cette prison?
- ✓ À quelle fréquence bénéficiez-vous de cette possibilité?
57. Quel rôle joue la foi/religion dans votre vie en ce moment?

58. Avez-vous déjà songé à l'éventualité de mourir en prison?

✓ Depuis votre incarcération, avez-vous déjà songé à mettre fin à votre vie?

59. Qu'est-ce qui vous préoccupe le plus quand vous pensez à l'éventualité de mourir ici?

60. Que souhaiteriez-vous si vous deviez mourir en prison?

61. De quels services aimeriez-vous bénéficier en fin de vie, et/ou de quels services pouvez-vous, à votre connaissance, bénéficier ici? (Soins palliatifs en hospice ou à l'hôpital, maison médicalisée, accompagnement spirituel, soins psychiques etc...)

✓ Connaissez-vous quelqu'un qui a bénéficié de ces services?

✓ Si oui, de quels services a-t-il (elle) bénéficié?

62. Y a-t-il des services qui ne sont pas à votre disponibilité ici, mais dont vous aimeriez profiter? Veuillez nous les décrire.

**Maintenant j'aimerais encore vous poser quelques questions sur de possibles solutions alternatives:**

63. Selon vous, quelle seraient les possibilités alternatives de logement ou d'hébergement des détenus âgés?

64. Pensez-vous que les détenus âgés qui sont très malades devraient être libérés?

✓ Veuillez nous expliquer vos raisons.

65. Quelles mesures l'administration pénitentiaire pourrait-elle prendre pour améliorer la qualité de vie des détenus âgés?

66. Souhaitez-vous ajouter quelque chose sur les soins de santé des détenus âgés?

67. Comment vous représentez-vous votre avenir?

**Merci pour l'entretien!**

## German Interview-guide

Hinweis:

Sehr geehrte/r Herr/Frau ..., als erstes möchte ich mich bei Ihnen für die Teilnahme an dieser Studie bedanken und dafür, dass sie uns den Zugang zu ihrer Krankenakte ermöglicht haben. Die Informationen, die wir daraus gewonnen haben, waren sehr nützlich. Während dieses Interviews werde ich Ihnen Fragen zu Ihrer Gesundheit, Ihrer Lebensqualität und zu Ihrer Meinung über das Älter werden im Gefängnis stellen. Das Ziel des Interviews ist, Informationen zu erhalten, die nicht aus der Krankenakte hervorgegangen sind. Wie bereits in den Informationen und der Einverständniserklärung angegeben, können Sie sicher sein, dass alle Antworten anonym und vertraulich behandelt werden.

1. Geschlecht:

**Ich würde das Interview gern mit einigen einführenden Fragen beginnen:**

2. Wie alt sind Sie?
3. Welche Sprachen sprechen Sie?
4. Welche Ausbildung haben Sie gemacht?
5. Als was haben Sie gearbeitet bevor Sie ins Gefängnis gekommen sind?
6. Welchen Tätigkeit oder Aufgabe haben Sie jetzt?
7. Wer zählt in Ihrem Leben zu ihrer Familie?
  - ✓ Welchen Familienstand haben Sie?
  - ✓ Haben Sie Kinder und Enkelkinder?
    - i. Falls ja, wie viele und wie alt sind sie?
  - ✓ Haben Sie Geschwister?
    - i. Falls ja, wie viele und wie alt sind sie?
8. Wie viele Freunde haben Sie ausserhalb des Gefängnisses?
9. Wie oft haben Ihre Familie und/oder Freunde Sie im letzten Monat besucht?
10. Wie oft haben Sie im letzten Monat Anrufe getätigt und/oder erhalten, sowie E-Mails/Briefe geschrieben und/oder von ihnen erhalten?
11. Wie oft würden Sie gern innerhalb eines Monats Besuch bekommen?

12. Gibt es eine Begrenzung der Anzahl der Besuche und/oder der Anrufe die Sie bekommen dürfen?
13. Wie viele Freunde haben Sie innerhalb des Gefängnisses?
14. Wie sind Ihre Lebensumstände hier im Gefängnis?
  - ✓ Leben Sie allein in einer Zelle oder teilen Sie sich eine Zelle (Einzelzelle, Gemeinschaftszelle, Wohngemeinschaft etc.)?
15. Wie oft waren Sie schon im Gefängnis (verschiedene Aufenthalte)?
  - ✓ Falls Sie bereits öfter im Gefängnis waren, waren Sie immer im gleichen Gefängnis oder in verschiedenen Gefängnissen?
16. Wie lange sind Sie (dieses Mal) schon im Gefängnis?

**Nun stelle ich Ihnen einige Fragen zu Ihren Diagnosen vor der Inhaftierung**

17. Haben Sie bereits vor der Inhaftierung an einer oder mehreren Erkrankungen gelitten?
  - ✓ Können Sie diese bitte aufzählen.
18. Haben Sie für diese Erkrankung(en) Medikamente erhalten?
19. Wurde die Behandlung im Gefängnis weitergeführt, nachdem Sie inhaftiert wurden?
  - ✓ Bitte erläutern Sie.
20. Bekommen Sie die gleichen Medikamente wie vor der Inhaftierung oder bekommen Sie Generika (wirkstoffgleiche Medikamente)?
21. Wie geht es Ihnen mit der Einnahme von Generika?
  - ✓ Denken Sie, dass diese genauso wirken?
22. Wann bekommen Sie normalerweise Ihre Medikamente?
23. Sind Sie mit den Zeiten der Medikamentengabe zufrieden?
  - ✓ Falls nicht, erklären Sie bitte kurz warum.
24. Wer gibt Ihnen die Medikamente?

**Diagnosen nach der Inhaftierung:**

25. Wurde bei Ihnen eine Eingangsuntersuchung durchgeführt als Sie ins Gefängnis gekommen sind?

26. Wurden nach der Inhaftierung neue Erkrankungen bei Ihnen diagnostiziert?

- ✓ Können Sie diese bitte für mich nennen.

27. Bekommen Sie Medikamente für diese neu festgestellten Krankheiten?

- ✓ Geben Sie diese bitte genau an und begründen Sie.

28. Nehmen Sie die verschriebenen Medikamente regelmässig ein bzw. bekommen Sie diese regelmässig verabreicht?

- ✓ Falls nicht, beschreiben Sie die Hindernisse.

**Nun möchte ich Ihnen einige Fragen zu Ihrem Gesundheitszustand und zum Zugang zur Gesundheitsversorgung stellen:**

29. Welche medizinischen Dienste haben Sie in den letzten 6 Monaten in Anspruch genommen?

- ✓ Allgemeinmediziner/Hausarzt
- ✓ Augenarzt
- ✓ Zahnarzt
- ✓ Spezialisten
- ✓ Ergo- und/oder Physiotherapie

30. Welcher Gesundheitszustand und welche Symptome waren der Grund für die Konsultation(en) und was waren die Folgen/Ergebnisse?

- ✓ Bitte erläutern Sie.

31. Sind Sie jemals wegen psychischer oder seelischer Probleme von einem Facharzt untersucht worden?

- ✓ Falls ja, welche Diagnose hat er gestellt?
- ✓ Wie kommen Sie damit zurecht?

32. Waren Sie in den letzten 6 Monaten in einem Krankenhaus oder in einem Pflegeheim?

- ✓ Wie lange haben diese Aufenthalte im Krankenhaus/Pflegeheim gedauert?
- ✓ Aus welchen Gründen haben sie stattgefunden?

33. Sind Sie in den letzten 6 Monaten gestürzt?

- ✓ Falls ja, wie oft und welche Umstände haben zu dem Sturz geführt?
- ✓ Welche Folgen hatte der Sturz? (Haben Sie beispielsweise einem Arzt oder der Gefängnisverwaltung von Ihrem Sturz berichtet, haben Sie Hilfe erhalten, um zukünftig Stürze zu verhindern, haben Sie Angst, dass Sie wieder hinfallen könnten?)

34. Haben Sie in den letzten 6 Monaten Schlafprobleme gehabt, zum Beispiel Probleme beim Einschlafen, nächtliches Aufwachen und/oder nicht in der Lage sein mehrere Stunden hintereinander zu schlafen und/oder waren Sie müde, wenn Sie wach waren?

35. Hatten Sie jemals Probleme, Gesundheitsleistungen im Gefängnis in Anspruch zu nehmen?

- ✓ Bitte erläutern Sie diese Probleme.

36. Haben Sie Probleme, die Medikamente zu bekommen, die Sie benötigen?

- ✓ Bitte beschreiben Sie diese.

**Mit den folgenden drei Fragen möchte ich mehr über Ihren Tabak oder Alkoholkonsum wissen. Ist das OK für Sie?**

37. Sind Sie ein Raucher?

- ✓ Falls ja, wie viele Zigaretten rauchen Sie an einem Tag?

38. Sind oder waren Sie alkoholabhängig?

- ✓ Bitte erläutern Sie.

39. Haben Sie je illegale Drogen wie Aufputzmittel, Beruhigungsmittel, Opiate, Marihuana (Cannabis) oder halluzinogene Drogen genommen?

- ✓ Bitte nennen Sie, welche Sie eingenommen haben und wie lange.

40. Hatten Sie in den letzten 6 Monaten eine oder mehrere der folgenden Beeinträchtigungen?

- ✓ Schmerzen in Beinen, Schultern, Armen oder Händen
- ✓ Rückenschmerzen Brustschmerzen beim Sport Kurzatmigkeit
- ✓ Ständiges Husten

- ✓ Geschwollene Beine
- ✓ Schwindelgefühl oder Gleichgewichtsstörungen
- ✓ Hautprobleme (z.B. Schuppenflechte)
- ✓ Magen- oder Verdauungsprobleme (Durchfall, Verstopfung)

**Jetzt möchte ich Ihnen einige Fragen zur Gesundheit und Lebensqualität stellen:**

41. Ist Ihre Zelle/Raum an Ihre gesundheitlichen Bedürfnisse angepasst und/oder hat sie eine besondere Ausstattung (zum Beispiel Spezialbett, höherer Stuhl, bessere Beleuchtung usw.)?
42. Haben Sie Schwierigkeiten mit der Umgebung und der Bauweise im Gefängnis?
- ✓ Erklären Sie kurz zum Beispiel zu viele Treppen, zu viel Lärm, keine Handgriffe an denen man sich beim Duschen oder beim Ein- und Aussteigen aus der Badewanne festhalten kann, der Weg ins Fernsehzimmer.)
43. Welche Strategien verfolgen Sie, um mit diesen Schwierigkeiten in Ihrer Umgebung klar zu kommen?
- ✓ Welche Hilfsmittel benutzen Sie?
44. Haben Sie die Möglichkeit, sich sportlich zu betätigen?
- ✓ Wenn ja, welche Sportarten betreiben Sie?
  - ✓ Wie oft pro Woche machen Sie Sport?
45. Werden Ihnen medizinisch empfohlene Hilfsmittel wie Rollstühle, Gehhilfen und/oder Gymnastikbänder (Thera-Bänder) gegeben und dürfen Sie diese im Gefängnis benutzen?
- ✓ Falls nicht, warum nicht?
46. Werden Sie aufgrund ihres steigenden Alters von ihrem Arzt krankgeschrieben (ärztliches Attest), um das Arbeitspensum im Gefängnis zu reduzieren?
47. Gibt es in Ihrer Umgebung etwas, z.B. Bänke und/oder Bereiche zum Ausruhen, die Sie während der Arbeit oder beim Hofgang zum Pause machen genutzt werden können?

48. Sind Gefangene, die älter als 65 sind, berechtigt in Pension zu gehen, wie andere Erwachsene im gleichen Alter?

- ✓ Falls ja, welche Freizeitgestaltungsmöglichkeiten gibt es für Sie?

49. Was würden Sie gerne mit Ihrer Zeit anfangen?

- ✓ Welche Tätigkeiten fänden Sie nützlich oder sinnvoll während Ihrer Freizeit und/oder Ihrer obligatorischen Arbeitszeit?

50. Bekommen Sie einen Lohn für Ihre Arbeit und/oder bekommen Sie Altersrente?

- ✓ Falls ja, wie viel pro Tag/pro Stunde?
- ✓ Können Sie dieses Einkommen im Gefängnis nutzen?

51. Bekommen Sie, falls nötig, finanzielle Unterstützung von jemandem?

- ✓ Falls ja, bitte erläutern Sie.

52. Gibt es Probleme, die mit dem Älter werden im Gefängnis verbunden sind?

- ✓ Falls ja, welche sind das?

53. Welche Lösungen würden Sie vorschlagen, um die Probleme von älteren Gefangenen zu verringern?

54. Denken Sie, dass Sie eher gefährdet sind, ein Opfer von körperlicher Misshandlung und/oder Gewalt zu sein als jüngere Gefangene?

- ✓ Bitte erklären Sie kurz.

**Im nächsten Abschnitt werde ich Ihnen Fragen zu Spiritualität/Glaube und Sterben stellen: Wir stellen die folgenden Fragen routinemässig und nicht, weil wir glauben, dass Sie bald sterben werden.**

55. Sind Sie religiös?

- ✓ Welcher Glaubensrichtung gehören Sie an?

56. Haben Sie in diesem Gefängnis Zugang zu Gottesdiensten o.ä.?

- ✓ Wie oft nehmen Sie diese in Anspruch?

57. Welche Rolle spielt Glaube/Religion zu diesem Zeitpunkt in Ihrem Leben?

58. Haben Sie schon einmal an die Möglichkeit gedacht, im Gefängnis zu sterben?

- ✓ Haben Sie seit Ihrer Inhaftierung jemals daran gedacht, Ihrem Leben ein Ende zu setzen?

59. Was beschäftigt Sie am meisten, wenn Sie daran denken hier zu sterben?

60. Was würden Sie sich wünschen, wenn Sie im Gefängnis sterben sollten?

61. Welche Dienste würden Sie gern am Lebensende haben und/oder von welchen Diensten wissen Sie, dass Sie sie hier erhalten können? (Hospizpflege, Palliativpflege, Pflegeheim, spirituelle Begleitung, Seelsorge usw.)

- ✓ Kennen Sie jemanden, der solche Dienste bekommen hat?

- ✓ Wenn ja, was (welche Dienste) hat er/sie bekommen?

62. Gibt es Dienste, die Ihnen nicht zur Verfügung stehen, die Sie aber gern bekommen würden? Bitte beschreiben Sie diese.

**Nun möchte ich Ihnen noch einige Fragen zu möglichen Alternativlösungen stellen:**

63. Was wäre Ihrer Meinung nach eine alternative Wohnsituation oder Unterbringungsmöglichkeit für ältere Gefangene?

64. Denken Sie, dass ältere Gefangene die sehr krank sind, aus dem Gefängnis entlassen werden sollten?

- ✓ Bitte erläutern Sie ihr Gründe.

65. Welche Massnahmen könnte die Gefängnisverwaltung treffen, um die Lebensqualität für ältere Gefangene zu verbessern?

66. Wie stellen Sie sich Ihre Zukunft vor?

**(Möchten Sie sonst noch etwas zu der Gesundheitsversorgung von älteren Gefängnisinsassen sagen?)**

**Dankeschön für das Interview!**

## Stakeholder Interviews

### French Interview-guide

#### Remarque :

Cher Monsieur, chère Madame, vous participez à l'étude „Agequake in prisons“ qui se consacre à la santé, au bien-être et à une prise en charge éthiquement acceptable des détenus âgés. Nous vous avons demandé de participer à cette étude en raison de votre expérience dans le travail en prison et/ou de vos connaissances de spécialiste dans ce domaine. Pendant l'entretien, je vais vous poser des questions sur les soins de santé des détenus âgés, mais aussi votre avis sur la question de savoir si oui et pourquoi certaines choses devraient être modifiées quant à la situation des détenus âgés. Ensuite je vous interrogerai sur d'éventuelles solutions alternatives pour le management, qui pourraient non seulement aider les détenus, mais également l'administration pénitentiaire.

#### Si vous êtes d'accord, j'aimerais commencer par quelques questions sur votre propre expérience :

1. Depuis combien de temps travaillez-vous déjà dans cette maison d'arrêt ou dans les prisons en général et/ou avec des détenus?
2. Depuis combien de temps connaissez-vous déjà la majorité des détenus de cette prison?
3. Quelles ont été vos propres expériences de travail avec des détenus âgés?

#### Les questions suivantes traiteront des soins de santé des détenus âgés:

4. Avez-vous eu des expériences sur le thème des soins de santé pour les détenus âgés?
  - ✓ Veuillez donner un exemple.
5. Comment estimez-vous la qualité des services de santé pour les détenus âgés?
  - ✓ Pouvez-vous donner un exemple?
6. Pouvez-vous nous décrire la manière dont les détenus âgés peuvent bénéficier des services de santé dans votre pays/canton? Par exemple un détenu de 60 ans avec des pathologies multiples comme le diabète, la tension artérielle et des maladies cardiaques.
7. À quelle fréquence les détenus âgés ont-ils accès aux professionnels médicaux comme des infirmières, des médecins, thérapeutes et spécialistes?

8. Qu'y a-t-il comme assurance maladie de base pour les détenus âgés (ou de quelle autre manière les frais de santé sont-ils financés)?
9. Les détenus ont-ils accès à des soins supplémentaires comme des soins dentaires, ou des soins ambulants ou hospitaliers supplémentaires?
10. Des assurances complémentaires peuvent/sont-elles envisageables pour ces traitements?
11. Existe-t-il des mesures préventives comme des formations sur le thème du mouvement, du tabagisme, de la dépendance à la drogue, des examens préventifs annuels, Test HIV etc qui sont proposées par la prison?
  - ✓ Veuillez mentionner brièvement lesquelles et à quelle fréquence (à quelles intervalles).
12. De quels aspects spécifiques devez-vous tenir compte dans le cas de détenus âgés toxicomanes?
13. Y a-t-il des problèmes de maltraitements physiques ou de violences contre les détenus âgés?
  - ✓ Veuillez expliquer.

**Maintenant si vous êtes d'accord j'aimerais vous poser des questions sur le déroulement des soins médicaux aux détenus âgés:**

14. Veuillez s'il-vous-plaît nous décrire la procédure lorsqu'un détenu âgé a par exemple la grippe, ou encore des douleurs à la cage thoracique et a besoin de soins médicaux.
  - ✓ En particulier : qui est consulté en premier et où l'examen a-t-il lieu?
15. S'il ressort de l'examen que le patient doit être hospitalisé pour son traitement, comment ce processus se déroule-t-il?
16. En outre, y a-t-il une surveillance du détenu pendant le transport et/ou à l'hôpital, et qui en est responsable?
  - ✓ Surveillance par un agent de sécurité
  - ✓ Surveillance médicale

17. Dans le cas où un traitement en ambulatoire est conseillé, pour lequel il/elle doit être emmené plusieurs fois par semaine à l'hôpital, comment ces services sont-ils effectués?
- ✓ Qui propose et dispense ces services, et y aurait-il du personnel médical à disposition, comme une infirmière, pour s'occuper des éventuels besoins ou problèmes pendant le transport?
18. Dans le cas où le traitement a lieu en prison, serait-il possible d'engager, pour les soins ou pour des aides nécessaires, du personnel soignant spécial ou supplémentaire si cela était nécessaire?
- ✓ En avez-vous déjà fait l'expérience?
  - ✓ Si oui, veuillez donner un exemple.
19. Les infirmeries en prison sont-elles facilement accessibles aux détenus âgés ?
- ✓ Combien de temps cela prend-il pour y arriver, est-ce loin, combien y a-t-il de portes et de contrôles?
20. Qui prend en charge les différents coûts des soins de santé et le cas échéant du transport (par exemple l'assurance maladie, la prison, le canton)?
21. Pouvez-vous nous citer un exemple de situation bien gérée dans le cadre des soins médicaux de détenus âgés?
- ✓ Cet exemple date-t-il de cette année ou est-il plus ancien?
22. Pouvez-vous nous citer un exemple de situation où les soins médicaux à un détenu âgé ont posé problème?
- ✓ Cet exemple date-t-il de cette année ou est-il plus ancien?
23. Avez-vous modifié l'approche concernant les soins de santé aux détenus âgés durant ces dernières années?

**Désormais j'aimerais vous poser quelques questions à propos des obstacles ou difficultés liées aux soins de santé des détenus âgés:**

24. Y a-t-il/voiez-vous des problèmes liés aux soins de santé des détenus âgés?
- ✓ Si oui, quels sont les trois plus gros problèmes?

25. Quelles solutions voyez-vous pour les problèmes auxquels sont confrontés l'administration et le personnel pénitentiaire avec les détenus âgés?
26. Recevez-vous un soutien pour les soins de santé aux détenus en général et pour les détenus âgés en particulier?
- ✓ Pouvez-vous s'il-vous-plaît préciser quel type de soutien vous recevez?
  - ✓ De la part de qui recevez-vous ce(s) soutien(s)?
27. Connaissez-vous, grâce aux directives de votre État/canton, les critères qui devraient être remplis en matière de soins médicaux de patients âgés en général et de traitement de la fin de vie en particulier?
- ✓ Veuillez expliquer quelles directives et/ou lois vous sont familières et quelle influence elles ont sur votre travail.
28. Souhaiteriez-vous avoir plus de formation continue pour être capable de mieux faire face aux problèmes des détenus âgés?

**Avec les prochaines questions j'aimerais en apprendre un peu plus sur le thème de „vieillir en prison“, en particulier sur la situation des détenus âgés:**

29. Existe-t-il des directives relatives à la rémunération du travail fourni par les détenus âgés, à la retraite à 65 ans et/ou à leur droit à des allocations liées à la vieillesse?
30. À votre avis, quelles pourraient être de possibles occupations, activités, et/ou tâches sensées et adaptées à des détenus âgés?
- ✓ Considérez-vous pertinente l'obligation de travail à temps plein pour les détenus âgés?
  - ✓ Si ce n'est pas le cas, quelles alternatives proposeriez-vous?
31. Selon vous, quelles prestations les prisons devraient-elles proposer afin d'améliorer la qualité de vie des détenus âgés?
32. Pensez-vous que les détenus âgés utiliseraient et/ou profiteraient de cette possibilité?
- ✓ Veuillez expliquer brièvement.
33. De votre point de vue d'expert, que devrait signifier/impliquer „bien“ vieillir en prison?
34. Que diriez-vous de loger les détenus âgés séparément?

35. Les détenus âgés de cette prison peuvent/pourraient-ils bénéficier d'un traitement en maison médicalisée dans les services de soins palliatifs?
- ✓ Si ce n'est pas le cas, pourquoi ces services ne sont-ils pas proposés?
36. Quelles sont les conditions minimales prises en considération pour l'accompagnement de fin de vie pour un détenu âgé ayant une maladie incurable?
37. Quelles sont les conditions minimales prises en considération pour le relâchement prématuré d'un détenu âgé ayant une maladie incurable?

Veillez répondre aux questions suivantes en vous basant sur l'illustration correspondante

**Illustration 1:**

Monsieur Gérard a 65 ans et a vécu dans la prison A pendant ces dix dernières années. Il fait du diabète et de l'hypertension artérielle. Pour son état chronique, il reçoit des médicaments à prescription obligatoire. Jusqu'à sa dernière chute, Monsieur Gérard était en bonne santé et capable d'accomplir ses tâches quotidiennes de manière autonome. Conséquemment à sa chute, il a désormais une hanche et un poignet cassés, le rendant ainsi dépendant des soins permanents d'autres personnes.

1. Monsieur Gérard a besoin d'aide pour ses tâches quotidiennes comme par exemple pour manger, boire, se doucher, s'habiller, aller aux toilettes et pour marcher. Que fait la prison concernée dans un tel cas ?
2. Qui est-ce qui l'aiderait dans ses tâches quotidiennes ?
3. Monsieur Gérard a besoin d'ergothérapie afin de récupérer ses capacités physiques au quotidien et pour éviter de futures chutes.
  - ✓ Quelle est la probabilité que Monsieur Gérard bénéficie de cette thérapie ?
  - Très probable       Probable       Peu probable
  - Très peu probable
  - ✓ De quoi cela dépendrait-il ?
4. Quel type de thérapie lui serait-il proposé vraisemblablement dans cette situation ?
  - ✓ Veuillez justifier.
5. À votre avis, quelles mesures préventives seraient-elles projetées afin d'éviter de futures chutes à Monsieur Gérard et aux autres détenus âgés comme lui (par exemple des poignées dans les douches, faire en sorte que les couloirs ne glissent pas, mise à disposition d'aides...)?

**Illustration 2:**

Madame Dupont a 72 ans et vit dans la prison B depuis 32 ans. À cause de son cancer en phase terminale, il est à prévoir qu'elle ne survive pas plus de 12 mois. Elle a des douleurs aiguës et a demandé des médicaments plus forts ainsi que des narcotiques. Elle n'a pas de famille hors de la prison et est appréciée des autres détenus et du personnel pénitentiaire.

1. Que conseilleriez-vous dans le cas de Madame Dupont?
  - ✓ Si elle devait être relâchée, quelles en seraient les justifications?
  - ✓ Comment se déroulerait le processus de décision? (par exemple qui serait impliqué?)
  - ✓ Serait-elle traitée en service de soins palliatifs ou pourrait-elle bénéficier d'un autre type d'accompagnement de fin de vie?
  - ✓ Qui est-ce qui s'en occuperait?
2. Décrivez les circonstances dans lesquelles vous déposeriez une requête demandant ce type de soins pour Madame Dupont.
3. Madame Dupont aura-t-elle accès à des médicaments plus forts / narcotiques?
4. L'accès aux narcotiques pose-t-il problème aux détenus âgés?
  - ✓ Veuillez justifier.
5. Vos réponses seraient-elles différentes s'il s'agissait d'un homme dans cet exemple?

**Maintenant, j'aimerais encore vous poser quelques questions sur l'analyse coûts/avantages:**

1. Les équipements suivants sont-ils disponibles pour le traitement des maladies en prison ? (1= dans l'enceinte de la prison; 2= disponible en dehors de la prison et nécessitant un transport à l'hôpital ou autre établissement)

- Assistance respiratoire (respirateur artificiel, aspirateur de sécrétions, oxygénothérapie)
- Traitement des affections vasculaires (bas de contention)
- Traitement des hernies abdominales (bandages)
- Appareils à dialyse
- Matériel à injections (IV, insuline)
- Matériel d'analyses médicales (analyses d'urine, tension)
- Défibrillateur
- Matériel d'atténuation de la douleur (oreillers, matelas)
- Équipements de physiothérapie
- Autres équipements \_\_\_\_\_

2. Au cas où ces équipements médicaux ne seraient pas disponibles dans la prison, à quelle distance un détenu âgé doit-il être emmené pour bénéficier de ces traitements?

✓ Quels moyens de transport sont-ils utilisés?

3. Quelle est la probabilité pour que la prison fasse construire un ascenseur (coût prévisible : 500 000 CHF), afin de faciliter la vie des détenus âgés ayant des problèmes pour se déplacer?
4. Serait-il possible de faire construire une partie de la prison qui serait adaptée aux personnes âgées (coûts prévisibles : 5 – 10 millions de CHF), pour garantir leur sécurité et améliorer leur qualité de vie?

**\*\*Y a-t-il encore quelque chose que vous aimeriez ajouter sur le thème des détenus âgés?**

**Dans ce cas, si vous êtes d'accord, j'aimerais pour conclure récolter quelques informations générales sur vous-mêmes :**

Sexe :

Âge :

Métier :

Formation, niveau le plus élevé atteint :

Pays:

Suisse – germanophone

Suisse – francophone

Royaume-Uni

France

Autres (préciser):

**Merci beaucoup pour l'entretien!**