

# **Ageing Prisoners and Ethics Behind Bars: Law, Human Rights and Health Care – Old (Age) Problems and New Challenges**

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Prison isn't easy for anyone, but it is especially punishing for those afflicted by the burdens of old age.<sup>1</sup>

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<sup>1</sup> Fellner, J., Graying Prisoners in the US, Human Rights Watch, 2013, <http://www.hrw.org/news/2013/08/18/graying-prisoners-us>, Accessed: 28.10.2013.

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and encouraging feedback during our PhD Committee meetings, was of great help by always sharing new information on the topic of ageing prisoners with me. In addition to that, he provided helpful comments on the first draft of my thesis. I am deeply grateful for them being role models to me, their valuable contributions, their work ethics and the time they invested to read and evaluate my dissertation. I also thank Prof. Winfried Kluth for having agreed to act as my external expert and for the time he took for evaluating and grading my work.

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## Contributions

This thesis is divided in a general introduction, seven different chapters – each chapter comprising one journal article – and a general discussion. Five of these published papers were a joint collaboration with members of the “Agequake in Prisons” research team. For two of the papers, the general introduction and general discussion of this thesis, I was the sole author but also received helpful comments that contributed to the quality of the papers and the other parts of the thesis. My detailed contributions to each article and the contributions of my co-authors are presented below. This description is structured using the order of appearance in the thesis.

Handtke, V., Bretschneider, W., Wangmo, T., Elger, B. (2012). *Facing the Challenges of an Increasingly Ageing Prison Population in Switzerland: In Search of Ethically Acceptable Solutions*. *Bioethica Forum*, 59(4), 134-141.

This paper was an invited publication to the special issue “Medicine in Prison” of the journal *Bioethica Forum*. The specific topics were divided among the authors and Violet Handtke took the role of the lead author in this publication. She wrote the Introduction and the ‘Accommodation of Older Prisoners’ section of the paper and was responsible for coordinating the group work. I contributed the section on the principle of equivalence and its meaning in the prison system. Dr. Tenzin Wangmo wrote the following section on ‘End-of-Life Care and Death in Prison’ and Prof. Bernice Elger was responsible for the Discussion section and addressed possible solutions for the identified problems. All authors critically reviewed all sections of the manuscript.

Bretschneider, W., Elger, B., Wangmo, T. (2012). *Ageing Prisoners' Health Care: Analysing the Legal Settings in Europe and the United States*. *Gerontology*, 59(3), 267-275.

In this publication, I took the lead and analysed a variety of national and international documents such as recommendations, guidelines and judgements. The first draft was reviewed by Dr. Tenzin Wangmo and together we decided upon a final structure. Dr. Tenzin Wangmo also revised my subsequent drafts. Prof. Bernice Elger gave helpful comments on later drafts of the manuscript and added her valuable expertise on this topic.

Bretschneider, W., Elger, B. (2014). *Expert Perspectives on Western European Prison Health Services: Do Ageing Prisoners Receive Equivalent Care?* *Journal of Bioethical Inquiry*, 11(3), 319-332.

This paper was written as part of a special issue on “Ethical Dilemmas in Prisoner Care” for the *Journal of Bioethical Inquiry*. Prof. Bernice Elger and I coded the Stakeholder interviews and decided upon the themes for the paper. I wrote the first draft of the paper, in the following process we both continued working on the paper, reviewing the drafts, re-analysing our results and finalising the paper.

Wangmo, T., Meyer, A., Bretschneider, W., Handtke, V., Kressig, R., Gravier, B., Büla, C., Elger, B. (2015). *Ageing Prisoners' Disease Burden: Is Being Old a Better Predictor than Time Served in Prison*. *Gerontology*, 61(2), 116-123.

For this publication Dr. Tenzin Wangmo took the lead. She conducted together with Dr. Andrea Meyer the statistical analysis. I together with another PhD student, contributed to the collection of data from which the paper is derived. Additionally, I assisted with questions related to data collection and the quality of the data. I critically reviewed and commented on the drafts of this manuscript, and approved the overall content and quality of the paper.

Handtke, V., Bretschneider, W. (2015). *Will I Stay or Can I go? Assisted Suicide in Prison*. *Journal of Public Health Policy*, 36(1), 67-72.

Violet Handtke and I intensively discussed the content and structure of this paper. It was a joint process of writing, reviewing and improving the quality of the manuscript. Thereby, we contributed equally to this work.

Bretschneider, W. (2012). *Fixierungsmassnahmen in Krankenhäusern: Ein wunder Punkt. [Restraint in Hospitals – A Sore Point]*. *Das Gesundheitswesen*, 74(12), 812-817.

While I was working on health care issues of ageing prisoners it became evident that the use of physical restraints is very relevant in the prison context. I conceptualized and wrote the manuscript based on the research done as part of my master thesis. Helpful comments on the structure were received from Dr. Tenzin Wangmo and Dr. Corinna Jung.

Bretschneider, W. (2014). *Die neue Schweizer Gesetzgebung zu bewegungseinschränkenden Maßnahmen auf dem medizinethischen Prüfstand. [The New Swiss Regulation on Restraint Measures on Medico-Ethical Trial]*. *Ethik in der Medizin*, 1-14 [epub ahead of print].

This single authored publication was based on a manuscript for the course “Ethik in der Pflege: Basiskompetenzen und aktuelle Fragestellungen” with Prof. Stella Reiter-Theil. My knowledge and interest on restraints in institutions provided a good basis for this analysis. I drafted and revised the manuscript. My colleague, Dr. Beatrice Annaheim read the final version of the paper and provided helpful comments.

## Summary

The structure of penal institutions and their impact on inmates raises complex ethical and human rights issues. The circumstance that the number of prisoners who are older and/or suffer from mental disorders is steadily growing in Switzerland and worldwide in general, creates additional problems. Therefore, the aims of this thesis are to provide information on the current health care situation of ageing prisoners in Switzerland, to better understand the legal and practical settings of health care provision for ageing prisoners and to analyse the ethical issues that arise from the need to provide adequate health care to inmates in the context of an increasingly ageing prison population.

This thesis is divided in a general introduction, seven chapters and a general discussion. The introduction provides general information on institutions and their characteristics, the role of punishment in institutions and the numerical changes of the prison population in the correctional system. Furthermore, an overview of possible reasons for the tremendous growth of the prison population is given. Special focus is put on the sub-group of ageing prisoners and their features. Their needs in accommodation and health care are presented in detail. The introduction then proceeds with a brief description of the ethical issues in relation to the health care for ageing prisoners and continues with an overview about project details of the “Agequake in Prisons” project.

A first theoretical overview about the challenges that the prison system has to face with the growing number of ageing prisoners and their special needs is given in *Chapter 1*. Special emphasis is put on the accommodation of older prisoners and the end-of-life care and death in prison. The principle of equivalence of care is used as a framework.

*Chapter 2* contains a review of national and international guidelines, legal frameworks and other documents relating to the health care needs of ageing prisoners. The results on the existence or non-existence of regulations that address the health care of ageing prisoners are critically examined. In this analysis focus is particularly put on Europe and the United States of America (USA).

*Chapter 3* explores current expert perspectives on Western European prison health care services and investigates if ageing prisoners receive equivalent care. Here, the difficulties of providing equivalent health care to ageing prisoners are described in detail. The factors that contribute to these difficulties are looked at. Possible solutions for the described problems are provided which shall give guidance to people working in correctional facilities.

*Chapter 4* reflects on the disease burden of ageing prisoners and the different impact that age and length of imprisonment have on their health.

The topic of end-of-life in prison is covered in *Chapter 5*. More and more prisoners grow old in prison and are likely to die there. Non-physician assisted suicide is under certain conditions available to the public in Switzerland. In this chapter it is argued that it should be made available for prisoners, too.

*Chapter 6* and *Chapter 7* give an insight into the topic of restraint measures. While *Chapter 6* addresses restraint measures in hospitals in Germany, *Chapter 7* explores the new legal regulation of restraint measures in Switzerland.

The last part of this thesis contains a general discussion of the presented work and summarises its findings. Furthermore, the implications of this study for research and practice in correctional facilities are described. It should be noted that *Chapters 1, 2, 3, 4, 5, 6* and *7* have been published in different European and American journals; therefore it is possible that there is an overlap between the description of the background, ethical issues and methods used.

Although, the delivery of health care for ageing prisoners does meet the standard of equivalent health care in certain prisons, it is of great concern that it is not achieved in every Swiss prison according to the Stakeholders that were interviewed. This thesis provides an insight into some of the most challenging aspects of old age inside prisons such as the provision of equivalent health care and contributes to the understanding of how the health care provision for ageing prisoners could be made more effective.

# General Introduction

## **Introduction**

### **Background**

The structure of penal institutions and their impact on inmates raises complex ethical and human rights issues. The circumstance that the number of prisoners who are older and/or suffer from mental disorders is steadily growing in Switzerland and worldwide in general, creates additional problems. This thesis focuses on the analysis of the ethical issues that arise from the need to provide adequate health care to inmates in the context of an increasingly ageing prison population.

### **Institutions and their Similarities**

The daily life of people is affected by public institutions in various ways. Among other things, public institutions exercise authority and provide basic services to the members of society. Some examples include educational institutions such as schools and universities, medical institutions like hospitals and nursing homes as well as correctional institutions like prisons. The latter have even been defined as *total institutions*: “a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” [36].

The so-called total institutions such as nursing homes, hospitals and prisons share common characteristics and can under certain conditions have a similar psychological impact on those living there. Although these institutions have different goals, they may raise similar ethical issues as their residents may receive health care on-site, provided by internal or external medical staff. One reason for this is that they all have a so called “institutional culture”, which comprises values, norms and informal attitudes [59]. In addition to the institutional culture, there is the feature of formal sanctions like *punishment* that Elster [31] necessarily attributes to institutions. Both in correctional and in medical institutions the application of restraints to residents – either by medical or by correctional staff – is or has been an element of their punishment culture.

### **The Role of Punishment in Institutions and Reasons for their Establishment**

The desire to punish is something that mostly every human being has felt [26]. Different forms of punishment are still widely accepted by society and seen as a fundamental and essential part of life [13]. In some societies, people living in institutions have to face verbal or even physical punishments almost every day [40-42,70]. In previous times there used to be even tougher and more serious forms of punishment than today. For instance the treatment of the mentally ill, who were housed in institutions comparable to hospitals with horrendous sanitary conditions and who were despised and ridiculed [5]. Mentally ill people who were considered to be dangerous were also put in prisons [5], which was not done for their own good as treatment was not available, but to protect society. Furthermore, in the 18<sup>th</sup> century it was likewise a common practice to beat patients [5]. Straitjackets and chains were applied in order to “tame” the patients. These standards were geared to the following theory: the more painful the taming, the better the outcome [5]. The punishment of criminal behaviour

has also a very long history and represents a symbol of social responsibility [6]. In the Middle Ages punishment used to be characterised by barbaric measures. The beginning of the 19<sup>th</sup> century brought a more decent procedure where the bodily pain was not the central element anymore [34]. Incarceration as the new system of punishment was born [30].

Liberty is a basic right and “a good that belongs to all in the same way”, its loss affects every person equally [34]. Imprisonment aims at deterrence by creating a fear of punishment and therefore reducing the risk of future offences based on a rational decision of individuals [1,14]. Imprisonment also seeks to prevent crimes by removing offenders from society [30]. Another justification for the use of punishment is the theory of retribution which aims at moral proportionality (the degree of moral offense should be mirrored in the punishment) to compensate the harm suffered by the victim [13,82]. Retribution is a victim-focused theory, on the contrary, the theory of rehabilitation, which is the process of preparing an offender to reintegrate into society with new skills in order to prevent future crimes, is rather offender-focused [47].

All of these theories of punishment are covered by a common agreement of society which is based on the main objective of safety and protection and which is usually not questioned [44]. Yet, there has been a shift away from the philosophy of rehabilitation and reintegration towards incapacitation and retribution<sup>1</sup> [67,85]. Despite this change, the use of torture and neglect are mainly not included in the modern concept of punishment anymore [25]. Still, crime is not necessarily related to the conditions of imprisonment, but also with other factors preventing crime. In fact, crime and the punishment of criminal behaviour are a “reality of social life” [6], which is clearly reflected in the number of people being punished in correctional facilities worldwide.

### **Longer Prison Sentences**

According to the World Prison Population List, the number of prisoners is rising steadily [80]. In the past 15 years the prison population increased from over 8 million in 1999 to more than 10.2 million in 2013. Ernest Drucker in his book “A Plague of Prisons” describes the rise as an ‘unusual event’ which occurred in the United States of America (USA) in the beginning of the 1970’s as a result of the so called getting ‘tough on crime’-policy [9,30]. Contributing factors for this worldwide phenomenon are policy changes that result in harsher and longer prison sentences to “protect” society, fewer chances of early release, and higher prosecution rates (due to better crime clearance rates) [28,76]. One of the best known examples for legislations that introduced longer prison sentences is the so called “three strikes and you’re out”-law [65]. It was first introduced in the state of Washington in 1993 and significantly prolongs the length of prison sentences (mandatory sentences from 25 years to life [7]). Other states have passed similar laws, like California in 1994 [48]. This political development reflects

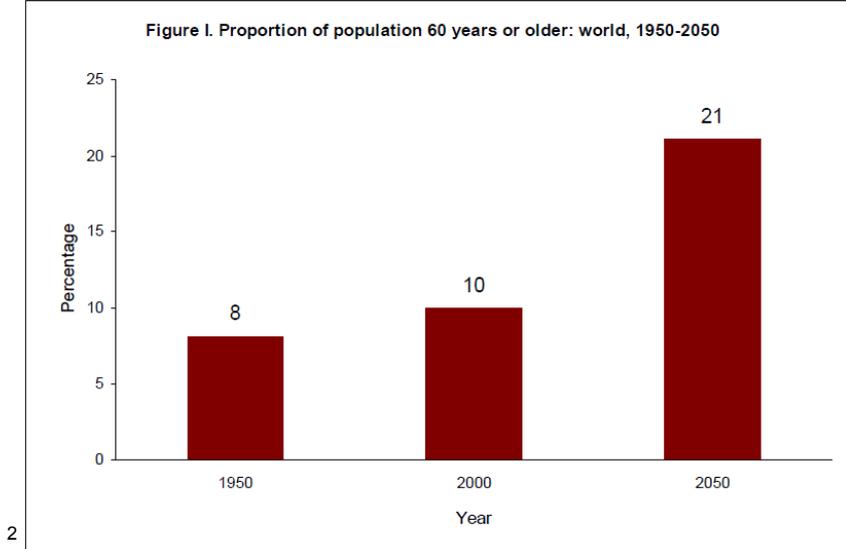
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<sup>1</sup> Only recently, in 2014, conservative Republicans and liberal Democrats have joined to introduce a policy change that could reduce the prison population in the USA, e.g. more discretion for judges (less mandatory minimum sentences) and establishing early release systems [63,65]. This development having started in 2013 when Attorney General Eric H. Holder Jr. announced new policies to minimize the expenses for prisons and the unfairness in the prison system [68].

once more the change in the meaning of punishment in today's society [11]. Criminal offenders will remain in prison for a longer period of time and they will grow old in these institutions [24].

### The Demographic Change

In addition to these concerning statistics and legal changes, the structure of the prison population has changed tremendously, too. Overall, population development is characterised by an increasing life expectancy worldwide [74] in combination with the baby boom period after the Second World War [10,24] and decreasing fertility rates since 1965 [10]. All these factors lead to an ageing of the world population meaning that the proportion of younger people diminishes and in turn, the proportion of older people rises [10] (see Figure 1).



Switzerland has a population of 8.1 million residents now compared to 7.1 in 1999 [75]. Amongst other influences that had an impact on this development, the life expectancy rose from 77 years in 1990 to 83 years in 2012 [74]. This demographic change has an effect on all facets of human life [64]. The increased life expectancy is also reflected in the prison system [6]. However, according to the World Prison Population List, the overall prison population did not grow to the same extent in Switzerland and went only from 6,259 (1999) [79] to 6,599 (2013) [80] with some fluctuations in between. Nonetheless, the number of older people in the prison system is marked by a continuous growth. While in 1999, 320 people above the age of 50 were incarcerated in Swiss prisons, this number had nearly doubled to 616 by 2013 [12].

Usually, the demarcation line for old age in the general population is 60 years or older [29]. Gorman describes the ageing process in general as “a biological reality which has its own dynamic, largely beyond human control” [37]. In the prison context one refers to accelerated ageing and there are several contributing factors to this phenomenon. A history of drug and/or alcohol abuse, insufficient

<sup>2</sup> Figure from Executive Summary, World Population Ageing 1950-2050, by Population Division, DESA, © 2013 United Nations. Reprinted with the permission of the United Nations.

diet, infectious and other types of diseases in combination with limited health care access before imprisonment facilitates premature ageing [28,60,76]. In the prison context, this adds up to 10 to 15 years [39] which means that 50 year old prisoners depict the health status of a 60 year old person living outside prison. Still, there exists no empirical evidence supporting this phenomenon [81]. Yet, in a review, Loeb and AbuDagga [54] identified the age of 50 as the most often cut-off age used in the literature on ageing prisoners.

### **The Population of Ageing Prisoners**

The growing population of ageing prisoners can be generally classified but they are not homogeneous and consist of different groups<sup>3</sup> [47]: (1) offenders who committed a severe crime and grew old in prison, (2) late first-time offenders who committed a crime when they were already old or (3) offenders who had a long prison history with leaving and re-entering prison constantly throughout their life (recidivists) [2,7,8,46]. Certainly, they represent a special population among the general prison population [2,71]. This is also attributable to sentencing policies since some of the actual aims of imprisonment like deterrence and rehabilitation seem to lose their effect when applied to older prisoners, calling into question the objectives of punishment [47]. Prisoners who are at the retirement age or who approach it do not belong to the target group of rehabilitation programs anymore [47,85]. Or even worse, incapacitation and retribution mirrored in long prison sentences can actually turn into a life sentence for older prisoners [85] and can represent a capital punishment [47].

Moreover, correctional facilities were designed to house fit and able-bodied people [25,39,46,61]. Older prisoners with their declining abilities have to adjust to the unsuitable environment inside prison with only few cells in prison adapted to their special needs [49]. Still, especially long-term prisoners tend to feel connected to the environment they have been living in for many years which is also due to the disappearing connections and contacts to the outside world. Institutional dependence and prisonisation [16,62] is obviously not limited to this age group, but it can be much more distinct than for other groups [6]. Prisoners in general and ageing prisoners in particular pose unique challenges and costs for the prison administration [47,56,65] as the (health) problems that prisoners usually have can be aggravated by the ageing process [6]. In addition to that, outdated and overcrowded facilities make it even more challenging to address the matters of punishment and housing for ageing prisoners [3].

### **Increasing Health Care Costs**

The positive effects of longer life expectancies and the rise in prices and costs for medical treatments [57] are accompanied by a slow but steady increase in health expenditures in Switzerland [73]. This is caused by the typically deteriorating health of people with an increased age [29]. Likewise, the costs for health care supply in correctional facilities have been rising [7,57,61]. Partly due to quality improvements and the amount of care provided [57]. According to numbers, in 1999 ten to twenty percent of the prison resources in the USA were spent on health care costs [58]. When comparing the amount of health care costs of an older inmate (in this report older than 60 years) with a typical adult

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<sup>3</sup> Different categorisations can be found in the literature, ranging from groupings into two [47,85] to four [24,27], being based on the same criteria.

inmate it is three times as much and also puts more pressure on the prison administration and their budget [57].

It is noteworthy that prisoners seem to use health care services more regularly than the general population [8]. An explanation could be that prisoners live in a system where their self-care is restricted as they have to access the health care service for any kind of medication or any medical product [55]. This is done for security reasons not comparable to the use of pharmacies by individuals outside prison [8]. But also the general health status of ageing prisoners has an effect on their health care use. McDonald even calls them “disproportionately heavy consumers of health care services” [57]. The above mentioned increasing numbers of ageing prisoners will therefore lead to an increase of health care expenditures in the correctional system at the same time [8].

### **Ageing Prisoners Health and their Health Care Needs**

Health care in prison is complex [56]. Prisoners of all ages have a worse health status than that of the general population [17,72]. The health care needs of younger and older prisoners differ tremendously as the rates of illness in older prisoners are higher [33,86], despite the fact that they benefit from an improved diet, reduced drug/alcohol use and medical treatment inside prison [22,76]. With the ageing prison population, chronic diseases are more prevalent which correspondingly leads to higher health care costs [1,60]. Physical conditions of ageing prisoners include hearing loss, poor eyesight, dental problems, diabetes, cardiovascular or respiratory problems [4,38]. The unique conditions of ageing offenders require them to get special medical care and devices like corrective aids and ambulatory equipment in comparison to younger offenders [24,28]. Furthermore, compared to the general population the prevalence of mental disorders like personality/behavioural disorders, depression and dementia is very high [33,69]. This can be explained, amongst other things, by the de-institutionalisation process of chronically mentally ill from psychiatric hospitals in the past. Also, the failure in treating mental illnesses in society before crimes are committed and the effect that imprisonment can have on human beings contributes to this fact [30]. To sum up, numerous individual and environmental factors influence the mental health of ageing prisoners [46]. For all these reasons, the physical and mental impairments are exponentially aggravated in older prisoners [24]. An increased use and need of health care services in- and outside prison is the consequence of such conditions [24,38].

The nature of the prison health care system also has a severe impact on this special group inside prison. Usually, prisoners have to sign up for a visit at the health care service, but it can be very difficult for physically impaired inmates to walk long distances to access facilities [39,46]. In addition to that, old, poorly designed and not well maintained prisons in themselves pose a risk to health [32,35]. Correctional facilities are not equipped to handle the health care needs of ageing prisoners, especially the need for adapting the environment with handrails, elevators, wider doorframes, adjusted beds or sanitary facilities [7,67]. Due to their physical health they may not be able to participate in work or exercise programs [47,78]. In other words, it appears that health care needs of ageing prisoners are

often not met [54]. Therefore, it is crucial to provide special services for them to meet their health care needs [1].

Another topic related to health care is the provision of end-of-life services. With the rising numbers of older prisoners the likelihood of them dying in prison increases [53]. This is already statistically reflected in numbers from the USA [50]. Therefore, end-of-life care needs to be either offered in prison or the possibility of seeking care for the prisoner outside prison should be maintained.

### **Ethical Issues in the Health Care for Ageing Prisoners**

Ricoeur defines ethics as “to live well, with and for others, in fair institutions”<sup>4</sup> [66]. Poor health care, the lack of availability of health care services or the withdrawal of health care is not part of imprisonment and of its inherent aim of punishment [43,50]. Imprisonment means deprivation of freedom of movement/liberty [15], but it does not mean deprivation of one’s right to health [45,52]. The right to health<sup>5</sup> includes adequate nutrition and housing, the right to prevention, treatment, control of diseases and equal and timely access to basic health services and it “is relevant to all States: every State has ratified at least one international human rights treaty recognising the right to health” [84]. It is also explicitly mentioned that facilities that provide health care services to the population should respect medical ethics [84]. Still, the tension between care and custody makes it very challenging to adhere to ethical principles.

Prisoners should not be discriminated because of their legal status and therefore should be able to access health services offered to the public [19,77]. Unfortunately, this is not always the case and it happens quite frequently that access is not granted [21]. The group of prisoners consists of individuals that are mostly socially disadvantaged which renders them more vulnerable to abuse and neglect [38,23,83]. The *Council of Europe* pointed out in Recommendation 93(6) that the “respect for the fundamental rights of prisoners, in particular the right to health care, entails the provision to prisoners of preventive treatment and health care equivalent to those provided to the community in general” [18]. The *European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) Standards* emphasises that “prisoners are entitled to the same level of medical care as persons living in the community at large. This principle is inherent in the fundamental rights of the individual” [20] and at least the 47 states (2015) who are party to the *European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment* should adhere to it. The principle of equivalence of care is one of the key aspects of medical ethics in the prison context as set out by the CPT and demands that prisoner’s health care should be equivalent to the provision of health care to the general public.

This principle is equally used to evaluate the standard of care in prisons [15]. Included is for example the adequate access to health care services, the quality of health care and the procedure of health

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<sup>4</sup> “visée de la vie bonne, avec et pour les autres, dans des institutions justes”.

<sup>5</sup> The full name of the right to health as used by the World Health Organization (WHO) is “The right to the highest enjoyment of the highest attainable standard of physical and mental health” [84].

care provision in- or outside prison. Its impact on the provision of health care in correctional facilities has been interpreted differently, as well as the implications that the principle has for this sector. Jotterand and Wangmo argue that “the principle of equivalence of care should go beyond equivalence to access and include equivalence of outcomes” [45]. Whereas Lines claims for the promotion of standards that achieve “equivalence of objectives” which means that the health care standards inside prison should be even higher than the ones available in the community [51]. These differing explanations illustrate the wide spectrum of how the principle of equivalence of care can or should be implemented in prisons. Another major challenge in the application of this principle is the realisation of ethical principles such as a trustful physician-patient relationship, confidentiality, beneficence or autonomy, during health care provision in prison [43,83].

The lack of qualified personnel working in health care units in correctional facilities has also been mentioned as a barrier to high-quality health care in the literature [24]. Adverse effects for the health of older prisoners due to ill-treatment or lack of knowledge – in particular of geriatric knowledge – could be a consequence.

### **The Use of Restraint in Institutions**

Access to health care facilities that are located outside prison is of major importance in order to provide equivalent care to offenders. For the transfer to these facilities, most systems apply a security driven approach which means that prisoners have to wear handcuffs and often or sometimes (according to the countries and contexts) also shackles while being transported. This practice is especially burdensome for ageing prisoners as their physical condition does not tolerate being put in stiff positions as easily as younger and fitter prisoners. Several court rulings indicate that the use of handcuffs must be necessary and proportionate to the assessed risk that an offender could pose to society [21]. In the decision *Hénaf v. France* of the *European Court of Human Rights (ECHR)* in 2004, the applicant described the use of handcuffs and chains during the transfer to the hospital as “being a routine of abnormal and degrading practice”. In this case, the prisoner was restraint to the bedpost with a chain attached to his ankle during the hospital stay, even though he did not pose a danger to himself or others at the time. The ECHR ruled that this treatment amounted to inhuman treatment and thus had been a violation of Article 3 of the *Convention for the Protection of Human Rights and Fundamental Freedoms*. Prisoners are not the only ones who have to face restraint measures on a regular basis. It is still a common practice in some hospitals and nursing homes to restraint patients that appear to be difficult and problematic.

## **Research Aims**

Currently, there is no empirical data available on the health care situation of ageing prisoners in Switzerland. The aims of this thesis are therefore to provide information on the current health care situation of ageing prisoners in Switzerland, to better understand the legal and practical settings of health care provision for ageing prisoners and to analyse the ethical issues that arise from the need to provide adequate health care to inmates in the context of an increasingly ageing prison population.

To fill these gaps of research, this thesis focuses on the following objectives:

- 1) Development of a theoretical overview about ethical issues in prisons relating to ageing prisoners.
- 2) Examination of the legal framework and regulations that address' the health care for ageing prisoners.
- 3) Identification and investigation of stakeholders' attitudes from three European countries regarding equivalent health care for ageing prisoners. The results thereof shall be used to identify the difficulties that stakeholders see in the provision of equivalent health care for older offenders.
- 4) Exploration and comparison of the somatic disease burden of younger and older prisoners in Switzerland based on their medical records. Followed by an examination of the results whether possible differences can be explained by age group and/or time served in prison.
- 5) Analysis of ethical issues and legal regulations of restraint measures in different (health) care establishments in Germany and Switzerland in order to see how this matter is addressed in an institutional context. These findings could serve as an example for health care provision outside prisons when applying the principle of equivalence.

## **Outline of the “Agequake in Prisons” Project**

This thesis is embedded in the project “Agequake in Prisons: Reality, Policies and Practical Solutions Concerning Custody and Health Care for Ageing Prisoners in Switzerland”. It is a project funded by the Swiss National Science Foundation (SNSF). The core project team consists of Prof. Bernice Elger, Dr. Tenzin Wangmo, Violet Handtke and me, Wiebke Bretschneider. The wider team comprises all co-applicants: Prof. Christophe Büla, Prof. Alberto Holly, Prof. Marcelo Aebi, Prof. Nikola Biller-Andorno, Dr. Astrid Stuckelberger and Dr. Julie Page. The project was supported by all co-applicants and many additional national and international collaborators from various disciplines. It is the first project in Switzerland that focusses on the health care of ageing prisoners in the correctional system. In this study, economic, medical, legal and ethical aspects are addressed and combined. The gathered data allows for a detailed analysis of health care information, such as number of disease, medication taken or access to (specialised) physicians.

The project officially started in October 2011 and will be completed in July 2015. It is a multi-centre study which applies a mixed-methods approach. The combination of qualitative and quantitative research was used to generate knowledge on the health care of ageing prisoners. For the data collection different tools were used. On the one hand a data extraction sheet was designed and used to facilitate data collection. On the other hand two semi-structured interview guides were developed, one for the stakeholder and one for the prisoner interviews. In addition to the interviews, a geriatric assessment was undertaken to evaluate the geriatric condition of interviewed prisoners.

### **Data Collection**

The process of data collection started in November 2011 and comprised a quantitative and a qualitative part that are briefly described in the following paragraphs.

#### *Quantitative Part*

The quantitative part of the data collection was undertaken in the German and French speaking cantons of Switzerland. Out of 109 prisons in Switzerland, 26 fulfilled the previously defined inclusion criteria. The inclusion criteria were prisons in the French and German speaking parts of Switzerland with (1) more than 20 places, (2) housing long-term prisoners and (3) housing older prisoners at the time of request. A participation rate of 57.7% (n=15) was obtained. From these participating prisons, 406 medical records were analysed which is a very frequent used data source to analyse the health care of prisoners, especially of older prisoners [54]. This sample is composed of 203 datasets from younger prisoners (below the age of 49) and 203 datasets from prisoners above the age of 50. In total, the sample consists of 122 datasets from French speaking cantons and 284 from German speaking cantons. All medical records of prisoners older than 50 years who were living in the respective prison and that agreed to participate were included for data collection. The same number of medical records from younger prisoners was analysed.

### *Qualitative Part*

The qualitative part of the study can be divided into two sub-parts: interviews with 35 prisoners and 40 interviews with stakeholders. Dr. Tenzin Wangmo and Dr. Catherine Ritter, who are members of the project team, supported the stakeholder data collection process. The remaining interviews with stakeholders and prisoners were conducted by Violet Handtke and me, Wiebke Bretschneider.

#### **Stakeholder Interviews**

In total, 40 interviews with stakeholders were conducted in three different European countries. The aim was to get a broad variety of people who work in prisons or whose work is related to the prison system to participate in this project. Their age ranged from 32 to 69 and their professions included for instance researchers, prison directors, health care and social workers.

#### **Prisoner Interviews**

Participants had to be older than 50 years, their health condition had to be satisfying and they had to have decision-making capacity. Prisoners who did not fulfil these criteria were excluded from interviews. All 35 prisoners were interviewed in prisons located in the German or French speaking parts of Switzerland. Their age ranged from 51 to 75. As mentioned before, the interview was divided into two parts. First, the questionnaire was completed then a comprehensive geriatric assessment followed. It consisted of the SF-12 (Functional Health and Well-being), MMSE (Mini Mental State Examination), CDT (Clock Drawing Test), Barthel Index (of Activities of Daily Living), MNA (Mini Nutritional Assessment) and the GDS-15 (Geriatric Depression Scale) to assess the functional independence and the need for assistance. This was done in order to get an overview about the physical and mental limitations that older prisoners have.

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## Chapter 1

# **Facing the Challenges of an Increasingly Ageing Prison Population in Switzerland: In Search of Ethically Acceptable Solutions**

Handtke, V., Bretschneider, W., Wangmo, T., Elger, B. (2012). Facing the Challenges of an Increasingly Ageing Prison Population in Switzerland: In Search of Ethically Acceptable Solutions. In *Bioethica Forum*, 59(4), 134-141.

# **Facing the Challenges of an Increasingly Ageing Prison Population in Switzerland: In Search of Ethically Acceptable Solutions<sup>1</sup>**

## **Summary**

The ever-growing population of ageing prisoners poses new challenges for prisons in Switzerland. Therefore, the principle of equivalence of care is used to explore and evaluate two health care related concerns of this special group: (i) declining abilities of older prisoners can pose enormous challenges to navigate in the prison environment with an architecture that is not age appropriate, (ii) another factor is the provision of end-of-life services in prison. Possible solutions like palliative and hospice care as well as compassionate release are examined. The need to find ethically acceptable ways of providing special health care services for ageing prisoners is discussed. Special emphasis is put on new obligations for health care professionals and stakeholders that are related to the correctional system.

## **Introduction**

The rise of the ageing population confronts society with unknown challenges. There are several factors that contribute to this development like decreasing birth rates and increasing life expectancy due to the efficient improvement of health care [1,3]. The greying of our society has an impact on nearly all aspects of life [7]. Especially the health care system is burdened by the steady rise of older people as health expenditures for this group range from one third to half of the total costs [1]. This development also influenced the composition of the prison population in Switzerland where the number of ageing prisoners is rising likewise. Older prisoners are considered to be 50 years and older due to the so called accelerated ageing process which attributes the health condition of a 60 year old person living in the community to them [10,18].

In addition to that, Switzerland has a unique system of separation of powers and 26 cantons that have their own constitutions and courts [26]. The cantonal constitutions include competences such as legislative powers to enact health care laws which results in a diversified prison system and huge differences in health care provision for prisoners within one country.

Still, the principle of equivalence of care as set out by different international intergovernmental organizations calls for health care in correctional institutions that is equivalent to that provided in the wider community [6,16,29,30]. Two health care related challenges that older prisoners have to face are addressed in this article. Furthermore, the framework of the principle of equivalence is used to examine ethically acceptable solutions.

## **Equivalence of Care – What Does this Mean in Prison?**

In 1982, the principle of equivalence of care was brought up for the first time in the United Nations document “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” [29]. Several other guidelines and regulations cite and refer to the principle of equivalence. Still, it is mainly a European phenomenon [8,11] due to the special human

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<sup>1</sup> This text is a summary of the original paper. The full text can be found in the PhD thesis of Violet Handtke.

rights framework with a close connection to the European Courts of Human Rights and the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. Also, the Swiss Academy of Medical Sciences mentions the principle of equivalence of care in its guideline “The exercise of medical activities in respect of detained persons” [27].

Even though these guidelines have been issued many years ago, it is still challenging to enforce the recommended practice in the correctional system in Switzerland and in other countries. Prisons itself constitute a closed environment and are therefore very different from the community [2,9]. The special and unique health care needs of older prisoners have to be addressed in order to guarantee for adequate health care access and treatment options. One of the main differences in prisons is the lack of free choice of one’s physician which means that treatment inside prison is mainly provided by the employed physicians. For prisoners it can be extremely burdensome to access specialised physicians outside prison or get a second medical opinion, despite the fact that this practice is recommended [6]. Physicians working inside prison also have to face difficulties. For them it is equally challenging to adhere to the principle of equivalence when they are under pressure to save costs and have to practice in less well-equipped health services than outside [2]. Other factors like security and organisational aspects also negatively influence their work in this environment [24].

The different ways of interpreting and practically applying the principle of equivalence can also lead to a variety of standards which hinders its uniform use. Therefore, it is very important to introduce specific characteristics for medical treatments to be able to know which of these have to be fulfilled in order to be considered equivalent. A focus should be put on the “why” and not on the “how” this principle should be adhered to in correctional facilities. Emphasis should be put on human dignity and its respect towards prisoners. Based on our shared humanity the provision of equivalent health care is an obligation that cannot be neglected for reasons of punishment. With imprisonment, the person loses the ability to care for her-/himself which renders the state responsible for the well-being of this person, which also includes the provision of health care [5].

To achieve equivalence in prison, it is necessary to provide health care of the same quality and standard like outside prison, which also includes the outcomes of medical interventions. Like mentioned before, the implementation of this principle in the day-to-day prison life is very complex [16,21]. In order to facilitate this procedure, the following steps should be taken: employment of health care staff independent from the prison administration and employment of staff trained to work in prison with an education adjusted to the needs of the prison population and in particular to the ageing prison population.

### **Accommodation of Older Prisoners**

For ageing prisoners it can be very challenging to adapt to the prison environment. but it is particularly important for elderly people to live in an environment that is appropriate to their age as it affects their health and well-being [31]. Prison architecture was prominently influenced by the picture of a young and strong inmate which resulted in buildings with the key task of guaranteeing a high level of security [19]. The lack of short distances to reach work, to go to the health care service or just the long way to the dining area three times a day can be very burdensome for older prisoners. In adherence to the

principle of equivalence of care, changes should be made in order to meet the special needs of ageing prisoners and to make prisons also an “age friendly” place. Restructuring of prisons or prison wings would be one way to decrease distances and increase the comfort, but also the adjustments of cells with higher beds, more light and sanitation that is equipped for the disabled could provide compensation for the declining abilities of older prisoners. Even the design and building of new correctional facilities adjusted to ageing prisoners’ needs could be a solution. Here, the location of these new prisons is of high importance as the reachability and easy access of hospitals and other specialized health care centres need to be guaranteed. This implies that these new facilities would need to be built in cities or close by [20].

On the other hand, there is still a dispute about how ageing prisoner should best be housed – separated from the general prison population or mixed with younger prisoners [20,23]. Different arguments that support both types of housing exist. Separate housing sites would facilitate the provision of specialised care like long-term, palliative and hospice care [28], whereas the mix of younger and older prisoners is said to have a positive impact on both groups.

Due to the heterogeneity in the group of older prisoners the prison system has to be flexible and adjust to their needs [17,20]. For long term prisoners it might be preferable to age in place, in the prison that grew to be their home opposed to late onset offenders who may have major problems in their new environment. These different needs of ageing prisoners have to be considered and likewise have to be reflected in the prison budget as the housing requirements of older prisoners must be taken into account.

### **End-of-Life Care and Death in Prison**

With the growing number of ageing prisoners, the prison system is facing new challenges relating to end-of-life care and death [13]. To this point, the needs of physically frail prisoners are not met in their current accommodation situation. No palliative or hospice care units can be found in Swiss correctional facilities. In the USA, services like that can be found in some prisons [12,14,25] and positive outcomes have been reported [4,15].

According to the principle of equivalence of care, prisoners at their end-of-life should be adequately cared for, should be supported in their activities of daily living, should have the possibility of being connected with their family and should have psychological and/or spiritual counselling offered to them. There is a lack of these services in most prisons in even highly developed nations which has led to an intense debate about compassionate release for old and sick prisoners [22,32]. Due to security concerns, a long administrative process and other reasons, compassionate release is only rarely granted [13,32].

Certain prerequisites have to be fulfilled to be eligible for compassionate release. In the USA, this must be an incurable, terminal disease. For prisoners with neurological diseases like Alzheimer’s or other dementias, this means that in most cases they do not meet these criteria. In case compassionate release is granted, it has to be ensured by the prison authority that adequate care for the released prisoner is guaranteed privately by family members or officially by care institutions.

## **Discussion**

Prisons constitute a challenging environment for ethical behaviour and decisions. To overcome this, health care staff should integrate as many actors as possible, i.e. public authorities and institutions, to find individual solutions for the health care needs of ageing prisoners and to realize equivalence of care inside prison. There are different ways of addressing the described challenges that the prison system has. Different approaches are acceptable, but should not lead to false compromises. Health care staff is responsible to point at poor conditions and not to accept short-term solutions that turn into long-term solutions as this is not compatible with the principle of equivalence.

Some solutions are related with additional costs, but there are also some that could lead to costs savings for prisons. One example would be the compassionate release of older prisoners that do not pose a threat to society anymore. Either because they are too sick or evaluated not dangerous.

It is urgently needed that health care providers in the prison system state the existing difficulties as they are the ones who know best. Actually, it is their ethical obligation to do this.

## **Conclusion**

Ethically acceptable solutions are urgently needed in order to address the new challenges that are connected with the rising numbers of ageing prisoners in the correctional system. The principle of equivalence of care is a helpful tool to support this process. A first step is to identify different solutions already used in Swiss cantons. It is an ethical duty of health care staff working in prisons to also look for long-term solutions and not for ones of a temporary nature only. In order to stimulate a broader discourse, it is also necessary for them to engage in and to support research activities in the prison setting. This is of high importance for the establishment of an ethically and scientifically sound decision making process.

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## Chapter 2

### **Ageing Prisoners' Health Care: Analysing the Legal Settings in Europe and the United States**

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## Ageing Prisoners' Health Care: Analysing the Legal Settings in Europe and the United States

*"The mood and temper of the public with regard to the treatment of crime and criminals is one of the most unfailing tests of the civilisation of any country." W. S. Churchill*

### Abstract

**Background:** Relatively little is known about the current health care situation and the legal rights of ageing prisoners worldwide. To date, only a few studies have investigated their rights to health care. However, elderly prisoners need special attention. **Objective:** The aim of this article is to critically review the health care situation of older prisoners by analysing the relevant national and international legal frameworks with a particular focus on Switzerland, England and Wales, and the United States (US). **Methods:** Publications on legal frameworks were searched using Web of Science, PubMed, MEDLINE, HeinOnline, and the National Criminal Justice Reference Service. Searches utilizing combinations of keywords relating to ageing prisoners were performed. Relevant reports and policy documents were obtained in order to understand the legal settings in Switzerland, England and Wales, and the US. All articles, reports, and policy documents published in English and German between 1774 to June 2012 were included for analysis. Using a comparative approach, an outline was completed to distinguish positive policies in this area. Regulatory approaches were investigated through evaluations of soft laws applicable in Europe and US Supreme Court judgements. **Results:** Even though several documents could be interpreted as guaranteeing adequate health care for ageing prisoners, there is no specific regulation that addresses this issue completely. The Vienna International Plan of Action on Ageing contributes the most by providing an in-depth analysis of the health care needs of older persons. Still, critical analysis of retrieved documents reveals the lack of specific legislation regarding the health care for ageing prisoners. **Conclusion:** No consistent regulation delineates the provision of health care for ageing prisoners. Neither national nor international institutions have enforceable laws that secure the precarious situation of older adults in prisons. To initiate a change, this work presents critical issues that must be addressed to protect the right to health care and well-being of ageing prisoners. Additionally, it is important to design legal structures and guidelines which acknowledge and accommodate the needs of ageing prisoners.

### Introduction

This paper discusses the legal guidelines pertaining to health care situations of ageing prisoners. In our society, prisoners constitute an isolated group as they live in an enclosed environment that is neither accessible nor visible to the public. Their freedom is restricted, and they remain dependent on the prison structure and management. In addition to the vulnerability that comes with being imprisoned, older prisoners are at a bigger disadvantage because of their increasing age and greater age-related health care needs [20]. Luna [22] conceptualized an approach called 'layers of vulnerability', which is highly applicable to the context of older prisoners' health care since they gain layers of vulnerability as they become older. In this context, Tarbuck [35] denotes this group as 'doubly

disadvantaged' because their age, situation, current health problems as well as their consequent health care needs constitute additional burdens. Furthermore, Rubenstein [31] states: 'The older person in prison is overlooked and ignored', which exacerbates their vulnerability as their needs are disregarded and their rights to proper health care remain grossly neglected.

In addition to greater risks for discrimination, the generally poorer health of older prisoners contributes to their vulnerable position. For instance, older prisoners suffer from more medical conditions compared to younger prisoners, and their disproportionate use of prison health care is an additional compounding factor [2,6]. These, along with other problems associated with prison such as overcrowding, lack of staff, and inadequate financial resources, can increase their difficult situation [26].

In contrast to research that discusses the vulnerabilities of prisoners, other studies claim that ageing prisoners adapt well to the prison setting, where their particular needs are better met [33,30]. Schnittker and John [32] argue that incarceration might even result in some health benefits. This can be due to the better diet and supportive activities offered in prison [18]. Lesnoff-Caravaglia [19] stresses that receiving regular meals, having the possibility to rest often, and access to health care provides older prisoners with an advantage over lower- and middle class men who are not imprisoned. In many cases, fulfilment of prisoner's right to health care depends on the organisational aspects of the prison environment, the attitude of the prison staffs towards prisoners, and the level of attention paid to ageing prisoners. Despite these positive side effects, imprisonment can also affect the health in many different ways through stressors such as violent behaviour of other inmates [32]. The mixed results were highlighted in an Israeli study, in which ageing prisoners considered their imprisonment both as blessing and punishment [10].

Still, the right to health care and access to it is an important issue for all prisoners<sup>1</sup>, young and old. The main purposes of imprisonment are retribution, deterrence, incapacitation, rehabilitation, and protection of citizens, but not the deprivation of prisoners' right to health [2,15,33]. However, prisoners often receive substandard care, and entering a prison interrupts their daily life routine [2,33]. Living in prison and the prisoners' lifestyle before incarceration affects their physical health, their ageing process as well as their mental health. The resulting adverse consequences are evident from the overrepresentation of persons with poorer health in prisons [3,38].

In addition to these health burdens, prisoners tend to age faster than the general population. This is because prisoners who are 50 years old suffer from diseases similar to those from which 60-year-old persons living in the community suffer [12]. This phenomenon is termed 'accelerated ageing' [38]. Based on this higher biological age of prisoners, most studies in prison define older prisoners as those who are 50 years or older [31]. Thus, the cut-off age for older prisoners is different from that of older adults in the community. We use this lower cut-off limit of 50 years to denote older prisoners. However, it should be noted that the World Health Organisation (WHO) refers to the United Nations (UN) agreed cut-off age of 60 years for older persons.

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<sup>1</sup> Since there are diverse organisational structures of imprisonment in Europe and the US, prisoners are referred to all individuals who are detained in jails, prisons, penitentiaries of different security levels, and any other kind of detention facilities.

Literature on the health care situation of ageing prisoners is available to varying degrees in different countries. Studies and reports evaluating the health and well-being of older prisoners have highlighted the physical [11,14,23] and mental health problems [16] that older prisoners face, and have also revealed the current state of health care services [4,29,40]. Others have examined the presence of special policies or programs for elderly inmates aimed at improving their circumstances in prison [1,27]. Still, the knowledge that we have so far does not provide a full picture of rights to health care and health care needs of older prisoners. This is concerning in light of the rising number of imprisoned people. For instance, according to the 8<sup>th</sup> edition of the World Prison Population List, there were over 9.8 million persons detained in penitentiary facilities in 2009, representing an increase of 12% over a period of 6 years. The growing number of prisoners points to an increasing number of elderly prisoners, who have either aged in prison or entered prisons at old age. Several factors have contributed to this increasing prison population including greater call for public safety, more older people being imprisoned, and longer prison sentences as part of policies such as the 'Three strikes (and you are out)' policy in the United States (US) [15], and the 1997 Crime (Sentences) Act in England and Wales. Therefore, the aim of this article is to present the current health care situation of older prisoners by critically analysing the relevant national and international legal frameworks, with a particular focus on Europe and the US. In Europe, concerns related to the problem of the growing number of ageing prisoners are particularly addressed by Switzerland and England and Wales<sup>2</sup>. They are thus used as case example to represent two different national models in Europe. Such a comparative analysis between two countries of Europe and the US is important to understand the current practices and experiences in these countries so as to best address health care needs of ageing prisoners.

## Methods

Using keywords relating to ageing prisoners, older prisoners, health care in prison, and prison law, computer-based searches were performed with the following databases: Web of Science, PubMed, MEDLINE, HeinOnline, and the National Criminal Justice Reference Service. All articles, reports, and policy documents published in English and German between 1774 and June 2012 related to the topic were included for analysis. No restrictions on the type of article (literature review, research study, case analysis, legal document) were set. Furthermore, all reference lists were checked. Additional searches were done to ensure that all relevant international regulations and conventions on this topic were analysed.

This search produced a total of 349 documents which were subsequently assessed for relevance. Only 71 met the standards for inclusion, comprising 42 papers, plus 7 national, 6 European, and 16 international documents/regulations/reports.<sup>3</sup> All documents mentioning the health care needs of elderly prisoners and legal guidelines implicitly or explicitly applicable to ageing prisoners' health care situation were included in this analysis. With a comparative cross-national approach, an outline was completed to distinguish positive policies in this area and to specify where changes are needed.

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<sup>2</sup> Northern Ireland and Scotland have different legal systems and are therefore not considered.

<sup>3</sup> For the entire list of references to the legal documents/guidelines, please contact the first author.

Regulatory approach on this issue was investigated using soft laws applicable in Europe and US Supreme Court judgements.

## **Results**

The legal settings regarding ageing prisoners' health care differ significantly between Europe and the US. In most European countries, the Department of Justice has the responsibility for prisoners' health care. In spite of existing soft law recommending the independence of health care services in prison, in only a few countries is the Department of Health in charge. In addition to highlighting the importance of an independent health service, this aims to avoid dual loyalty conflicts. In the prison setting, the responsible health care professionals continuously face conflicts between the duty to care for their imprisoned patients, the interests of the prison administration, and security considerations. Therefore, the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) points out the importance of professional independence in health care matters in the prison system, and recommends a close linkage between health care service of prisons and of the community.

Even though there are several documents that could be interpreted as guaranteeing adequate health care for ageing prisoners and addressing in particular their special needs, there is no specific regulation that completely informs this issue. From this in-depth analysis of relevant documents, it is evident that the terms 'advanced age' and 'other status' are prominently mentioned. The use of the term 'other status' leaves room for interpretations, which on the one hand is very advantageous as age could be a possible 'other status'. On the other hand, there is no legal rule affirming the possibility of applying these guidelines in the case of health care provision for ageing prisoners. The legal settings regarding the health of older prisoners are discussed here in detail, and are separated by country: Switzerland, England and Wales, and the US. This interpretation of national legal settings is followed by analysis of European guidelines, International law, and specific case laws that directly affect the formulation of regulations for older prisoners.

### *Switzerland: Older Prisoners' Health Care*

The Swiss Confederation comprises 26 cantons (states), each of which has different regulations concerning the health care of prisoners, and no centralised system. It is a civil law jurisdiction, and on the national level, there are three prison concordat (Strafvollzugskonkordate) agreements. These agreements should provide a certain level of cooperation and uniformity within the Swiss prison system. Although these concordats have several regulations, none describe the treatment of ageing prisoners or their special health care needs. In contrast, the Swiss Academy of Medical Sciences (SAMS) regularly publishes medical-ethical guidelines on different topics, and one from 2002 refers to 'The exercise of medical activities in respect of detained persons'. An addendum to these guidelines was published in 2012.

It is important to mention that these guidelines contain the 'principle of equivalence'<sup>4</sup> under point 5 and indicate that imprisoned persons are entitled to medical treatment comparable to that obtained by the general population. Therefore, Swiss prisons should offer ageing prisoners the same standard of health care that older persons in the community receive.

Importantly, Article 387 (paragraph 1 letter c) of the Swiss Criminal Code states that the Federal Council (Bundesrat) can approve additional provisions on the execution of punishments and measures for ill, fragile, and older prisoners. This means that there is a legislative competence which could and indeed should be exercised in order to set up regulations for ageing prisoners, and that addresses in particular their health care needs. The growing numbers of older people entering the prison system in Switzerland depicts the urgent need for a regulation. For instance, in 2003 there were 292 new older prisoner admissions in Switzerland, and this number was 521 in 2010. Federal statistics in Switzerland report that in 2010, there were 700 people above the age of 50 institutionalised in Swiss prisons [5].

#### *England and Wales: Older Prisoners' Health Care*

The legal system in England and Wales is different from that of Switzerland. Their common law judicial system is based on precedents and statutes. In Great Britain, the rights of prisoners were first established in 1774 with the Act for Preserving the Health of Prisoners in Gaol, and preventing the Gaol Distemper. This Act was the first Parliamentary legislation to specifically address health in prison. Although a very important step, its impact on the future handling of prisoners was minimal, made evident from the Prison Act of 1952. In this Act, only one section addresses the health of prisoners, concerning their discharge from prison for health reasons. Of course, one reason for the dearth of attention to prisoner health could be that this Act was written in the 1950s, when the health care of prisoners was not yet an important political or social issue.

The Prison Rules of 1999 provide a framework on health care of prisoners, but they do not contain an enforceable set of minimum standards. Interestingly, they introduce a classification of prisoners by age, which could have an impact on the possible future separation of older prisoners from other age groups in prison. The conditions for the temporary release of prisoners can be found in these rules as well, and is connected to prisoner's health and medical treatment. For England and Wales, it is important to mention that between 1995 and 2009 the prison population increased by 66% due to tougher sentencing. Changes in legislation and policy led to an increased maximum sentence. In December 2011, the number of imprisoned people in England and Wales was as high as 87,960 individuals. The population of prisoners aged 50 years and over in England and Wales in March 2011 was 7,147.

Furthermore, a change in the system of health care provision for prisoners took place in 2004 due to unacceptable conditions in prisons and the growing pressure to improve quality of health care

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<sup>4</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'.

for prisoners. The responsibility for prisoners' health care shifted from the Home Office (Department of Crime) to the Department of Health, i.e., the National Health Service (NHS). England and Wales' standard of health care in prisons is: 'to provide prisoners with access to the same range and quality of services as the general population receives from the National Health Service'. This means that the principle of equivalence is applicable for ageing prisoners in England and Wales, too. One of the Key Audit Baselines, issued in May 2004, states: 'Services take account of any special needs arising from ethnicity, disability, gender, age and religion' [13]. Still, scholars point out that a national strategy for ageing prisoners is lacking [8,39].

#### *The US: Older Prisoners' Health Care*

The legal system in the US is comparable to that in England and Wales, as the US also adheres to the common law jurisdiction. The US houses the highest number of imprisoned people worldwide. A major contributing factor to this is the high number of incarcerations for low-level or non-violent crimes, with long sentences. In their 2012 report *Old behind Bars - The Aging Prison Population in the United States*, Human Rights Watch (HRW) highlighted the alarming numbers of older prisoners in the country [15]. In this report, HRW concluded that the number of state and federal prisoners aged 55 or older increased from 1995 to 2010 by 282%, which means that 124,400 prisoners of this age group were incarcerated in 2010.

A particularly noteworthy fact about prisoners in the US is their legal right to health care services. The primary legislature used as a means to alleviate poor prison conditions is the Eighth Amendment to the US Constitution. This amendment prohibits infliction of cruel and unusual punishment, and is often utilized to ensure adequate provision of health care, including psychiatric care for inmates. In contrast, many Americans outside the prison system lack health insurance. However, budgetary restraints on correctional facilities are challenging the nation's ability to guarantee health care access to prisoners without diluting the quality of that care [24].

The Congress of the National Prison Association adopted the Declaration of Principles in 1870, and principle 33 states that '... hospital accommodations, medical stores and surgical instruments should be all that humanity requires and science can supply'. In their principle Protection, they state that 'contemporary standards for health care, nutrition, personal well-being [...] must be observed'. In addition, the rights designated for older adults through the Older Americans Act of 1965 and the Americans with Disabilities Act of 1990 are applicable to older prisoners as well.

The above-mentioned national guidelines and legislatures support adequate health care for all prisoners, and could be interpreted as promising fair and equal health care for ageing prisoners. Some states in the US provide prisoners of advanced age with special programmes, services or housing [1]. Particular examples include the Silver Fox programme and the Senior Living Unit at Central California Women's Facility [15]. Nevertheless, without a specific legal regulation, there is a possibility that certain groups of ageing prisoners are overlooked in some areas.

### *European Guidelines*

On the European level, it was only in the latter half of the 20<sup>th</sup> century that the health of prisoners was specifically addressed. In 1953, the key human rights document, the European Convention on Human Rights (ECHR) was released. The ECHR is one of the most important regulatory instruments in Europe, and the European Court of Human Rights is the judicial body that upholds the rights safeguarded by the ECHR. Although Article 3 of the ECHR is extensively used to support the right to health for prisoners [21], it was only in the 1980s that prisoners and their needs came into focus. This was due to revisions made to the Council of Europe's 1973 Standard minimum rules for the treatment of prisoners by Recommendation No. R (87) 3 on European Prison Rules<sup>5</sup>.

Another important piece is the Council of Europe's Recommendation No. R (98) 7, which addresses the problem of prisoners' advanced age in section III, letter C. It recommends that elderly prisoners should be accommodated in a way that allows them to participate in everyday prison life without being segregated from other prisoners. This is an interesting position as there are other trends which support the separation of aged prisoners to avoid exposure to additional stress or abuse by younger prisoners [25]. Recommendations have even suggested structural changes in prisons in order to put the principle of equivalence of care into practice.

To protect detainees in the member states of the Council of Europe, the CPT was established in 1989. One of its main findings on health care service in prisons at the European level is: 'An inadequate level of health care can lead rapidly to situations falling within the scope of the term "inhuman and degrading treatment"'. Regarding the cases of mentally ill prisoners, the CPT emphasises that the health care service in prisons should include the possibility to hospitalise these prisoners outside the prison system, in public health care institutions. It also concludes that this would be an appropriate measure from an ethical point of view. In case of ageing prisoners, a similar procedure could be applied to treat them appropriately. A strong point of criticism regarding the CPT's work is that it does not recognize ageing prisoners as a particularly vulnerable group that needs special attention. Prisoners of advanced age are only mentioned under point 'iv. Prisoners unsuited for continued detention', which is a rather weak statement, considering the magnitude of the ageing prisoners' problem. Hence, this should be urgently revised in order to address the unique needs of ageing prisoners.

### *International Human Rights Law*

On the international level, there are various regulations and recommendations which can be interpreted as securing health care for ageing prisoners. One of them is the International Covenant on Economic, Social and Cultural Rights (ICESCR). Although the rights of older persons are not explicitly mentioned in the ICESCR, a general comment on the economic, social and cultural rights of older persons was published under Point 13. This comment stresses the need for a convention for the rights of this subgroup, similar to the conventions for women and children, which are already in place.

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<sup>5</sup> Recommendation No. R (87) 3 of the Committee of Ministers on the European Prison Rules was replaced by Recommendation No. R (06) 2 of the Committee of Ministers.

Nevertheless, these documents have little impact as there is no enforcing power or resulting punishment associated with failure to conform to the conventions.

Principle 5 (2) of the UN Body of Principles for the Protection of All Persons under any Form of Detention or Imprisonment (1988) affirms that 'Measures applied under the law and designed solely to protect the rights and special status of ... aged, sick or handicapped persons shall not be deemed to be discriminatory. The need for, and the application of, such measures shall always be subject to review by judicial or other authority'. Thus, even though the protection of the aged persons would be possible in principle, in actual practice, there are no such measures.

In 1990, another step was taken when the UN Basic Principles for the Treatment of Prisoners (BPT) were adopted and proclaimed by General Assembly resolution 45/111. These contain the principle of equivalence in the following form: 'Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation', and state that there should be no discrimination on grounds of 'other status' (such as age).

The 1991 UN Principles for Older Persons points out different aspects of care. Under the heading 'Care', it states: 'Older persons should have access to health care in order to maintain or regain an optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness'. Furthermore, the principle 'Dignity' particularly mentions fair treatment regardless of age or any other status of the older persons. This statement clearly calls for equal treatment for older persons, and it should be applicable to prisoners as well. As mentioned above, the term 'other status' is used in most of these documents, and age of a person could also be implied as a 'status'. But as age is not particularly emphasised, it makes it difficult to apply and enforce these guidelines in practice.

The UN also published a broad range of documents refining standards and treatments of ageing persons. Point 27 of the 1st International Plan of Action on Ageing reflects the strongest stance on ageing taken so far. It states that 'The respect and care for the elderly, which has been one of the few constants in human culture everywhere, reflects a basic interplay between self-preserving and society-preserving impulses which has conditioned the survival and progress of the human race'. This opinion should be reflected in the prison system as well. Overall, the Plan points out the importance of 'adequate living accommodation and agreeable physical surroundings' for older adults. Of course inside a prison, adequate living space has an even bigger importance, since prisoners must spend all of their time in the prison or on the prison grounds.

During the second World Assembly on Ageing, which took place in 2002, a Political Declaration and Madrid International Plan of Action on Ageing was introduced. One of the central themes of this plan is the 'Provision of health care, support and social protection for older persons, including preventive and rehabilitative health care'. The implementation of necessary measures for the target group can be done in the prison setting much more easily, as the direct contact between patient and health care provider already exists. Moreover, the report stresses, under point 61, the need for adequate policies in order to forestall major cost increases by reducing disability levels.

The WHO's Health in Prisons Programme (HIPP) reveals that the special needs of minority groups in prison are too often ignored, even though a focus on ageing prisoners is lacking. The most

significant WHO document contributing to the health care of prisoners is the Moscow Declaration of 2003, also known as the Declaration on Prison Health as part of Public Health. The guiding principles of this Declaration are a summary of the four most important articles, principles and statements of the ICESCR, BPT, PME, and CPT Standards.

The 2010 Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment declared that detainees should continue to enjoy all human rights after being imprisoned. The report highlighted that detainees belong to the most vulnerable and forgotten sectors of our societies. It also pointed out that there is usually a strict hierarchical structure in prisons, in which elderly people, people with disabilities, and/or prisoners with diseases suffer the most [26]. Still, empirical data on victimisation of older prisoners is scarce [37].

### *Case Laws*

In Europe, there are a number of cases which deal with health care of prisoners. Three of them are closely considered here. The ECHR in *Kudla v. Poland* decided that the health and well-being of the imprisoned person has to be adequately secured. This judgement does not of course specifically address the case of an ageing prisoner, but can be cited in order to remind the responsible persons to safeguard this fundamental right. In *Price v. UK*, the Court defined the categories of ill-treatment that fall under the scope of article 3 ECHR. It sets a minimum level of severity that must be attained, but factors such as age of detained persons could alter the assessment. Finally, in *Mouisel v. France*, the court ruled that age is a factor that must be specifically addressed when assessing the suitability of a person for detention.

The judgements of the Swiss Justice System (Schweizer Bundesgerichtshof) do not provide sufficient information about the health care that older prisoners should receive or have the right to receive. For England and Wales, the compassionate release of Reginald Kray in 2000 and Ronald Arthur Biggs in 2009 are examples of how the prison system reacted to the situation of terminally ill prisoners [35], but no judgement regarding the health care of ageing prisoners exists.

So far, the US Supreme Court does not consider health care as a fundamental right. The only condition under which the US government is obligated to provide medical care is when people are imprisoned [34]. In *Estelle v. Gamble* (1976), the Supreme Court developed the concept of 'deliberate indifference'. This case dealt with prison health care issues and prisoners' right to health care and stated that: 'An inmate must rely on prison authorities to treat his medical needs ...' Furthermore, the Supreme Court judges concluded that 'deliberate indifference to serious medical needs of prisoners constitutes the 'unnecessary and wanton infliction of pain'. In 1983, the United States Court of Appeals (7th Circuit) decided in *Wellman v. Faulkner*: 'When a state imposes imprisonment as a punishment for crime, it accepts the obligation to provide persons in its custody with a medical care system that meets minimal standards of adequacy'. The report *At America's Expense: The Mass Incarceration of the Elderly* published in June 2012 clarifies that most prisoners still only receive a constitutional minimum level of care [2]. Despite this, Perlin and Dlugacz [28] noted a positive aspect, namely that some US courts refer to international human rights conventions as examples of the 'best practice' in this area, even in cases where the US did not ratify the convention.

## **Discussion**

Using legal systems in Switzerland, England and Wales, and the US, the problem of health care needs of ageing prisoners and lack of legal guidelines were analysed in this article. Only a handful of judgements discuss the right to health care and health care needs of prisoners. In most cases, they do so indirectly. The guidelines found in these judgements are not applicable on an international level. Therefore, they have only a limited influence. This lack of legally binding force creates an extra burden for older prisoners since there is no enforceable right to adequate health care.

Nevertheless, there have been several efforts to better the situation of prisoners, and it is important that governmental measures continue to be proactive and not reactive in order to create a solid basis for offering adequate health care to ageing prisoners. Also critical is to ensure that the measures appropriately respond to the needs of older prisoners, just as they do to other vulnerable groups like juvenile or female prisoners.

In light of the existing problem of lack of specific health care provision for ageing prisoners, more attention must be paid to their needs. So far, no one-size-fits-all solution exists to solve this problem worldwide. Scholars and policy makers do not agree as to what is or could be the best way to provide health care to this growing population and point to the urgent need for research to further develop the existing knowledge and search for novel and better solutions. Such solutions could include the development of training programs for correctional staff members working with ageing prisoners [7], continued training aimed at building up knowledge about the ageing process [17], and granting ageing prisoners access to primary and secondary physicians trained as geriatricians [36].

## **Conclusion**

In principle, ageing prisoners' needs are not fundamentally different from the needs of older persons in the general population [9]. However, the environment in detention facilities cannot be compared to that in the community at large. Therefore, the growing population of older prisoners will increase the burden on the prison health care system, and the resources critical to address older prisoners' health care needs are likely to be even greater than the costs for public health care services in the general ageing population.

After analysing the existing regulations and laws on this topic, it is evident that the status of prisoners is seldom considered. This may be due to the unpopularity of prison as a social and political concern. Another possibility is the lack of influence that ageing prisoners have. The prisoners' point of view could broaden the perspective on this topic, and the foremost aim should be to include them in discussions on how to improve their situation. Although imprisoned, they should be able to rely on legal support and the concern of a society to better their welfare.

While no international regulation (as of yet) specifically addresses health care for older prisoners, it is urgently needed to guarantee a minimum level of care and quality of life. One step towards ensuring better treatment of older prisoners is through the elaboration of legal regulations, recommendations, and other instruments which can cement their health care rights. Further attention and action are needed to ensure their concerns will be addressed. The following issues are crucial: (a) providing necessary health care for ageing prisoners, (b) providing an adequate supply of medications,

(c) attending to their special accommodation needs, (d) ensuring a comfortable workspace, (e) establishing age-appropriate working hours, (f) securing rest facilities during working hours and breaks, (g) adapting free time activities to their physical abilities, (h) developing and implementing educational programmes for prison staff, (i) arranging and incorporating palliative and end-of-life care, and (j) safeguarding ageing prisoners from violence and exploitation. Without a concrete and equitable policy for older prisoners, there is the danger that the needs and concerns of older prisoners will be overlooked. States and institutions have an obligation to act immediately and to set examples for other states. The first possible step towards guaranteeing adequate health care for older prisoners could be the adoption of an international standard. Thereafter, it would be the obligation of all states to introduce specific regulations and domestic laws that safeguard the well-being of older prisoners and assure that their health care needs are met.

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## Chapter 3

### **Expert Perspectives on Western European Prison Health Services: Do Ageing Prisoners Receive Equivalent Care?**

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# **Expert Perspectives on Western European Prison Health Services: Do Ageing Prisoners Receive Equivalent Care?**

## **Abstract**

Health care in prison and particularly the health care of older prisoners are increasingly important topics due to the growth of the ageing prisoner population. The aim of this paper is to gain insight into the approaches used in the provision of equivalent health care to ageing prisoners and to confront the intuitive definition of equivalent care and the practical and ethical challenges that have been experienced by individuals working in this field. Forty interviews took place with experts working in the prison setting from three Western European countries to discover their views on prison health care. Experts indicated that the provision of equivalent care in prison is difficult mostly due to four factors: variability of care in different prisons, gatekeeper systems, lack of personnel, and delays in providing access. This lack of equivalence can be fixed by allocating adequate budgets and developing standards for health care in prison.

## **Introduction**

The growing ageing population is a challenge for modern societies as they must respond to the familial, social, and economic costs associated with demographic changes. The trend towards greater numbers of older adults also is occurring amongst incarcerated persons, who now live and grow old in institutions that were not designed for older or dependent people [5]. This is creating significant challenges for prisons with regards to addressing the health needs of elderly inmates [6], which can be further compounded by the accelerated rate of ageing in prison. For example, a 50-year-old prisoner can suffer from diseases more often associated with those of a 60-year-old person in the non-incarcerated community [1,24]. In light of this, the term “ageing prisoners” will refer to those who are above the age of 50 years, which is consistent with other studies. As these studies note, the health care needs of elderly prisoners are generally not met due to the structure and location of the incarceration facilities [13,18,19,25,28]. The geographical position of many prisons can make it difficult to access health care services in a timely manner, and the generally old and poorly equipped buildings that house prisoners are often not suited to the needs of ageing prisoners, who may have greater difficulties navigating this environment [14,15]. These conditions and the fact that the prevalence of chronic mental and physical diseases is particularly high in elderly prisoners [11,17] frequently result in unmet health needs. Moreover, the rising proportion of older adults with dementia in prison [23,21] further complicates the provision of health care services in this setting.

Whether young or old, prisoners should be guaranteed access to a minimum standard of health care. According to the United Nations’ Principles of Medical Ethics, adopted more than three decades ago:

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* [30] (Principle 1, *emphasis added*).

Since this statement, the call to provide “equivalent” quality and degree of health care to prisoners as compared to those in the community has been adopted in various national and international guidelines [4,16,27]. The principle of equivalence also comprises “equivalent medical ethics,” i.e., the same ethical principles apply as outside prisons, including justice, respect for autonomy, non-maleficence, and beneficence [20]. Equivalence aims to ensure both ethically and legally acceptable standards of health care for detainees and the protection of their health and their human dignity despite their imprisonment. Even with its inclusion in national and international guidelines and the so-called *soft law* (recommendations by international bodies that are not fully binding), several authors express doubts as to whether the principle of equivalence of care is an ethically satisfying concept. For instance, Lines [22] pleads for health care standards inside prisons that are even higher than the standards outside, and Niveau [26] describes particular situations where the equivalence principle can be insufficient to ensure appropriate health care for prisoners. Others argue that the principle lacks sufficient clarity and therefore it is often left to prison health care personnel to decide how this principle is applied in prisons or to policymakers to determine how it is interpreted [2,10,31].

Despite these shortcomings, the principle continues to provide important guidance in the prison context, especially when it comes to ageing prisoners [29]. It has been argued that the principle should be applied as fully and inclusively as possible, meaning that access to all preventive and medical measures available in the general population should be granted to prisoners and in a timely manner [8,9,12]. Another aspect of this principle that needs to be integrated in prison medicine is respect for patient autonomy, including the right to refuse treatment and strict observation of patient confidentiality.

To determine whether the standard of equivalence is and can be meaningfully applied in all prisons worldwide is a methodologically difficult task. In this study, we therefore focus on relatively developed Western European countries where one would expect fewer obstacles to the realisation of equivalent care than in less prosperous countries or in countries that have not ratified the *European Declaration of Human Rights*. In a first explorative step, we decided to examine the experiences of different experts working in the prison context to illuminate their concerns regarding health care provided to ageing prisoners. The goal was to gain insights into the approaches that exist in countries with well-developed public health care systems with respect to the provision of equivalent health care to ageing prisoners. In this paper, we confront the intuitive definition of equivalent care with the practical and ethical challenges experienced by the experts. This examination also contributes to the often purely theoretical discussion as to whether equivalence of care is an ethically meaningful and sufficiently defined principle when applied in practice.

## Methods

Interviews were carried out with national and international experts working in prison settings in three relatively wealthy Western European countries (C1, C2, and C3) with developed public health care systems in order to seek their opinions and experience surrounding the care of ageing prisoners. The inclusion of three countries with somewhat comparable public health systems was deemed important so that comparison about practices could be made. C2 and C3, as well as some regions of C1, have previously engaged in regulatory efforts to implement the principle of equivalence in their prison medicine, and in most parts of C2 and C3 and some (but not all) regions of C1, independent community health services provide health care in prison. Ethics committee approval was obtained in C1 in 2011 and then consecutively in the two other countries. To protect anonymity, and taking into account the rather small community of people working in prisons and on prison-related topics, no country or participant identities are provided. The aim was to create an atmosphere of trust and openness during the interviews and to prevent stigmatisation.

Participant recruitment involved purposive and convenience sampling. On the one hand, experts were requested to participate in the study based on recommendations from study collaborators (names of possible interview candidates were given orally during project meetings or sent via E-Mail). On the other hand, contact persons within the health care service and the prison administration were asked to participate in the qualitative part of the study or to provide recommendations of those we should interview in the respective prison during quantitative data collection (the overall study applied a mixed-methods approach). Prospective participants were directly invited based on their working area. We also contacted several scholars who had previously published on the topic. All participants were informed about the study via e-mail or over the phone and joined the study voluntarily. Individual anonymity was guaranteed with the assurance that all data would be presented in a way that would not identify participants or particular prisons, cases, or situations. Cover letters specified that a cut-off-age of 50-years-old would be applied for a prisoner to be classified as an "ageing prisoner" and, if needed, the term was clarified during the interviews.

Semi-structured interviews were conducted with experts belonging to one of three categories: (a) health care professionals or researchers working in prison; (b) members of prison administrations (such as directors, personnel responsible for social reintegration) and policy makers; (c) members from relevant international and non-governmental organizations (IOs, NGOs) and ombudsmen. Policymakers included experts working outside of prisons, mostly from fields such as public administration and law.

During the interview, experts were asked about their personal experience in the prison context and their perceptions about health care access and provision of health care to ageing prisoners (in their specific region or country). Participants' opinions related to general conditions of elderly prisoners, such as environmental issues, retirement, activities in prison, and death and dying, as well as possible future improvements for this population.

Four researchers involved in the overall project conducted the interviews, which took place in French, German, and English. More than half of the interviews were done face-to-face. However, due to cost and time constraints, a sizable number of interviews participants located abroad were

conducted via Skype or telephone. Permission to record the interviews was obtained from the participants. Either the interviewer or project assistants transcribed all interview recordings in the original language. Transcribed documents were double-checked by independent assistants to ensure quality of gathered data and all identifying information was coded to ensure anonymity. Translation of quotes from French and German to English were carried out by bilingual assistants in the corresponding two languages and checked for consistency.

Analysis of the transcribed data involved a number of steps. First, data were read several times by the two authors to gain familiarity. Second, data were imported into the qualitative analysis software MAXQDA 11 to facilitate the coding process. The authors then independently coded the data, specifically searching for quotes where the principle of equivalence or related words such as “similar,” “same,” “equivalent,” or “equal” were mentioned. In addition, the authors looked for codes that directly or indirectly mentioned examples of equivalence or a lack of equivalence of care. Third, the authors discussed their respective codes and interpretations of participants’ statements. In addition, two more members of the research team (Violet Handtke and Tenzin Wangmo) were included in the process to discuss quotes and codes, respectively. Changes to the coding system were made based upon several team discussions. This paper presents the four problems most frequently reported by participants as interfering with equivalent health care for ageing prisoners.

## **Results**

A total of 77 national and international experts were contacted. Forty agreed to participate in the study, 11 experts refused participation, and 26 did not reply to the several requests made. Twenty-four experts were from C1 (14 from language region *a*, and 10 from language region *b*), and 16 were from C2 and C3. From the 40 interviews, three participants were members of international NGOs or IOs and they possessed experience in all 4 regions (C1a, C1b, C2, and C3). A total of 45 percent of the participants were physicians, health care professionals or researchers (hereafter HCP); 40 percent worked in prison administration (prison directors, personnel responsible for probation or social reintegration, etc.) or were involved in policymaking concerning prisons (abbreviated together PA); and 15 percent worked for an international organisation, an NGO, or an NGO-like institution, visiting prisons and investigating complaints (NGO/IO/Omb). All experts possessed several years of experience working in the prison field or with prison-related questions. They had direct knowledge of prisons with the capacity to hold between 40 and 450 prisoners and prison regimes that included open, semi-open, and closed correctional facilities (and even a combination of regimes in one prison). Prisoners’ length of sentences and times spent in each prison also varied. Some prisons housed mainly prisoners with long-term sentences or measures, other prisons had shorter average stays and therefore a less stable prisoner population. The experts we interviewed were between 32 and 69 years old (with an average age of 49.5 years), and 13 were female and 27 male. The average length of the interviews was approximately 70 minutes, with duration ranging from 30 to 115 minutes.

During the 40 interviews, several themes concerning ageing prisoners emerged, for example related to prison conditions in general, different criminological and judicial approaches, and health care aspects. In this paper we focus on experts’ experiences concerning general access to health care

in prison. Interviewees mentioned that equivalent care is difficult to achieve in prison and described four reasons accounting for this: the variability of care in different prisons, the presence of gatekeeper systems, a lack of personnel, and delays in the provision of timely health care. While these concerns impact general access to health care of both ageing and young detainees, the consequences affect ageing detainees more frequently and more severely because they are more often ill and in need of health services. Interviewees also indicated a range of other specific areas where health care for ageing prisoners is compromised such as handcuffing, end-of-life care, dental care, or limited access to special equipment. For reasons of space and due to the richness of the qualitative data we obtained, in this paper we will not focus on these latter aspects and instead address them in other forthcoming publications.

### *Equivalent Care Is Difficult To Achieve*

An important finding of our study is that expert's experiences in the three countries seem to be very similar. Many interviewees from all three countries referred directly or indirectly to the principle of equivalence of care. The general experience is that care "identical" to that outside of prison is difficult or impossible to reach in prisons, but that the provided care is still of a somewhat comparable level:

Actually, the fact that they are incarcerated makes it impossible for them to have access to the same care provided by physicians to the general population ... because this is in fact very difficult. We are starting in [our country]; the idea is to make it possible to offer the same quality of care in the prison environment as outside ... as much as it is possible given all the constraints of incarceration ... it is not exactly possible. Though [in the prison] where I am working I would say that this is true. ... I think that it [care] can be compared with the outside. (34 C3, HCP)

Lack of free choice of one's physician is one particular reason for the absence of equivalence of care in prisons: "The provision of equivalent care is of course not 100 percent possible. Well, the free choice of a physician does certainly not exist" (25 C1a, HCP). The complicated context of imprisonment also is a general obstacle to equivalent health care: "The circumstances in which we have to provide care in prison, well they are very complicated, because prisons are not built for providing care" (26 C1b, PA). Experts also report that it may be even more difficult to respect the principle of equivalence of care for ageing prisoners than for younger prisoners:

Already for a normal detainee, the principle of equivalence of care is very difficult to respect. ... So it is not surprising: for an ageing detainee – ... because he suffers from arthritis, because ... he has mobility problems – it is obviously even more difficult to respect it [the principle of equivalence] (31 C1b, NGO/IO/Omb).

However, a few interviewees felt that in some situations detainees in general can access health care more easily in prison than outside. This is especially the case for those who are in bad

health and who did not previously seek care outside of prisons due to social misery, addictions, and general negligence of their own health needs.

In principle, he [an ageing prisoner] was a retired person who was receiving invalidity insurance for many years before being imprisoned. Now, he has regular contacts with the physician and routine testing. Compared to a similar patient living in freedom, I think it is even better, as in those conditions [outside prison] he might not have the time and may not feel like going to the physician once a week, but here [in prison] the distances are much shorter (15 C1a, PA).

In the past, people always used to say, you cannot be sick in prison, or it's sink or swim, somehow this was the kind of mentality [that was prevalent]. Today, I claim once again, health care is better [in prison] than outside prison. A bit better, well I am totally convinced ... I could give you one example. ... He [a prisoner] came in a state of total decay ... and when I look at him today ... a young man in perfect shape. ... It is tremendous what kind of developments you see in here. This is partly due to the fact that they are no longer in their old environment; they don't have access to drugs anymore that can harm them, but it's also the health care. ... [I]magine in your private life if you have to decide about going to the physician. Your deductible will be charged, right. The person in prison doesn't have to think about these questions, he can go to the physician just like that. For that reason, it's certainly better (1 C1a, PA).

[In prison] they enter a health care provision system, something they never had before. [The system] is even, as you say, proactive, and this is the moment for them to realise that they really have to take care of their health, and that it is possible for us to help them (7 C3, HCP).

Interviewees believe that for ageing detainees who do not have any family visiting or providing care, medical follow-up is often better in prison than when they leave and return to their difficult social situations.

We can consider that they get the same health care like people in liberty. I would even say that they have more follow-ups than at home because there is nursing staff available constantly [in prison], and there are physicians coming every day to the prison. We can organise regular meals and regular intake of medications under supervision. So we observe that sometimes when older people are released, a big problem is to make sure that they will continue the medical follow-ups as they may not have family or relatives anymore. They face difficulties to access the same care and follow-up as they had in prison (27 C1b, HCP).

With regards to mental health, however, participants noted that psychiatric care for prisoners remains difficult both inside and outside of prison due to the acute and chronic negative effects incarceration has on mental health.

#### *Health Care Varies Significantly In Different Settings*

Many experts pointed out that there are a number of different types of prisons within countries (they vary in size, number of available places, security conditions, design, and age) and that health care organisation and quality varies significantly between different detention facilities within the same country: “[A]t some establishments, some health care departments are very good but that's very rare” (17 C2, HCP). One specific explanation that was given for this is the hierarchical attachment of prison health personnel to different ministries (“this is a very big subject,” 19 C1, NGO/IO/Omb), such as a department or ministry of justice or the interior as opposed to a department or ministry of health. The size of the prison, the number of detainees, and over-crowding were other factors that were identified as positively or negatively influencing the provision of health care.

The rule is ... that people should get the same level of health care in prison as they would get in the community. However, we know that doesn't always happen and we know that health care really varies; it really, really, varies. So we have [a high number of] different prisons, and they all have health care staff working in them. Some of them will have health care staff working 24 hours. Some of them will just have health care staff members who visit during the day, as you would in a general practitioner surgery in the community. So they vary. The level of health care provision varies, depending on the kind of prison it is, and depending on how many prisoners there are (16 C2, NGO/IO/Omb).

One of the participants pointed out that it is often a matter of luck whether the provision of health care in a given prison is equivalent to the health care that a prisoner would get outside.

And it really does tend to come down to the number of prisoners that each establishment is holding and the category of offender. So, if you're talking about, maybe somewhere like prison [name removed] and in a city prison which has a higher population of quite violent offenders, an older offender within a prison like that is going to struggle to get access to health care, which they should be getting. Whereas maybe we've got prisons [name removed], who are much more further forward in terms of health care screening and access to health care and things like that. So it's really, you know, it's luck really. And it just depends on what prison you're being held at (17 C2, HCP).

Prison location was also a factor thought to account for the variability in access to health care, because distance to the next available hospital can negatively affect access to hospital consultations

as well as of hospital specialists visiting prisons. One expert describes the positive effect of the proximity to in-patient health care:

But the transfer time from the gate of the prison to the hospital is like, is two minutes maximum. So it's very, very, fast. And well we were quite lucky in that respect because a lot of other prisons in [C2] are located at some distance from their nearest hospital (35 C2, HCP).

In some prisons, general health exams or screening for certain diseases take place at entry and at regular intervals later on. Other prisons, on the contrary, cannot offer these screenings or examinations.

At our prison it is established, there are very good medical examinations on admission, and a thorough check-up is done which only a small number of people in society could afford or would even do at all. Therefore, we are above-average I think (5 C1a, PA).

It is my intention to fight for the achievement that all regional prisons finally get a health care service. This is not the case right now. In prison [name removed] for example we do not have this yet. In bigger prisons we have health care services and also medical treatment by physicians, which is ensured everywhere. ...[T]his is important for me, the medical treatment by physicians must be ensured, and during admission the state of health must be assessed (29 C1a, PA).

In other prisons, consultations are only practiced if detainees actively ask for health care services: "For infectious diseases, we don't do preventive medical check-ups, for that we follow a problem-oriented approach with the patient and we don't do any preventive medical check-ups" (14 C1a, HCP).

Experts admit that care available for ageing prisoners is particularly affected by the variability within a country's or a region's prison system.

Many [small prisons] do not have a health care service. And then there are surely prisons that have a good health care service, and since they have a good health care service with qualified personnel, they take special situations into account. But this is probably the exception, because ... I assume that half of the prisons do not have their own health care service or regularly on-site nursing staff and that is simply necessary for chronically ill and elderly people (22 C1a, PA).

There are some [prison health services] which are quite developed, such as in the region [name removed], where prison [name removed] has a very good social care unit

for older age prisoners. However, there are ... places where development hasn't been as quick (28 C2, PA).

According to one interviewee, prisoner rights need to be more clearly defined in order to reduce the observed variations.

I think what tends to happen in the prison service at the moment, and that's not just to do with health care, that's across the board, is that prisoners aren't clear about their rights in some respects. And what that means is that there's a lot of room for manoeuvre at each establishment, and some are just going to be very much better at providing those services than others are (17 C2, HCP).

#### *Gatekeeper Systems Interfere With Equivalence of Health Care*

According to the experts, in many prisons detainees may only obtain access to health care through written requests to the health service and oral requests, especially in emergency situations, to prison guards. As one participant explained, "a detainee asks for an appointment through a note, lets us know through the prison officer, or catches the attention of a prison nurse" (8 C3, HCP).

What is a bit complicated in prison is that a lot is done on a written basis. That means that a detainee who wants a consultation must express this in writing. ... There are two ways of doing this, it can be made in the cell; the consultation request is [then] either dropped into one of the confidential mailboxes distributed in the prison's hallways – every day the mail is picked up by the prison officers who hand it over [to the infirmary] – or in dedicated boxes and then nurses sort out the requests and distribute them as quickly as possible, which does not mean right away (9 C3, HCP).

Experts repeatedly mentioned that equivalence of care can be compromised because in many prisons nurses and even prison guards function as gatekeepers. While it was implied that gatekeepers (such as receptionists, triage nurses, or even general practitioners (GPs) also can exist in the community, the point made by the interviewees was that patients living outside prison have the opportunity to change their GP or go to a different public or private hospital to increase the chances of getting the intended treatment. In contrast, detainees do not have the free choice of physicians or health care services and must obtain access to services through the prison health care system. Prison nurses and often also prison guards decide about immediate or deferred access to the prison physicians, as they have the responsibility of assessing and transferring prisoners to the appropriate health care provider:

So initially, if you had an older prisoner who woke up feeling unwell, it may be flu or something like that. The first point of contact would be the prison officer who opens their cell in the morning. So it would be up to them to make a very quick and instant decision as to the severity of their complaint. Do they need health care straight away, or is it a

case of wait-and-see how they are a bit later? Are they telling the truth or is it just the case that they maybe don't want to come out of bed that day? So they have a lot of judgement to make about an individual, an older prisoner, or any prisoner who's telling them they don't feel well (17 C2, HCP).

Training of prison guards was therefore described as an important factor in ensuring equivalent access to care in prison, especially with regards to ischemic heart disease as prisoners do not have the ability to access emergency departments or ambulances directly themselves: "Then there are the emergencies. Now emergencies are another matter. During an emergency, the detainee has to alert us, knocking at the door, calling, asking for the prison officer and convincing him that he [the prisoner] is not feeling well" (9 C3, HCP).

In these cases, the process of communication between security and health care personnel is of great importance, especially with regards to time-sensitive issues that in certain cases can have a great impact on the health outcome: "As staff are instructed in our prison, when something like indefinable chest pains happens, to immediately call the health care service, actions are actually taken rapidly" (5 C1a, PA).

In daily routine, guards and not health care providers are in direct contact with prisoners. This also means that detainees may be seen in consultation if guards request a HCP to do so.

They [prisoners] can contact the staff at any time. They [prisoners] can fill in and hand in a note requesting [a] health care visit at any time, or they can ask the staff to complete it and hand it in for them. Then we try to fix an appointment as soon as possible or the staff asks me to take a look at somebody who maybe does not want to go by him-/herself, but for them it is obvious that there is a problem. Those are the most common ways that exist here (24 C1a, HCP).

We have them close by [the detainees], and then, even if they are not asking for a consultation themselves, either the prison officer on the one hand or the nurses who distribute the medications on the other hand informs them [the detainees] that they might need to see the doctor, or they tell us, that the physician should be called because we think he is not well. So there is all this surveillance, I would say a little bit disarrayed, but still very functional, and something that does not necessarily exist outside in the general population (6 C3, HCP).

Interviewees pointed out that in many prisons nurses act as further gatekeepers: "Then he [the patient] will always be first seen by the nurses and they enquire a little further why and where it hurts and they try to get an idea" (13 C1a, PA). Nurses are the ones who further decide whether or not the detainee should be seen by a physician and when: "Most places will probably have a nurse-led triage system in place where they can also access doctor/GP support if necessary" (10 C2, HCP).

Interviewees were aware that this can interfere with equivalence of care in countries where patients outside of prisons have direct access to physicians.

One interviewee even reported that in certain situations she is not sufficiently qualified to decide whether a detainee needs to be transferred to the hospital or not:

I send him [the detainee] with a medically trained police escort [to the hospital] and call [the hospital] and tell them that he is coming now. But I think that this is quite problematic with older patients, because around here people often have heart pain and it can be stomach pain, too. It can be anything. We can simply ask more precise questions, also together with the guards, and we tell them to measure the blood pressure, etc. But this is always more like cosmetics, since the blood pressure doesn't tell you much, of course it can be extremely high, then you know. But all this is a bit of a joke; it's done mainly just to calm people down (25 C1a, HCP).

#### *Lack of Personnel Causes Delayed Access to Equivalent Health Care*

Experts repeatedly refer to capacity limitations and time constraints of security and health care personnel. Of particular concern is the shortage of security personnel: "Where there is a shortage of escorts then the appointment may have to be lost; again that's an area we are critical of when we find that happening" (28 C2, PA).

[F]or many older prisoners, what they really need is specialist health care, to go to a consultant. So they would be referred to hospitals. It's sometimes quite difficult getting people to appointments in hospitals, because although they have the right to do that, it can be quite challenging for the prison in arranging the security. ... So we often find that appointments are missed, either because there wasn't a transport available or because there weren't staff available, because mostly staff members have to escort the prisoner to the hospital. And he may want one or two staff members and sometimes they aren't available. So we find that people do miss out on their hospital appointments and can be waiting for hospital appointments for quite a long time (16 C2, PA).

Another interviewee shared how an occupational therapist cannot treat elderly patients the same way as is done outside prison due to lack of time.

We have an occupational therapist, and she has a mixed task of caring for ... all the people coming back from surgery and all physical traumas. Because we have quite a young population, multiple times injured from car accidents, so all causes of fractures, things like that, they can absolutely not be done in ... two seconds ... this occupational therapist cannot take care of older patients as would be done outside (12 C3, HCP).

Experts also felt that health care providers are forced to concentrate on emergency care due to the lack of personnel relative to the number of cases that the respective service has to treat.

Well, I have great admiration for the medical service, since we are understaffed and they really do the best they can with limited resources. I wish we had at least one-and-a-half additional positions in the health service and in this respect, when I comment on the quality, I have to say, emergencies, including somatic ones, these cases are surely treated adequately and without undue delay, but there is not enough time to care for [the patients] (2 C1b, PA).

A member of the prison administration noted that insufficient personnel was particularly a problem in smaller prisons. Since the prisons are small, they cannot afford to employ additional persons even when necessary to take care of ageing prisoners who are imprisoned there: “And the problem is also that I cannot employ too many nursing staff and with older people there is the danger that they die. And then we have fluctuations and suddenly we have less [older people] again” (5 C1a, PA).

Some interviewees also reported that health care personnel are lacking particularly during night and weekend shifts: “There should simply be substantially greater human resources. That would be a time issue also, you would have to be here day and night and this is just not possible with the human resources, simply impossible” (4 C1a, HCP). Similarly, another participant noted: “No, we function with a nursing service seven days a week, but not at night. ... We do not have the staff to do it, particularly on the weekends” (8 C3, HCP).

Higher priority given to security than to health needs of prisoners and the fact that the number of health care provider positions has not been adapted to actual needs partly explain the shortage of health personnel.

In case you ever get more posts, nowadays one considers more and more, hey, security: Do we maybe need more night watch, do we need more personnel in the hallway, which would be legitimate, and therefore, well, maybe the health care service will lose the race. And perhaps it has not been considered, or it has not been taken into account that the number of positions in the health care service may have been correct 20 years ago, but obviously at that time the prison population used to be much sturdier. It [the prison population] was younger and sturdier (2 C1b, PA).

Study participants also noted how the health personnel shortage is due to limited monetary resources: „Region [name removed] doesn't have any money. And it is practically impossible to get any more posts” (4 C1a, HCP).

Finally, the perception that public health authorities do not feel responsible for the provision of prison health care is described as a major reason for the lack of sufficient and adequately trained personnel.

The whole issue, the whole concern basically falls through because there is no qualified personnel. Hence, a lot needs to be done. Awareness is growing due to certain deaths [in prison]. But there are huge questions left with regard to practice. There are still regions in which the public health system says this doesn't concern us; this is a job for the judiciary, which is totally wrong ... but if even the public health system does not want to get involved, how is it supposed to get better if the regional public health authority says that the prison does not concern them? This is difficult. And once this level is reached and there is mounting evidence that the state has this duty also being criminally liable, but also with government liability in case it is not done correctly. But then the question is raised who pays and how much does it cost and then most of the times it costs too much (22 C1a, PA).

#### *Delays to Accessing Health Care Compromises Equivalence*

A significant number of experts were critical of the fact that prisoners have to wait longer than patients outside to access care. Significant delays regarding care inside prisons and, in particular, care that necessitates transfers to hospitals were described:

In terms of outside hospital visits, [health care] researchers have [described] peoples' stories of appointments being cancelled at the last minute because there aren't enough officers to accommodate their trip to the outside hospital, which, obviously, if you cancel an appointment with a specialist, you're going to then wait several months for another one (17 C2, HCP).

The difference is perhaps that in short-stay prisons and also in detention centres, if somebody needs to go to the hospital for somatic reasons, and there is a daily limit for possible outside transportations – that is to say, the ability of a detainee to get out of prison for going to the hospital – which causes sometimes quite significant delays, for the implementation ... of a consultation or hospitalization [regarding] diagnosis. Now when people need radiotherapy for example ... or things like that, it gets very complicated. The system becomes completely blocked. The number of [allowed] outside transportations and of ... I think it must be four a day, which is very low. Actually, this has consequences regarding the police guards, etc. (34 C3, HCP).

Interviewees attributed delays of in-prison-care to different factors including availability and training of security and health personnel.

If the prison officer felt that it was sufficiently bad that they [prisoners] needed health care attention, [in] some establishments they'll be told to go down and queue for the health care, which can obviously be problematic if they're feeling very poorly. If they

thought it was very severe that they needed a doctor or a nurse to come and visit them in the cell, then arrangements would be made. But that could be quite a lengthy process (17 C2, HCP).

One expert described the delays that can happen concerning access to mental health care, in particular for ageing detainees. He highlighted it as a problem that is difficult to solve:

I think the difficulty I've seen is where ... there is some uncertainty in mental health services outside about where the person fits, do they fit in the old-age service or do they fit in the forensics service. And so, you know, there are some people who don't get treated very quickly. And so that, I think, is an on-going, it's quite a genuine difficulty. It's not very easy to sort out but it's certainly delayed care to older prisoners (11 C2, HCP).

Some experts state that standards for acceptable and unacceptable delays are urgently needed.

I think it needs to be clearly identified, what the prisoner can expect in terms of their health care, how long they should be expected to wait for medication, how quickly a nurse or a doctor should be expected to provide that care, or assist a prisoner who is feeling poorly. And the same with prison officers, you know. How long should they be expected to wait before a doctor comes over to see [the detainees], if they reported being unwell in their cell. ... If we had clear expectations about what the prisoner, what the health care provider, and what prison service staff should be expected to do, or respond to, and the time scales involved, then that's going to be very clear cut in terms of when that doesn't happen. ... Because at the moment, it's just, there's nothing standardised, it's just luck. It's how lucky you are to have a good officer or a good member of health care staff available. And that's just simply not good enough, there needs to be a national standard, a national level of health care (17 C2, HCP).

In our experience, generally speaking, they [the provision of the same type of private and secondary care services] do happen. So standards are broadly equivalent. However, there are delays in the system due to security considerations. So we criticise that where we see it because we believe the time scale should be the same. There are [community health service] target waiting times for various treatments for the general population. We expect to see prisoners receiving care within those targets, but that does not usually occur. And where necessary we expect to see within prisons additional facilities for social care and medical care for prisoners (28 C2, PA).

Others pointed out that, especially in prison, the subjective burden of delays, in particular for ageing detainees, may be greater than outside prisons. A consequence of the delays may be mental decompensation and other negative health consequences.

Immediately, [the prisoner] imagines, this could be something worse, and if he gets informed a bit, he would probably say, I need a quick clarification to ascertain that it is not ... cancerous. And in this concrete case like this, in my opinion, we treated the whole issue simply in a “run-of the-mill” manner. The prisoners had to wait for three weeks for the in-depth medical assessment and during those three weeks he almost went berserk (2 C1b, PA).

And again, in some evidence that was submitted to [a] select committee review team was a statement by a prisoner who had told the prison officer who opened his cell in the morning that he felt very unwell. He [the prisoner] thought he might have had a stroke, and he [the officer] said he would arrange for a doctor or a nurse to come over. It was two hours later that they [health care service] finally came and saw him in the cell and said actually he needs immediate attention, an outside hospital. And because of the time delays involved, he [the prisoner] was actually left paralyzed by the stroke. Whereas, you know, the doctor, the hospital had said if they could have acted instantly they could have saved a lot more of his brain from being affected by the stroke. So as you can see from this example, it again is very much dependent on how good that initial prison officer is in recognising health complaints in all prisoners, but particularly in older prisoners (17 C2, HCP).

## **Discussion**

Our study is important as it sheds light on significant and under-researched issues surrounding prisoners' health care [8,9]. Additionally, we aim to understand the provision of health care to ageing prisoners from the perspectives of experts. Those experts have direct experience regarding the practice of health care or the decision to provide health care for prisoners in general and older prisoners in particular. Finally, we examined the notion of the principle of equivalence of care in prison medicine, which has so far only been explored in a legal and theoretical manner. Thus, we empirically present this theoretical concept for the first time. A main finding of the study is that experts from all three countries recount similar aspects that make the realisation of equivalent health care difficult in prison: variability within correctional systems, the presence of gatekeepers and gatekeeping protocols, a lack of personnel, and delays in the provision of care. These factors reportedly affect all detainees suffering from diseases and those who might be exposed to them, and they disproportionately affect ageing detainees, since they tend to shoulder higher prevalence rates and a greater burden of chronic diseases.

Another major finding is experts' opinion that health care for ageing detainees is very good in some prisons while it is not adequate or equivalent in other settings. In the former, it may be possible

to actively improve the health of ill prisoners of any age as compared to their health status outside prison where they may not receive close follow-up for various reasons. This seems to imply that improvements in health care to reach the level of equivalence are possible in the latter prisons where health care has been described as falling short. Of course, international recommendations from the United Nations and the Council of Europe (COE) have purposefully used the term “equivalent” and not “equal” care to acknowledge the reality that health care in prison has to struggle with conditions and available resources that render health care somewhat different in prison. However, with adequate resources, a number of non-equivalent factors could be changed, at least to some extent, such as the free choice of a physician. For example, COE recommendations stipulate:

Remand prisoners should be entitled to ask for a consultation with their own doctor or another outside doctor at their own expense.

Sentenced prisoners may seek a second medical opinion and the prison doctor should give this proposition sympathetic consideration. However, any decision as to the merits of this request is ultimately his responsibility (Article 17) [3].

Still, this assumes that the prisoner’s doctor agrees to come to the prison which is time-consuming and generates additional costs that might not be covered by health insurance and therefore would need to be paid for by the detainee. As a consequence, free choice of physicians remains a privilege for those incarcerated. It also implies higher costs for the prison in terms of security personnel available to organise the meetings between the outside physician and the detainee. Nevertheless, in cases where the mutual trust between a physician and an incarcerated patient is destroyed or where the need for the prisoner to get a second opinion is very important, administrative barriers should be dealt with. These actions should be supported by all involved parties. In the following sections, we first address the questions as to what can be changed with adequate resources. Then, we discuss what should be changed to obtain a “minimal” standard of equivalence, in particular for ageing prisoners.

There is little doubt that given adequate budgets for health care in prison, delays due to lack of personnel can be reduced significantly, by providing a sufficient quantity of personnel as well as the necessary training, particularly in geriatrics. The question remains whether it is acceptable that prisons often are located far away from hospitals. Outside of prison, people may choose to live in remote areas and accept the possibility of delays in receiving health care should they become ill. Likewise, ageing patients suffering from chronic diseases might choose to move into regions where health care is easily accessible. Since imprisonment is deprivation of freedom, but not curtailment of access to health care, it appears justified to conclude that prisons housing detainees at high risk of health problems should be located at a reasonable distance from an acute care hospital. In most cities located in C1, for example, ageing patients suffering from ischemic heart disease have access to a coronarography within 10 to 15 minutes and that type of standard could, for example, be used to determine “equivalent” acceptable delays in transport of prisoners with a similar condition.

Experts in our study felt it was difficult to alter the use of gatekeepers to determine access to health care in prison. Even in low-security detention centres, where detainees are allowed to access the health unit freely, cells are usually locked during the night and require the intervention of security personnel in order to get access to medical care. However, during the time when detainees are locked in their cells – often 23 hours a day in most remand and high-security prisons – direct phone lines to the medical centre could be a simple means to avoid the delicate and possibly fatal gatekeeper role. At present, such phone lines seem to be rare and only one expert in our study knew of a prison where such an access system exists. In the non-incarcerated community, patients essentially have direct access to physicians without a gatekeeper. Equivalence would thus imply that detainees should be able to talk to and see physicians directly. This change is feasible if the provision of health care in prisons is restructured. Enforcement could be supported, for example, by providing adequate budgets for health care services inside prison. The number of positions for health care personnel could be increased, and instead of employing mostly nurses, prison health care systems could pay for more GPs. These GPs could then respond directly to health care requests (or direct care could be provided by a nurse practitioner, where appropriate). Therefore, there is reason to believe that most of the reported problems are amenable to change. It is possible to reach a high level of equivalence of health care for ageing and ill prisoners.

Experts in our study, however, identified a lack of standards as a major obstacle to equivalent care in prison medicine. When it comes to defining obligatory changes and an appropriate budget for prison health care, more detailed evaluation standards are needed. Ethicists and policy makers who develop such standards [7] should be mindful that equivalence of care does not mean “equal” budgets for health care in prison and outside prisons [8,26]. Instead, equivalence refers to the individual needs of both ageing prisoners [12] and young prisoners that must be met to grant comparable levels of treatment and care for prisoners and non-prisoners alike. It is important to take into account the disease prevalence and burden of the population in a given prison and to adapt budgets flexibly to these parameters [9]. Likewise, defining “equivalent” delays remains complex [22]. While it may be possible to establish the average waiting time to see a GP for a non-incarcerated patient in a given region, delays will always be adapted to individual patient needs. In some cases, delays of more than a few minutes may contribute to the early death of a patient, and, in other cases delays may result in decreased chances of a healthy recovery. Then there will be instances where delays only result in prolonged inconvenience or suffering. An example would be a several-day delay in accessing flu treatment in some prisons. The ethically most appropriate definition of delays would imply immediate access to a doctor for each detainee, followed by an assessment to define subsequent delays on a case-by-case basis. The way a patient suffering from the same symptoms would be treated with appropriate diligence in the community needs to be the applied standard for prisoners as well. Courts or any other complaint mechanism that evaluate concrete cases would continue to judge whether treatment is equivalent (see, e.g., the 2006 case of *Khudobin v Russia* and the 2007 case of *Testa v Croatia*).

Experts point out difficulties in obtaining higher budgets in their regions due to a lack of political willingness to spend more money “on detainees.” However, a more transparent discussion of

equivalence might encourage countries to allocate resources in a more evidence-based way. If the health care needs of prisoners were taken seriously, countries would be more motivated to search for more humane and more efficient alternatives. In particular, this would encourage less expensive measures of punishment instead of imprisonment. The latter ought to be reserved only for highly dangerous detainees.

Our study has several limitations. First, we do not claim that our results are representative of the opinions of all experts working in the prison setting, nor would we claim them to be representative for health care provision in all prisons in the included countries. Our findings also may be biased due to the selection process. Participants may include particularly motivated experts, as they agreed to participate in this study despite their high work load. However, we think that this bias remains small, as we contacted a wide array of experts. Another limitation is the fact that for practical reasons interviews were conducted by four different researchers with diverse cultural and scientific backgrounds using different mediums (in-person interviews, Skype, or telephone). These factors could have influenced the topics and the depth in which certain topics were discussed with the participants. However, as we obtained similar answers in the three countries concerning the major results discussed in this paper, we have reason to believe that the sample, interviewer, and interview setting biases remain minor. Furthermore, in this paper we focused on the opinion of experts and did not include the viewpoint of prisoners on this issue which limits the perspective. Still, we would assume that prisoners are even more critical than experts, hence the perspective of the latter should be taken very serious. Finally, the most serious bias may be caused by social desirability. We would expect prison administrators and health care providers to be at risk of presenting a somewhat idealised picture of their care for ageing prisoners. On the other hand, some of the NGO members as well as other experts might provide a particular critical view of prison health care, because they have been selectively confronted with problematic cases. Also, some experts, such as prison directors, would not be aware of all problematic cases due to medical confidentiality. However, these biases work in opposite directions. Overall, we believe that the study findings reflect not only experts' subjective opinions but also give a realistic picture of various facets of health care received by prisoners. It is an important and valid first step to stimulate discussion about equivalent health care in prison as our results reflect the attitudes of a very important expert group. Expert opinions will be crucial to understanding existing problems in more detail, to overcome flawed perceptions, and to generate a more detailed definition of the principle of equivalence of care in prison.

## **Conclusion**

Although the principle of equivalence was introduced more than 30 years ago in influential international *soft law* [3,30], experts agree that even in relatively wealthy European countries, health care is not always equivalent in prisons, particularly for prisoners suffering from diseases and at higher risk to becoming ill, such as ageing prisoners. According to the interviewed experts of this study, equivalent care is possible and exists in some prisons. The reported variability of health care in different prisons seems to be due to a lack of detailed standards as to the concrete meaning of equivalence. This lack of clarity interferes with adequate allocation of resources to and within prison

systems. There is a clear need not only to obtain more data on the provision and outcome of prison health care but also to address in detail what the principle of equivalence means in terms of staffing, delays, and acceptable gatekeeping systems used to allocate access to health care.

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### **Conflict of Interest**

None.

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## Chapter 4

### **Ageing Prisoners' Disease Burden: Is Being Old a Better Predictor than Time Served in Prison?**

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## Ageing Prisoners' Disease Burden: Is Being Old a Better Predictor than Time Served in Prison?

### Abstract

**Background:** The number of older prisoners entering and ageing in prison has increased in the last few decades. Ageing prisoners pose unique challenges to the prison administration as they have differentiated social, custodial, and health care needs than prisoners who are younger and relatively healthier. **Objective:** The goal of this study was to explore and compare the somatic disease burden of old and young prisoners, and to examine whether it can be explained by age group and/or time served in prison. **Methods:** Access to prisoner medical records was granted to extract disease and demographic information of older (>50 years) and younger (≤49 years) prisoners in different Swiss prisons. Predictor variables included the age group and time spent in prison. The dependent variable was the total number of somatic diseases as reported in the medical records. Results were analysed using descriptive statistics and a negative binomial model. **Results:** Data of 380 male prisoners from 13 different prisons in Switzerland reveal that the mean ages of older and younger prisoners were 58.78 and 34.26 years respectively. On average, older prisoners have lived in prison for 5.17 years and younger prisoners for 2.49 years. The average total number of somatic diseases reported by older prisoners was 2.26 times higher than that of prisoners below 50 years of age (95% CI 1.77 – 2.87,  $p < 0.001$ ). **Conclusion:** This study is the first of its kind to capture national disease data of prisoners with a goal of comparing the disease burden of older and younger prisoners. Study findings indicate that older inmates suffer from more somatic diseases and that the number of diseases increases with age group. Results clearly illustrate the poorer health conditions of those who are older, their higher health care burden, and raises questions related to the provision of health care for inmates growing old in prison.

### Introduction

The prison population has increased due to more stringent and longer sentences, resulting not only in a greater number of prisoners, but also more prisoners becoming old in prison [13,17,23]. An increasing and ageing population of prisoners is evident in many countries, and the most prominent changes are seen among the prisons in the USA [23] and the UK [29]. Due to accelerated ageing, older prisoners are defined as those who are aged 50 years and over [20,26], rather than 65 years and older in the community; because a 50-year-old prisoner tends to represent the health burden of someone who is 10 – 15 years older in the community [16,27].

The ageing of the prison population poses unique challenges to the prison administration as older prisoners present varied social, custodial, and health care needs compared to those who are younger and relatively healthier [13,20,21]. Literature on the health care of prisoners, and older prisoners in particular, is limited [26], although a gradual increase is evident from studies published in medical [13,17], gerontology [7,15,16,21,28], and public health journals [30,33,34]. These and other studies provide new knowledge pertaining to disease burden and quality of health care received by prisoners. For instance, two US national studies concluded that prisoners have a higher disease

burden than the general population and that prisons fail to meet prisoners' health care needs [6,34]. A recent study examining whether time served in prison contributes to mortality among parolees highlighted the negative consequences of imprisonment [30]. Study findings showed a positive relationship between time in prison and mortality; however, it also reported that the higher mortality is recoverable once a person is released and continues to live in the community. It should nevertheless be pointed out that literature assessing the effect of imprisonment on health and mortality remains scarce, and the findings are inconclusive because studies have shown both negative and positive effects of imprisonment [24,25,31].

Several studies report on older prisoners' health burden associated with incarceration. Colsher et al. [8] interviewed 119 older prisoners (>50 years), capturing their health and functional status. They noted that older prisoners suffer from arthritis, hypertension, ulcers, prostate problems and myocardial infarction. Study results also revealed that those who are older (>60 years) are more likely to report these conditions than those younger (50 – 59 years). Another study of 203 older prisoners (>60years) from the UK concluded, similar to the US national studies above, that the health of older prisoners is worse than younger prisoners and older adults in the community [16]. Older prisoners reported suffering from psychiatric, cardiovascular, musculoskeletal and respiratory diseases [14,16]. Similar to the UK study comparing the health of older and younger prisoners, a literature review on prisoner health drew the same conclusion that older prisoners have poorer health outcomes than younger prisoners [13]. Another literature review also found that older prisoners tend to report a greater decline in health subsequent to imprisonment [26].

Further studies have also examined the disease burden of prisoners comparing the results among prisoners of different age groups [3-5,18,19], concluding that multiple morbidity is high among prisoners, with mental illnesses, infectious diseases, and drug abuse as common health problems [32,34,35]. Aday [1] and Deaton et al. [9] pointed out that older prisoners report suffering from 3 – 4 chronic conditions. Baillargeon et al. [4] explored the prevalence of major disease using a cohort of 170,215 prisoners between 1997 and 1998. The diseases most often reported according to International Classification of Diseases (ICD-10) were infective and parasitic diseases, followed by disease of the musculoskeletal system and connective tissue, and disease of the circulatory system. Among male prisoners, increased prevalence by age was reported for hypertension, low back pain, diabetes, arthritis, hernia and heart disease. Specifically, hypertension and diabetes were more frequently present among those who were aged >50 years than those who were younger. A similar investigation was done a decade later with a cohort of 234,031 prisoners from 2006 – 2007, with an emphasis on specific chronic medical conditions [19]. These authors also found hypertension, diabetes, ischemic heart disease and chronic obstructive pulmonary disease to be common, with prevalence increasing with age.

In the context of Switzerland, a few studies exist on the health problems of prisoners [10-12]; however, the emphasis was not specific to older prisoners and they did not capture national data. Therefore, a national project entitled 'Agequake in Prisons' was designed to understand the overall health and health care circumstances of ageing prisoners in Switzerland. In order to be able to compare the health of old and young prisoners, information was gathered for both on different health

variables, such as disease burden, medications, visits to GPs and nurses, and general health care access. In this manuscript, we explore the somatic disease burden of old and young prisoners and examine whether this disease burden can be explained by age and/or time served in prison.

## **Method**

To capture the disease burden of prisoners, the study recorded the reported diseases from the medical records of 406 prisoners. These records belonged to 203 older prisoners (>50 years) and 203 younger prisoners ( $\leq 49$  years). Older prisoners were defined as those 50 years and older in accordance with available literature [16,26,27]. Research ethics commission (REC) approval was sought and obtained from 10 regional RECs in Switzerland, where the relevant prisons are located. Permission to extract data from prisoners' medical records was also obtained from the federal commission for medical confidentiality.

### *Selection of prisons*

There are 109 prisons in Switzerland with capacity for 6,978 inmates. Of these prisons, 26 provide space for a total of 2,879 places (41.3%) and fulfilled our inclusion criteria of: (i) long-term imprisonments, i.e. prisons incarcerating those who have a sentence of 1.5 years or more, (ii) more than 20 places and (iii) housing older prisoners at the time of request. Excluded prisons were those which housed juvenile prisoners, were semi-detention or remand prisons or deportation centres, had a capacity for 20 individuals or less, and did not have any older prisoners. A total of 11 prisons refused participation due to lack of time and resources. Ultimately, 15 out of 26 prisons, holding 2,198 prisoners (76.35% of the eligible population) in 11 different cantons representing two linguistic regions of the country (German speaking and French speaking), agreed to participate.

### *Data collection*

Data collection took place on a rolling basis starting from November 2011 and ending in April 2014. Before embarking on data collection, we requested prison health service staffs to advertise the study and collection of information from medical records to prisoners. Most prisons informed prisoners about their rights to opt out of data collection using flyers with a description of the study and information about how to opt out. These flyers were made available in different languages: German, English, French, Spanish and Italian. In a few prisons, the opt out option was communicated to the prisoners either by a nurse, the prison administration or one of the researchers. A medical record was made available by the prison health service if no opt out request was made. During the study period, we received a total of 14 opt out requests.

Medical records of all prisoners aged over 50 years were obtained from the participating prisons, except for 1 prison. This exception was made because the prison housed many older prisoners but could only provide the researchers with limited space and time availability in which to gather data. For this prison, a decision was made to randomly select approximately half of the older prisoners' medical records. From all prisons, an equal volume of data belonging to younger prisoners was randomly collected. Data gathered relevant for this paper included demographic and all somatic

disease information recorded in the medical records. Thus, psychiatric diseases falling into the ICD-10 category of 'mental and behavioral health' are excluded from the analysis and will be presented in another paper. If noted in the medical records, information on smoking, alcohol and drug use was also obtained.

Data from the medical records were extracted by 2 research assistants using a data extraction document developed by the research team. Recorded data on these documents were then entered into an EpiData file. Disease information was coded using ICD-10, which allows classification of diseases into 22 different diagnosis categories and is a standard tool used in epidemiological, clinical, and health settings [36]. Data entry was supported by several assistants and independent assistants checked the entered data for errors.

### *Data analysis*

To explain disease burden in prisoners, two predictor variables were established: an age group factor distinguishing between older and younger prisoners, and time spent in prison, defined as the time in years between a prisoner's date of entry into prison and the date of data collection. Demographic variables were also recorded. The dependent variable of total number of diseases was defined as the total number of somatic diseases reported in the prisoner's medical record.

Descriptive statistics were used to situate the demography of the sample studied, the disease prevalence and the disease burden by ICD-10 categories. To understand the impact of age group and time spent in prison on disease burden, we used a negative binomial model which is typically used for count data exhibiting over dispersion (the observed variance is larger than the observed mean) [2]. Coefficients were reported as the incidence rate ratio (IRR), i.e. a one-unit increase in the predictor value leads to an increase/decrease of the outcome by a factor of  $e^b$ , whereby  $b$  is the estimated parameter [22]. The model contained age group and years in prison (linear and quadratic polynomial) as predictors of interest, correcting for the following covariates: prison and marital status. The same model was also analysed without covariates but the results were comparable to the adjusted model and are hence not reported here. All analyses were performed using IBM SPSS 21.0.

## **Results**

### *Participant characteristics*

Of the 406 collected medical records, 26 were female prisoners (13 older and 13 younger) belonging to two prisons. Their data were excluded due to small numbers. The remaining data of 380 male prisoners from 13 different prisons are presented here. By linguistic regions, 266 (70%) prisoners were from German-speaking cantons and 114 (30%) from French-speaking cantons. The lower number of prisoners from the latter region is because of the smaller size of the French-speaking region. From both age-groups, two-thirds characterised themselves as a current smoker, with the mean number of cigarettes smoked per day being 20.42 (SD 12.54). A similar percentage acknowledged consuming alcohol in the past, with the amount ranging from very little to a lot. Less than half (43.6%) reported having used drugs (from them, 69.8% were younger prisoners). The drugs consumed included one or a combination of the following: cannabis, cocaine, opiates, and benzodiazepines. The age range of

the entire sample was between 20 and 75 years, and the mean ages of older and younger prisoners were 58.78 and 34.26 years, respectively (table 1). On average, older prisoners had lived in prisons more than twice as long as those who belonged to the younger group. The prisoners demographic information is presented in table 1 and the characteristics by prison in table 2.

**Table 1.** Sample descriptives by age group of prisoners

Demographic and disease information	Younger prisoners ( $\leq 49$ years)	Older prisoners ( $> 50$ years)	All Prisoners
Age (n = 380), years	34.26 $\pm$ 7.38	58.78 $\pm$ 5.82	46.52 $\pm$ 13.96
Imprisonment (n = 340), years	2.49 $\pm$ 2.48	5.17 $\pm$ 6.31	3.84 $\pm$ 4.98
Marital status (n = 358)			
Single	70.1	29.9	43.9
Married/divorced/widowed/ other	33.8	66.2	56.1
Religion (n = 294)			
Christian	39.7	60.3	51.4
Non-Christian	60.8	39.2	48.6
Nationality (n = 359)			
Swiss	31.5	68.5	49.6
Other	70.7	29.3	50.4
Total different diseases <sup>a</sup>	1.62 $\pm$ 1.83	4.27 $\pm$ 3.78	2.94 $\pm$ 3.25

Values are mean  $\pm$  SD or percentages. The total study population was 380, divided equally between the two age groups. Values of n differ since they do not include missing data.

<sup>a</sup> Total number of different diseases includes all diseases reported in the medical records, except for psychiatric conditions.

**Table 2.** Characteristics of prisoners by prison

Prison No.	Linguistic region	Prisoners, n	Age, years	Imprisonment, years	Total diseases reported, n
1	German	24	47.54 $\pm$ 12.78	6.85 $\pm$ 5.92	2.96 $\pm$ 2.27
2	German	26	46.23 $\pm$ 13.22	2.00 $\pm$ 1.67	1.92 $\pm$ 1.65
3	German	30	45.00 $\pm$ 15.11	2.94 $\pm$ 2.63	3.17 $\pm$ 3.22
4	German	42	46.55 $\pm$ 13.94	2.67 $\pm$ 3.65	3.60 $\pm$ 4.21
5	German	14	45.79 $\pm$ 18.40	1.48 $\pm$ 2.38	5.21 $\pm$ 5.15
6	French	80	47.32 $\pm$ 13.30	4.13 $\pm$ 4.55	3.30 $\pm$ 3.15
7	French	20	43.20 $\pm$ 12.85	1.36 $\pm$ 0.93	2.05 $\pm$ 2.11
8	German	34	45.18 $\pm$ 13.75	1.22 $\pm$ 0.94	2.09 $\pm$ 2.78
9	German	14	47.00 $\pm$ 15.83	1.51 $\pm$ 0.90	2.36 $\pm$ 2.90
10	German	4	51.50 $\pm$ 8.35	2.95 $\pm$ –	5.25 $\pm$ 5.56
11	German	72	47.44 $\pm$ 13.80	6.15 $\pm$ 7.19	2.90 $\pm$ 3.22
12	French	14	46.36 $\pm$ 17.95	2.57 $\pm$ 5.09	1.00 $\pm$ 1.47
13	German	6	45.67 $\pm$ 17.97	7.01 $\pm$ 4.25	4.33 $\pm$ 4.18

Values are number or mean  $\pm$  SD

### *Disease distribution*

Excluding psychiatric diseases, older prisoners reported on average 4.27 diseases with a range of 0 – 19, and younger prisoners reported 1.62 diseases with a range of 0 – 9 (table 1). The total number of diseases by prison is provided in table 2. Of the total sample of prisoners, 24.2% (n=92) did not report any somatic diseases. Forty-six percent (n=175) had 1 – 3 diseases, and 29.7% (n=113) had 4 diseases or more. Of those reporting 4 or more diseases, approximately 4/5 were older prisoners, and only 22.1% were younger prisoners. From the different ICD-10 categories, among older prisoners, the following were the five most prevalent: (i) diseases of the musculoskeletal system and connective tissue; (ii) diseases of the circulatory system; (iii) endocrine, nutritional and metabolic diseases; (iv) diseases of the digestive system, and (v) symptoms, signs and abnormal clinical and laboratory findings (table 3). Similar to older prisoners, younger prisoners mostly suffered from: (i) diseases of the musculoskeletal system and connective tissue; however, the other ICD-10 categories differed: (ii) diseases of the digestive system; (iii) certain infectious and parasitic diseases; (iv) diseases of the respiratory system, and (v) diseases of the skin and subcutaneous tissue. Specific disease conditions reported by older prisoners included hypertension, back pain, diabetes, obesity, and disorders of lipoprotein metabolism and other lipidemias. Younger prisoners reported suffering from back pain, acne, migraine, allergy, and asthma.

**Table 3.** ICD-10 diagnosis characteristics by younger and older prisoners

Most reported ICD-10 diagnosis <sup>a</sup>	Younger prisoners (n = 308 diseases)	Older prisoners (n = 811 diseases)	All prisoners (n = 1,119 diseases)
Certain infectious and parasitic diseases	30 (9.7)	33 (4.1)	63 (5.6)
Neoplasms	8 (2.5)	16 (1.9)	24 (2.1)
Disease of the blood and blood forming organs	3 (0.9)	11 (1.3)	14 (1.3)
Endocrine, nutritional and metabolic diseases	20 (6.5)	94 (11.6)	114 (10.2)
Disease of the nervous system	20 (6.5)	38 (4.7)	58 (5.2)
Diseases of the eye and adnexa	17 (5.5)	47 (5.8)	64 (5.7)
Diseases of the ear and mastoid process	2 (0.6)	14 (1.7)	16 (1.4)
Diseases of the circulatory system	17 (5.5)	129 (15.9)	146 (13.0)
Diseases of the respiratory system	28 (9.1)	49 (6.0)	77 (6.9)
Diseases of the digestive system	33 (10.7)	74 (9.1)	107 (9.6)
Diseases of the skin and subcutaneous tissue	23 (7.5)	33 (4.1)	56 (5.0)
Diseases of the musculoskeletal system and connective tissue	55 (17.8)	151 (18.6)	206 (18.4)
Diseases of the genitourinary system	10 (3.2)	32 (3.9)	42 (3.8)

Certain conditions originating in the perinatal period	0 (0.2)	2 (0.2)	2 (0.2)
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	22 (7.1)	62 (7.6)	84 (7.5)
Injury, poisoning and other consequences of external causes	16 (5.2)	7 (0.9)	23 (2.1)
Factors influencing health status and contact with health services	3 (0.9)	17 (2.1)	20 (1.8)

Data are n with percentage in parentheses. A total of 288 prisoners reported 1,119 medical conditions.

<sup>a</sup> From the ICD-10 categories, excluding mental and behavioral health.

#### *Disease Prevalence and Its Relation to Age Group and Time Spent in Prison*

The estimated average total number of somatic diseases reported by older prisoners was 2.26 times higher than that of prisoners below 50 years of age (IRR 2.26, 95% CI 1.77 – 2.87,  $p < 0.001$ ). There was a curvilinear relationship between years spent in prison and the average total number of diseases reported. Thus, the number of diseases increased more strongly during the first years in prison compared to subsequent ones. The corresponding IRR values were 1.05 (95% CI 1.01 – 1.08,  $p = 0.010$ ) and 0.998 (95% CI 0.996 – 0.999,  $p = 0.005$ ) for the linear and quadratic trend, respectively. Note that the linear trend was tested at the average number of years in prison, which was 3.84 years. The parameter values were all conditional on the covariates included and also on the respective other predictor. Table 4 depicts the descriptive mean values of the total number of diseases reported by age group and for four classes of years spent in prison. This table shows that the total number of diseases reported was higher in the older age group irrespective of the class of years spent in prison. Hence, the age group effect was not due to older prisoners having spent more time in prison. It also highlights that within the older age group the total number of diseases more strongly increased during the first years in prison but less so later on, whereas in the younger age group there was no apparent trend.

**Table 4.** Number of diseases by age group and time spent in prison

Imprisonment, years	Younger prisoners				Older prisoners				Total			
	total diseases, n	age, years	imprisonment, years	n	total diseases, n	age, years	imprisonment, years	n	total diseases, n	age, years	imprisonment, years	n
0–2	1.60	33.46	0.98	96	3.79	58.81	0.91	67	2.50	43.88	0.95	163
2–4	1.80	34.12	2.79	41	3.82	59.50	2.69	40	2.80	46.65	2.74	81
4–8	1.17	36.04	5.46	24	4.94	58.58	6.06	31	3.29	48.75	5.80	55
>8	3.75 <sup>a</sup>	39.50	10.21	8	5.06	59.39	15.97	33	4.80	55.51	14.85	41
Total	1.69	34.27	2.49	169	4.25	59.04	5.17	171	2.98	46.73	3.84	340

All prisoner data are mean values.

<sup>a</sup> The greater number of diseases here could be due to the small number of younger prisoners who fitted this category.

## Discussion

Studies examining the disease burden of prisoners mostly hail from the USA. It should thus be noted that the results presented here may not be directly comparable with US or other European studies due to the different health care and penal systems. However, it is important to ground the current findings in light of those which are already available. Our study sample, like other studies [4,19], constituted mostly male prisoners. Additionally, our older sample, similar to other studies [4,8,16,19], reported diseases of the musculoskeletal system and connective tissue, the circulatory system and endocrine, nutritional and metabolic diseases. When comparing different disease distributions by age group, infectious and parasitic diseases (e.g. sexually transmitted diseases, TB, or hepatitis/HIV) were 2.5 times more common among the younger compared to older prisoners. Infectious diseases were found to be the most prevalent disease in the Texas study [3,4]. An in-depth analysis of particular chronic diseases, such as hypertension, heart disease, diabetes, arthritis, and chronic pain, that occur more frequently among older prisoners [8,13,16,19] were not considered in the analysis of this Swiss study, but will be a goal for future analyses from the dataset.

On average an older prisoner reported 4.27 somatic diseases, indicating a high disease burden relative to the younger prisoners reporting only 1.62 somatic diseases. The disease burden of older prisoners is comparable to what is known from available studies [1,9]. Since the older group has on average lived in prison for double the amount of time, one might be quick to assume that the higher disease burden is due to the time effect. This, however, was not the case for our sample. Results indicate that the age group had a significant effect on total number of diseases even when controlling for time spent in prison. This finding is different from studies which have indicated a link between the deteriorating health of older prisoners and their incarceration [8,26]. This varying result could be explained by different data sources (i.e. use of self-reported health perception) and comparison groups included. Moreover, an important factor could also be the health care system of a nation, which certainly needs further examination. Similar to the UK study [16], our study also indicates that the health of older prisoners is poorer than that of younger prisoners. However, we cannot state whether the health of older prisoners or all prisoners is worse than that of the general population [6,34,16] since this comparison was not examined and this would be an area of interest for future manuscripts.

The fact that older prisoners suffer from more somatic diseases and that the number of diseases increases with age group is significant and raises questions about prison conditions and the adequacy of the prison health care system. The outcomes of this study identify the poorer health conditions of older prisoners, their higher health care burden, and raises questions related to the provision of health care for aging prisoners. Although this issue has been raised by several authors [13,28,33], our empirical data contributes new information supporting this concern. With an increasing number of sentences resulting in imprisonment, and for longer periods of time, it is expected that the prison system will house more ageing prisoners. Conditions in prison need to ensure that proper, timely and necessary health care is delivered to prisoners in order to enable them to maintain good health, remain independent for as long as possible, and experience health equal with those in the community. There is a significant cost implication too - maintaining good health and preventing

disease is cheaper than responding to deteriorations in health, both for the prison system and society at large.

As with all studies, there could be errors associated with data entry and coding in our analysis. We sought to reduce these errors through independent data checking. The medical details of 11 prisons fulfilling the inclusion criteria remain unknown, but they composed only 23.65% of the eligible sample. Certain types of prisons, such as remand prisons and short-term prisons, were excluded. However, this was done purposely since the study aimed at understanding the overall consequences of ageing in prison, which could only be implemented if the individuals surveyed spend a considerable amount of time there. Finally, in this paper we focused on somatic diseases only. Thus, diseases included in the ICD-10 category of 'mental and behavioral health' were excluded from our analysis. We know that 28.4% of the sample was serving indeterminate security measures as their prison sentence, implying mandatory psychiatric treatment and/or evaluation. Despite these limitations, this study is the first of its kind to capture the somatic disease data of prisoners at the national level with a goal of comparing health of older and younger prisoners.

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## Chapter 5

### Will I Stay or Can I Go? Assisted Suicide in Prison

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## **Will I Stay or Can I Go? Assisted Suicide in Prison**

### **Abstract**

Assisted suicide (AS) is a controversial practice with which physicians and nurses are confronted more and more often. In Switzerland, it is available for Swiss residents and in certain cases for foreigners. Prisoners meet the same prerequisites for AS as the general population and should therefore be eligible for it. Ethical issues, such as informed choice and the autonomy of prisoners, and organizational questions need to be addressed. They must not lead to a denial of this practice. Even though prisons constitute a special area of work for medical staff, it is important to address the possibility of AS in prison openly. This can raise awareness of the difficulties health care professionals face working in closed institutions.

In 2011, 431 persons in Switzerland decided to end their lives by assisted suicide (AS) [4], which is legally condoned when it is not performed out of “selfish motives” (Article 115 Swiss Criminal Code (SCC)). Another specificity is that physicians hold no special role in this process; the doctor’s role is limited to prescribing the needed pentobarbital [6]. The legal regulations in Article 115 SCC provide no guidance on the criteria that must be fulfilled to be eligible for AS, other than altruistic assistance. Non-profit right-to-die organizations such as EXIT or Dignitas do have their own guidelines and more stringent criteria. EXIT, very much like Dignitas, states that it assists members (support and direct assistance requires a membership in a right-to-die organization) who suffer from a hopeless prognosis, unendurable pain, or an undue handicap [5]. According to a ruling of the Swiss Federal Court (BGE 133 I 58), severe mental suffering can also qualify for AS in exceptional cases. The person requesting AS needs to be competent and able to execute the suicide himself or herself, and the choice needs to be informed, constant, and autonomous. While AS is available through these organizations to the Swiss population and in some cases also to foreigners [3], it is not as yet available for prisoners.

We would like to argue that prisoners also meet the eligibility criteria of right-to-die organizations. To do so, we address possible ethical concerns about informed choice and autonomy, making it possible for prisoners to choose AS. We also believe that AS should be a valid alternative to life-long imprisonment.

Prisoners need to fulfil the same prerequisites for AS as the general population. However, the established processes will not differ from the general population on three points: (i) agency, meaning the ability to administer to themselves the deadly medication, will depend on the health status and can be determined by physicians working in prison, (ii) competence of the prisoner, in case of doubt, can be assessed by in-house mental health professionals in addition to the usual examination by a physician and assisting personnel of the right-to-die organization, and (iii) consistency of the choice needs to be evaluated over time because it can vary [14]. Particular attention has to be paid to physicians involved in these assessments, as they have to comply with the principles of medical ethics in prisons, and have to make sure to avoid any dual loyalty conflicts. Their main duty is to act in the

interest of each patient, and not to obey to any obligations/rules/guidelines promoted by their employer [11].

Do incarcerated persons meet standards of informed choice? To be able to choose AS, one needs to be aware of all the alternatives at hand. Unfortunately, these options are severely limited for prisoners in the Swiss correctional system. No end-of-life services, such as palliative or hospice care, are offered systematically, neither in-house nor as so-called “palliative-care in reach” [13]. Death in prison due to old age or disease has not yet been accepted as a reality. Thus, the fates of dying prisoners are decided on a case by case basis, often culminating in emergency transport to the hospital, for a prisoner to die there. The United Kingdom and the United States have begun to establish end-of-life care in prisons, collaborating with community services [9,13]. Yet, access to palliative care even in those countries remains limited [16]. Switzerland is still struggling to find viable solutions. Compassionate release certainly does not provide ‘control’ at the end of life [7], as it involves lengthy bureaucratic and judicial processes, based on “clinically flawed and procedural barriers” [16] such as a definite prognosis. There are few requests for compassionate release granted and, most importantly, rarely in time [1,13]. Therefore, the usual objection that inmates might decide differently if they were not in prison might be true, but it neglects the most essential part of their reality – being imprisoned – and ignores the current limitation in choices that an inmate can make about his or her own death in Swiss correctional facilities.

Other objections can be raised about the autonomy of the prisoner. Deprivation of liberty and housing certainly reduces the autonomy of a prisoner in elements of his or her personal life. The SCC specifies in Article 74 that: “Their 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”. While a prisoner’s autonomy may be reduced in certain areas, such as the choice of physician or the frequency of family visits, it does not impact existential choices of the person. This persistent respect for autonomy is, for example, acknowledged when a prisoner chooses to refuse life-saving treatment or to make an advance directive, such as in the case of hunger-striking prisoners [12], or to issue do-not-resuscitate orders [9]. Conversely, the correctional system has a duty of care towards the persons it detains, securing their lives and ensuring the security of the persons placed under its care, including suicide prevention [8]. This duty should not impede the autonomy of prisoners in regard to existential questions, such as AS, as it is surely thought of as protection, but not as an absolute power of the correctional system over the prisoners and their decision-making about the end-of-life. Special attention must be paid to possible coercion in the prison system, be it by other inmates or routinely used sanctions by the correctional system, such as placements in isolation or strip cells. Comparable to hunger-striking prisoners, it is important to know the person’s true wishes [17], and medical staff, as well as staff from non-profit right-to-die-organizations, should be very thorough in their assessment.

Accordingly, prisoners can fulfil all the prerequisites for AS despite their legal status. Thus they should have access to these services in case their health status has, as described in the criteria above, for example a hopeless prognosis.

The same would seem to apply if a prisoner seeks AS as an alternative to life-long imprisonment. In Switzerland the sole justification for preventive detention is incapacitation (protection

of the society), not retribution, and it must be based on the suspicion of future harm [2]. Prisoners in preventive detention are often elderly prisoners charged with sexual offences, those having committed particularly heinous crimes, or having been judged as particularly dangerous based on psychiatric evaluations. Hurst and Mauron analysed the arguments used for AS and by euthanasia groups. For them “something other than death itself is viewed as the ‘worst evil’ which should be averted” [7]. For a prisoner the ‘worst evil’ may well be the life-long detention he or she has to face. On this account, it must be considered a sufficient suffering. Deprivation of liberty, perceived poor quality of life, and limited perspective: restrictions on social contacts and life planning, free time activities, nutrition, and other semi luxuries (for example, alcohol, tobacco, and sweets), no access to and participation in the ‘real world’ for the rest of one’s life are strong arguments in favour of AS for so-called ‘lififers’. The situation in Switzerland is even more special, as in 2004 lifelong detention without the possibility of revision was first introduced to the Swiss Constitution (Article 123a). Four years later, it was implemented with Article 64 para. 1<sup>bis</sup> SCC. It is particularly severe and practically excludes any hope for the prisoner to be released again into society.

In addition to ethical concerns that might be raised against AS, prisoners face practical and organizational concerns as well. Potential difficulties are: access to right-to-die organizations and visits from them in prison may be restricted by security requirements; where to perform AS which, outside prisons, is usually done at someone’s home (but has been extended to institutions, for example, nursing homes) [3]; or the investigations that follow AS as an ‘unnatural death’. We do not want to turn a blind eye to these challenges that correctional institutions face, as they will be the ones required to implement AS. But we believe that in light of the “aging crisis” [15] in corrections, end-of-life care for inmates is of vital importance and has to include AS in those countries where it has been decriminalized. This would adhere to the principle of equivalence of care [10]. Enhancing public safety by multiplying life-long detentions must include reflections on possible alternatives. Policy makers should acknowledge that life-long incarceration can cause mental suffering to a point where AS needs to be a viable option for prisoners, as it is for people living in the community.

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## Chapter 6

### **Restraint in Hospitals – A Sore Point/ Fixierungsmaßnahmen in Krankenhäusern – Ein wunder Punkt**

Bretschneider, W. (2012). Fixierungsmaßnahmen in Krankenhäusern – Ein wunder Punkt [Restraint in Hospitals – A Sore Point]. *Das Gesundheitswesen*, 74(12), 812-817. (Impact Factor: 0.709)

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## **Restraint in Hospitals – A Sore Point**

### **Summary<sup>1</sup>**

Restraint measures are used for several medical situations, for example when patients are in a state of anxiety or for security reasons. Their use in psychiatric care and nursing homes is widely debated, whereas their use in hospitals is rarely discussed. This is of particular concern because restraints are prescribed under various circumstances in hospitals. Yet, they have an ambivalent character because they are viewed as a custodial measure. In Germany, it is common practice to use restraint measures during health care provision and the number of applications has risen in the past years.

The aim of this paper is to examine the German civil law legislation on restraints and medical reasons for employing restraints in German hospitals. First, the different concepts and definitions of restraint measures will be looked at. Second, possible associated consequences and problems are described. Finally, the admissibility, preconditions, procedures and recommendations for actions are discussed.

The paper concludes that the use of restraints should only be performed after a thorough assessment of the patient and his or her wishes. Here, a holistic approach is required to evaluate the current life situation, biography, identity, values and will of the patient – all of this should play a role in the evaluation process. Furthermore, a determined time slot should be included in the civil law legislation, which defines a maximum length of time for how long restraint measures may be applied. Also, a transparent and standardised system of documentation in hospitals should be implemented in order to have the factual possibility to monitor the application of restraint measures. Such a task could be undertaken either by internal or external professionals with the help of certain control mechanisms/procedures.

As a vulnerable group, patients are dependent on clinical staff members, who must in all circumstances do their best to respect the autonomy and rights of their patients. Therefore, special attention should be paid to the education of medical personnel. This could be done by incorporating the topic of restraint measures and their consequences in the curriculum at the very beginning of the medical training. Awareness of health care personnel regarding the use of restraints should be increased and interdisciplinary collaborations among judges, clinicians and nurses must be developed and/or enhanced in order to improve the flow of information and the interdisciplinary exchange on this ethical and moral issue.

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<sup>1</sup> This paper was written and published in German, a concise English summary is therefore provided here. The entire German text can be found on the following pages.

## **Fixierungsmaßnahmen in Krankenhäusern – Ein wunder Punkt**

### **Zusammenfassung**

Fixierungsmaßnahmen werden in den unterschiedlichsten medizinischen Versorgungssituationen angewendet. Ihr Einsatz wurde bisher vor allem in der Psychiatrie und in Pflegeheimen problematisiert, wohingegen die Anwendungen in Krankenhäusern kaum diskutiert wird. Dies ist besonders beunruhigend, da Fixierungen in Krankenhäusern unter den verschiedensten Umständen angeordnet werden, jedoch als freiheitsentziehende Maßnahme einen ambivalenten Charakter haben. Ziel dieses Artikels ist es, die zivilrechtliche Gesetzgebung für Fixierungen und die medizinischen Gründe für die Vornahme von Fixierungen in deutschen Krankenhäusern zu analysieren. Ich werde zeigen, dass die Vornahmen von Fixierungen erst nach einer eingehenden Beurteilung des Patienten und seiner Wünsche vorgenommen werden sollten. Als vulnerable Gruppe sind Patienten von den Mitgliedern des medizinischen Personals abhängig, die unter allen Umständen ihr Bestes tun müssen, um die Autonomie und Rechte ihrer Patienten zu respektieren. Das Bewusstsein des Gesundheitspersonals in Bezug auf Fixierungen muss geschärft werden und die interdisziplinäre Zusammenarbeit von Betreuungsrichtern, Ärzteschaft und Pflegepersonal verbessert werden, um den Informationsfluss und -austausch zu dieser ethischen und moralischen Frage zu verbessern.

### **Hintergrund**

Selbstbestimmung ist ein wichtiges, wenn nicht sogar das zentrale Thema unserer heutigen Gesellschaft. Dieses Autonomieprinzip hat sich mittlerweile auch in Gebieten durchgesetzt, in denen bisher eine eher zurückhaltende Anwendung vorzufinden war. Im medizinischen Sektor zählen vor allem Entscheidungen dazu, die am Lebensende getroffen werden. Im Juni 2010 hat der Bundesgerichtshof in einer elementaren Grundsatzentscheidung die Selbstbestimmung von Patienten gestärkt, indem klargestellt wurde, dass der Abbruch einer lebenserhaltenden Maßnahme, in diesem Fall das Durchtrennen des Schlauchs der PEG-Sonde auf Grundlage des Patientenwillens (Patientenverfügung), keine strafbare Handlung darstellt [4].

Dessen ungeachtet gibt es Situationen, in denen Zweifel am respektvollen Umgang mit der Patientenautonomie aufkommen. Dies ist vor allem der Fall, wenn es um die Fixierung von Patienten in Krankenhäusern geht. Als freiheitsentziehende Maßnahme steht sie in einem auffälligen Gegensatz zum Bild vom selbstbestimmten Menschen. Bei der medizinischen Versorgung in Deutschland sind Fixierungsmaßnahmen dennoch gängige Praxis. Die Zahl der freiheitsentziehenden Maßnahmen gemäß § 1906 IV Bürgerliches Gesetzbuch (BGB) hat in den letzten Jahren stark zugenommen.

Bisher beschränken sich die Bearbeitungen zum Thema Fixierung größtenteils auf die Praxis in der Psychiatrie und in Pflegeheimen, sodass Nachholbedarf für den stationären Bereich in Krankenhäusern besteht. Die Patienten in Krankenhäusern befinden sich aufgrund von teilweise schwersten Erkrankungen in einer Position, in der sie in besonderem Maße auf die Achtung ihrer Rechte durch Pflegepersonal und Ärzte angewiesen ist. Ziel dieses Artikels ist es, Gründe für die Vornahme und die stetige Zunahme von Fixierungsmaßnahmen in Krankenhäusern zu analysieren, sowie die Debatte über Fixierungen erneut zu entfachen. Der Artikel gibt als erstes einen

medizinischen und juristischen Überblick zu Fixierungsmaßnahmen, anschließend wird die Problematik anhand des gerichtlichen Verfahrens verdeutlicht. Als Drittes werden Verbesserungspotentiale in der Patientenbetreuung aufgezeigt.

### **Klärung der Begrifflichkeiten**

Um einen Ausgangspunkt für die Betrachtung zu schaffen, muss als erstes geklärt werden, was eine Fixierung ist und welche Besonderheiten es gibt. Eine Fixierung ist jede mechanische Bewegungseinschränkung. Sie hat grundsätzlich einen freiheitseinschränkenden Charakter. Im Allgemeinen wird der Begriff Fixierung als physische Einwirkung verstanden, er ist jedoch nicht darauf begrenzt, sondern kann auch mit Hilfe von Medikamenten erfolgen. Das klinische Wörterbuch ‚Psychembel‘ beschreibt eine Fixierung generell als eine mechanische Befestigung. Mit einer freiheitseinschränkenden Maßnahme wird der willkürliche Positionswechsel verhindert, die selbstständige Entfernung der Fixierung durch den Betroffenen ist nicht möglich. Um eine Maßnahme als Fixierungsmaßnahme einzustufen, kommt es nicht auf die Häufigkeit an, mit der sie durchgeführt wird. Das heißt, nur weil eine pflegerische Maßnahme täglich, routinemäßig erfolgt, verliert sie deshalb nicht den Charakter einer Fixierung. Auch der Zweck und die Gründe der Maßnahme haben keinen Einfluss auf die Einstufung als Fixierung. Es ist ohne Belang, ob die Fixierung eines Patienten zum Schutz des Personals erfolgt oder zum Schutz des Patienten vor sich selbst. Zu beachten ist, dass bei einem Patienten, der sich in einem komatösen Zustand befindet und bei dem gewollte Bewegungen ausgeschlossen werden können, das Hochziehen des Bettgitters keine Fixierung, sondern eine reine Sicherheitsmaßnahme darstellt [10].

### **Fixierungsarten**

Dem ärztlichen und pflegerischen Dienst auf Krankenhausstationen stehen verschiedene Möglichkeiten zur Fixierung von Patienten zur Verfügung: einerseits die mechanische Fixierung und andererseits die Fixierung durch die Verabreichung von Medikamenten (chemische Fixierung). Zu den mechanischen Fixierungsmitteln im Umgang mit Patienten zählen unter anderem Bettgitter, Schutzdecken und Gurte für Rumpf und Extremitäten. Bei der Fixierung mit Gurten gibt es unterschiedliche Fixierungsmöglichkeiten, die von der 1-Punkt-Fixierung (zum Beispiel Fixierung des Handgelenkes) bis zur 5-Punkt-Fixierung (Fixierung des Bauches, sowie beide Hand-, und Fußgelenke) reichen. Die Verabreichung von Medikamenten kann ebenfalls eine Art der Fixierung darstellen. Es handelt sich in diesem Fall um Präparate, die eine sedierende Wirkung haben. Inwieweit die Medikamentengabe eine freiheitsentziehende Maßnahme darstellt, ist jedoch strittig [12]. Wenn die beschriebene Wirkung auf den Patienten beabsichtigt ist und es sich nicht nur um eine Nebenwirkung handelt, die in Kauf genommen wird, um das Behandlungsziel zu erreichen, handelt es sich laut Hoffmann beim Einsatz von Sedativa um eine Fixierungsmaßnahme [10]. Klie hingegen ist anderer Ansicht und bewertet die beabsichtigte und auch unbeabsichtigte sedierende Wirkung auf den Patienten als Fixierungsmaßnahme, ganz gleich, ob sie bezweckt ist oder nicht. Gleichwohl betont er, dass nicht jede Medikamentengabe unter Generalverdacht stehen darf [10]. Die Beurteilung, ob eine Sedierung des Patienten beabsichtigt war oder ob es sich nur um eine Nebenwirkung gehandelt hat,

ist in den meisten Fällen kaum überprüfbar, da therapeutische Zwecke auch vorgetäuscht werden können.

### **Fixierung als medizinische Maßnahme**

Die Fixierung von Patienten stellt keinen Heileingriff dar, sondern kann als Prozedur bezeichnet werden, um dem Patienten den Weg zur Genesung zu erleichtern. Es gibt verschiedene Motive, die für eine Fixierungsmaßnahme sprechen. Meist handelt es sich um patientenorientierte Gründe, bei denen Sicherheitsaspekte und Wohl des Patienten im Mittelpunkt stehen. Die häufigsten Anlässe für die Anordnung einer Fixierung sind die Selbstgefährdung des Patienten oder die Fremdgefährdung durch den Patienten. Auch behandlungsorientierte Gründe können Auslöser für Fixierungsmaßnahmen sein. Mithilfe von Fixierungen sollen vorhersehbare Schäden verhindert werden, zum Beispiel bei starker Unruhe, die gesundheitliche Beeinträchtigungen zur Folge haben kann, bei hohem Verletzungsrisiko und bei einer Gefahr für die Gesundheit durch die eventuelle Entfernung von Infusionen. Fixierungen sind hingegen nicht gerechtfertigt, um Stürzen und dergleichen im Allgemeinen vorzubeugen.

### **Folgen und Probleme von Fixierungsmaßnahmen**

Eine Fixierungsmaßnahme kann nicht nur einen Schutz vor selbstgefährdendem Verhalten darstellen, sondern gleichzeitig die Verletzungsgefahr erhöhen. Es kann zu Strangulationen und Hautabschürfungen kommen, die Gefahr von Dekubitalgeschwüren erhöht sich und auch ein plötzlicher Herztod kann durch Fixierungsmaßnahmen bei Patienten auftreten [14]. Diese Folgen zählen zu den direkten Gefahren. Indirekte Gefahren stellen Immobilisation und medizinische Komplikationen dar, die eine Verschlechterung des Allgemeinzustandes und der Lebensqualität zur Folge haben.

Laut Schumacher können Fixierungen helfen, die Gesundheit zu erhalten und eine Verschlechterung derselben zu vermeiden. Die Maßnahmen stellen das Mittel dar, das den Patienten vor Selbstverletzungen schützen soll [20]. Lipp hingegen stellt fest, dass ein einmal ausgeübter körperlicher Zwang nicht mehr rückgängig gemacht werden kann [15]. Außerdem können fixierte Patienten generell Angstzustände entwickeln oder das Vertrauen in die Pflegekräfte und Ärzte verlieren [8]. Dies kann sich wiederum negativ auf den Heilungsprozess auswirken und die Arbeit mit diesen Patienten nach Verlegungen, zum Beispiel in Pflegeheime, erschweren. Weltweit zeigt keine Studie den positiven Effekt von Fixierungen, die Daten über negative Folgen sind hingegen alarmierend.

Großkopf und Klein kritisieren zudem ganz deutlich das fehlende Problembewusstsein bei den Pflegekräften, gerade in Bezug auf die juristischen Vorgaben. In ihren Augen werden Fixierungen viel zu oft leichtfertig vorgenommen. Als Grund nennen sie die Sorge um den Patienten, aber auch die Sorge, selbst für etwaige Schäden haften zu müssen [8].

Bevor eine Fixierungsmaßnahme angeordnet wird, muss die Notwendigkeit genau geprüft werden, beziehungsweise nach anderen, weniger einschneidenden Alternativen gesucht werden. Die Eruierung des Patientenwillens ist der wichtigste Punkt, da er die Entscheidungsgrundlage für oder

gegen eine Fixierungsmaßnahme bildet. Auch die ständige Aufsicht, die für fixierte Patienten gewährleistet sein müsste, stellt sich oft als problematisch dar. In der Praxis ist davon auszugehen, dass Patienten immer wieder fixiert werden, um das Personal zu entlasten.

### **Zulässigkeit von Fixierungsmaßnahmen**

Für die Zulässigkeit einer Patientenfixierung müssen bestimmte Voraussetzungen erfüllt sein, die sich aus § 1906 BGB ergeben: Dies ist zum einen die Einwilligung des Patienten beziehungsweise seines Betreuers in die Fixierung und unter Umständen das Vorliegen eines Fixierungsbeschlusses gemäß § 1906 IV BGB. Zum Beispiel muss das Betreuungsgericht benachrichtigt und ein Fixierungsbeschluss beantragt werden, wenn absehbar ist, dass der nicht einwilligungsfähige Patient voraussichtlich länger als 24 Stunden fixiert wird [9]. Der betreuungsgerichtliche Beschluss ist grundsätzlich auf ein Jahr befristet und erlischt mit Ablauf der Befristung. Entfallen die Voraussetzungen für die freiheitsentziehende Maßnahme bereits vor Fristende, wird die Genehmigung gegenstandslos. Zum anderen muss Gefahr im Verzug sein, vor allem bei akuter Eigengefährdung [19], oder die Notwendigkeit zu einem ärztlichen Eingriff, einer Heilbehandlung oder einer Untersuchung bestehen. Wird ein Patient mehrfach fixiert, bedarf jede einzelne Maßnahme der Genehmigung [18]. Ferner muss die Fixierungsmaßnahme medizinisch geboten sein und dokumentiert werden. Eine Legitimation von Fixierungsmaßnahmen durch Fixierungsrichtlinien oder andere krankenhausinterne Dienstanweisungen ist nicht möglich [10].

### **Fixierungsanordnung**

Die Anordnung einer Fixierung muss regelmäßig vom ärztlichen Personal vorgenommen werden, eine Delegation auf das Pflegepersonal ist nicht zulässig. Dadurch soll gewährleistet werden, dass das ärztliche Personal selbst die Notwendigkeit einer Fixierung feststellt. In Ausnahmefällen ist eine Fixierung durch Pflegekräfte möglich, wenn etwa sofortiges Handeln nötig ist. Danach muss jedoch schnellstmöglich ein Arzt hinzugezogen werden [21]. Die Fixierungsanordnung muss schriftlich erfolgen und persönliche Angaben zum Patienten, zum Beispiel Namen und Geburtsdatum, den Grund der Fixierung, die Dauer und die Art der Fixierung beinhalten, sowie zusätzlich die Anzahl und Art von begleitenden Pflegemaßnahmen, die Häufigkeit von Kontrollen (Sichtkontrolle) sowie die Unterschrift des anordnenden Arztes [8].

### **Aufklärung**

Vor der Realisierung einer Fixierung muss der betroffene Patient oder im Fall einer Betreuung die betreuende Person, über die bevorstehende Maßnahme aufgeklärt werden. Insbesondere über Art, Dauer und den Grund für die Maßnahme, aber auch mögliche Gefahren. Die Verantwortung für die Aufklärung trägt die Person, die die Fixierungsmaßnahme vornimmt beziehungsweise anordnet, also entweder das ärztliche oder das Pflegepersonal.

## **Einwilligungsfähigkeit**

Um wirksam in eine Fixierungsmaßnahme einwilligen zu können, muss der betroffene Patient eine natürliche Einsichts- und Urteilsfähigkeit besitzen [3]. Diese liegt vor, wenn der Patient in der Lage ist, Bedeutung, Wesen und Tragweite der Maßnahme einzuschätzen und eine Entscheidung darüber zu treffen. Es kommt demnach allein auf die Einwilligungsfähigkeit an und nicht etwa auf die Geschäftsfähigkeit [10]. Auch Patienten, die bereits unter Betreuung stehen, können grundsätzlich wirksam einwilligen, allerdings ist der Einwilligungsvorbehalt aus § 1903 BGB zu beachten [21]. Bei der Einwilligungsfähigkeit handelt es sich nicht um einen Zustand. Aufgrund einer Diagnose kann demnach nicht auf die Fähigkeit zur Einwilligung geschlossen werden. Bei der Beurteilung der Einsichtsfähigkeit von Patienten ist deshalb eine gesonderte Einzelfallbetrachtung unerlässlich. Diese sollte besonders gewissenhaft vorgenommen werden, denn mit deren Verneinung wird dem Patienten jegliche Möglichkeit genommen, seinen Willen zu verwirklichen.

## **Einwilligung**

Die Einwilligung kann mündlich, schriftlich oder konkludent, d.h. durch Kopfnicken oder Ausstrecken des Armes zum Anlegen der Fixierungsurte erfolgen, aber auch eine mutmaßliche Einwilligung durch den Patienten ist denkbar. Eine mutmaßliche Einwilligung liegt vor, wenn der Patient nicht in der Lage ist, willkürliche Bewegungen auszuführen und den Willen dazu auch nicht erkennen lässt, sowie eine Fixierung in seinem objektiven Interesse liegt, wie es bei Komapatienten der Fall ist [6]. Bei fehlender Einsichtsfähigkeit des Patienten ist gemäß § 1896 BGB der gerichtlich bestellte Betreuer – sollte er für diesen Aufgabenbereich zuständig sein – berechtigt, in einmalige oder kurzfristige Fixierungen einzuwilligen. Die Einwilligung muss in diesem Fall schriftlich erfolgen [21]. Die alleinige Einwilligung durch Angehörige, die nicht die Funktion des Betreuers innehaben, ist nicht möglich, da die rechtliche Legitimation fehlt [8].

Im Fall von volljährigen Patienten muss zusätzlich eine Genehmigung durch das Betreuungsgericht erfolgen, hierbei handelt es sich um einen Fixierungsbeschluss. Ein solcher ist nach Meinung einiger Autoren bereits bei Fixierungen nötig, die weniger als 24 Stunden andauern [10]. Wird die 24-Stunden-Grenze überschritten oder findet die Fixierung des Patienten regelmäßig statt, so ist ein solcher Beschluss zwingend notwendig. Des Weiteren muss die Fixierungsmaßnahme dem Wohl des Patienten dienen, um überhaupt genehmigungsfähig zu sein. Auf der Grundlage einer Betreuung sind Fixierungen nur im Rahmen eines selbstgefährdenden Verhaltens durch den Patienten zulässig [21]. Zu arbeitserleichternden Zwecken dürfen Fixierungen nicht verwendet werden, sie müssen generell den Erforderlichkeitsgrundsatz erfüllen. Liegt eine Einwilligung des Patienten vor, entfällt die richterliche Prüfung. Sollte eine Ablehnung erfolgen, muss über die möglichen Konsequenzen einer unterbleibenden Fixierung aufgeklärt werden.

## **Die Rolle des Betreuungsgerichts**

Das Amtsgericht ist mit seiner Familien-, Vormundschafts-, und Betreuungsabteilung für Betreuungs- und Vormundschaftsverfahren zuständig und damit auch für die Genehmigung von Fixierungen, es nimmt daher eine wichtige Rolle ein. Wenn der niedrigschwellige Umgang mit Fixierungsmaßnahmen

bereits bei der Genehmigung beginnt, ist die Wahrscheinlichkeit hoch, dass dies in der Umsetzung weitergeführt wird. Eine Fixierung gegen den Willen eines urteilsfähigen Patienten stellt einen schwerwiegenden Eingriff in das Selbstbestimmungsrecht des Patienten dar. Aus diesem Grund ist jede Bewilligung in der juristischen ebenso wie in der medizinischen Praxis sorgfältig gegen mögliche Alternativen abzuwägen.

Für die regelmäßig oder über einen längeren Zeitraum erfolgende Fixierung eines betreuten Patienten, der sich in einer Anstalt, einem Heim oder einer sogenannten sonstigen Einrichtung befindet, ohne untergebracht zu sein, d.h. ohne Zwangseinweisung, ist gemäß § 1906 IV BGB ein Fixierungsbeschluss vom Betreuungsgericht erforderlich. Der Begriff der sonstigen Einrichtung ist weit zu fassen, sodass auch Krankenhäuser, Alten- und Pflegeheime darunter fallen. Außerdem muss eine freiheitsentziehende Maßnahme nicht immer zur gleichen Zeit erfolgen um regelmäßig zu sein. Darunter fallen vielmehr auch Maßnahmen, die immer bei bestimmten Anlässen vorgenommen werden [20]. Auch ungeplante Wiederholungen sind genehmigungspflichtig. Ebenso wenig heben kurzzeitige Unterbrechungen die Genehmigungspflicht auf. Es ist immer der Gesamtzeitraum der Fixierungsmaßnahme zu berücksichtigen [6]. Die Formulierungen „regelmäßig“ und „über einen längeren Zeitraum“ sind kritisch zu betrachten, da eindeutige Zeitangaben fehlen. Dies erschwert die Arbeit mit fixierten Patienten für Ärzte und Pflegekräfte zusätzlich, denn so gibt es keine Gewissheit, ob und wann eine Genehmigung vom Betreuungsgericht eingeholt werden muss. Auch dem betroffenen Patienten und seinen Angehörigen fehlt es an Rechtsklarheit.

Fraglich ist, welche Beurteilungsgrundlage der zuständige Richter hat, um sich für eine Genehmigung der Fixierung zu entscheiden und ob die Autonomie des Patienten bei der Entscheidung eine Rolle spielt, insbesondere dann, wenn von einem „Massengeschäft für Betreuungsgerichte“ die Rede ist [13].

Entscheidungsgrundlage für den Richter ist das ärztliche Zeugnis, welches gemäß § 321 II FamFG (Gesetz über das Verfahren in Familiensachen und in den Angelegenheiten über die freiwillige Gerichtsbarkeit) für die Genehmigung einer freiheitsentziehenden Maßnahme erforderlich ist. Das Bundesverfassungsgericht hat dazu in seinem Beschluss vom 23.03.1998 klargestellt, dass es eine unverzichtbare Voraussetzung eines rechtsstaatlichen Verfahrens ist, dass Entscheidungen, die den Entzug der persönlichen Freiheit betreffen, auf ausreichender richterlicher Sachaufklärung beruhen. Außerdem müssen sie eine in tatsächlicher Hinsicht genügende Grundlage haben, die der Bedeutung der Freiheitsgarantie entsprechen [5]. Die richterliche Inaugenscheinnahme eines jeden Patienten vor der Genehmigung einer Fixierungsmaßnahme sollte grundsätzlich immer erfolgen [14]. Dies ist jedoch kaum realisierbar und in der Praxis eher die Ausnahme. Daher beruht die Entscheidung meist auf Informationen, die sich aus der Fixierungsanordnung des Arztes ergeben. Auch die Einsicht in die Pflegedokumentation kann hilfreich sein, indem sie Auskunft über bereits erfolgte Alternativmaßnahmen zur Fixierung geben kann und sich daraus eine Begründung für eine trotzdem erforderliche Fixierungsmaßnahme ableiten lässt.

Nach Angaben eines befragten Amtsgerichts in Sachsen-Anhalt erfolgt keine gesonderte statistische Erfassung von Fixierungsbeschlüssen. Weder die genaue Anzahl der Genehmigungen noch die Anzahl der Ablehnungen wird erfasst. Auch werden die entsprechenden Beschlüsse nicht

gesondert verwahrt, sondern die Betreuungsakte bildet die Grundlage für die Bearbeitung durch den jeweiligen Richter [16]. Aus der Statistik über Unterbringungssachen gemäß § 312 FamFG, ergibt sich folglich nur ein ungenauer Einblick in die Anzahl der Fixierungsmaßnahmen, da unter der Nr. 2 des Paragraphen alle Genehmigungen von freiheitsentziehenden Maßnahmen nach § 1906 IV BGB erfasst werden. Weder kann auf die Art der Fixierungen geschlossen werden, noch wird deutlich, in welcher Einrichtung, zum Beispiel Pflegeheim oder Krankenhaus, die Fixierung erfolgte. Eine statistische Erhebung in diesem Bereich ist jedoch unerlässlich und sollte in Krankenhäusern und Gerichten gleichermaßen erfolgen.

### **Bewertung**

Eine Fixierung ist eine schwerwiegende Form der Autonomiebeschränkung. Aus heutiger Sicht stellt jede ruhigstellende Maßnahme einen Eingriff in die Grundrechte eines Menschen dar. Sie ist immer das letzte Mittel der Wahl (*ultima ratio*). Geisler betont, dass Autonomie und Fürsorge keine Konzepte sind, die sich gegenseitig ausschließen, erst ihr Zusammenwirken ermöglicht einen patientengerechten Umgang [7]. Zivilrechtlich soll die Regelung des § 1906 IV BGB die betroffenen Personen in einem Bereich schützen, der so Hoffmann und Klie, von den meisten Menschen als sehr eingriffsintensiv wahrgenommen wird [10]. Nach Aussage von Großkopf und Klein prägen jedoch Unsicherheiten und Unkenntnis von Seiten der Ärzte und der Pflegekräfte den Krankenhausalltag [8].

Ursachen für die fehlende Bereitschaft, sich im medizinischen und juristischen Bereich mit diesem Thema auseinanderzusetzen und etwas zu verändern, liegen vor allem am zusätzlichen Arbeitsaufwand und steigenden Personalkosten. Für das Umdenken in diesem Bereich sprechen allerdings das positive Outcome bei den Patienten und die Respektierung des Selbstbestimmungsrechts.

Fehlende Strukturen und einheitliche Dokumentationssysteme innerhalb eines Krankenhauses begünstigen die unkontrollierte Vornahme von Fixierungen. Eine Überprüfung wird damit fast unmöglich und wäre mit einem immensen Zeit- und Kostenaufwand verbunden. Durch fehlende einheitliche Krankenhausstatistiken gibt es auch keine Möglichkeit eine Abgleichung mit den gerichtlich genehmigten Fixierungen vorzunehmen. Aufgrund dieser bestehenden Problematik sollten Mechanismen geschaffen werden, die eine Auswertung der Fallzahlen überhaupt möglich machen. In den Krankenhäusern könnten etwa die bereits vorhandenen elektronischen Dokumentationssysteme für eine detaillierte Erfassung genutzt werden. Gleichzeitig sollte es bei der Erstellung der Gerichtsstatistik möglich sein, die in den Gerichtsakten vorliegenden Daten zu freiheitsentziehenden Maßnahmen zu erfassen.

Überdies fehlen eindeutig festgelegte Zeitfenster, in denen Fixierungsbeschlüsse beantragt werden müssen und an denen sich die Mitarbeiter in Krankenhäusern und anderen Einrichtungen orientieren können. Ein erster Schritt wäre hier die Schaffung einer einheitlichen gesetzlichen Regelung, die genau vorgibt, ab welchem Zeitpunkt das Amtsgericht eingeschaltet werden muss.

## **Vorgehensweisen und Handlungsempfehlungen für das Vornehmen von Fixierungsmaßnahmen**

Mit der Fixierung von Patienten wird auf unterschiedliche Art und Weise umgegangen. In Krankenhäusern wird zum Beispiel mit vorgegebenen Standardvorgehensweisen gearbeitet, den Standard Operating Procedures (SOP), die eine Anleitung für die Mitarbeiter im Krankenhaus darstellen und Mindestanforderungen definieren. Oberstes Ziel einer SOP ist die Schaffung von Handlungssicherheit, auch im Sinne des Patientenschutzes. Darüber hinaus dienen sie der Vereinheitlichung der Arbeitsprozesse und der Qualitätssicherung [2].

Im Jahr 1995 wurden außerdem gemäß § 92 Sozialgesetzbuch XI auf Landesebene Pflegeausschüsse zur Beratung über Fragen der Finanzierung und des Betriebs von Pflegeeinrichtungen gebildet, die allerdings unterschiedlich stark aktiv sind. Der Bayerische Landespflegeausschuss hat hingegen Pionierarbeit geleistet und 2006 den Leitfaden „Verantwortungsvoller Umgang mit freiheitsentziehenden Maßnahmen in der Pflege“ entwickelt [14]. In diesem Leitfaden befinden sich umfangreiche Darstellungen zur Vermeidung von Fixierungsmaßnahmen sowie zur fach- und sachgerechten Umsetzung von notwendigen Maßnahmen. Ein besonders wichtiger Punkt ist ein entsprechendes Pflegekonzept und Leitbild, das von der jeweiligen Klinikleitung in Bezug auf Fixierungsmaßnahmen vorgegeben wird. Obwohl dieser Leitfaden hauptsächlich auf freiheitsentziehende Maßnahmen in Pflegeheimen gerichtet ist, stellt er ein wichtiges Instrument dar, das Anregungen für den medizinischen Therapiebereich liefert.

Ein Grundanliegen der modernen Medizin ist es, die Autonomie von Patienten zu fördern und zu respektieren [17]. Die Umsetzung kann allerdings nur gewährleistet werden, wenn verschiedene Schritte vollzogen werden. Eine Handlungsoption, um das Vornehmen von Fixierungsmaßnahmen besser kontrollieren und regulieren zu können, ist die Verbesserung der Zusammenarbeit von Betreuungsrichtern und Ärzteschaft. Mit einem solchen Schritt kann der Informationsfluss erhöht werden und ein Erfahrungsaustausch stattfinden, der den betroffenen Patienten zu Gute käme. Eine gezielte externe Kontrolle der Krankenhäuser wird jedoch von Vennemann abgelehnt, da sie nur zu gegenseitigem Misstrauen führen und eine Sachverhaltsaufklärung unnötig erschweren würde [22]. Eine krankenhauserinterne Kontrolle im Rahmen anderer Qualitätskontrollmaßnahmen wäre allerdings sehr nützlich.

Außerdem ist ein ausgeglichenes Verhältnis zwischen Pflegekräften und Ärzten von großer Bedeutung, um das Wohl des Patienten in den Mittelpunkt stellen zu können [1]. Beide Parteien tragen Verantwortung und sollten gemeinsam über Fixierungsmaßnahmen reflektieren und sie regelmäßig überprüfen. Illhardt spricht von der Macht des Konsenses und betont die Bedeutung der gemeinsamen Wahrnehmung, um alle Interessen gleichermaßen vertreten zu können [11]. Um diesen Effekt noch zu verstärken, wird im Leitfaden des Bayerischen Landespflegeausschusses empfohlen, einen Beauftragten für freiheitsentziehende Maßnahmen zu benennen, der speziell für Schulungen und Begutachtungen zuständig ist und als Ansprechpartner für Ärzte, Pflegekräfte, Patienten und Angehörige dient [14]. Im Rahmen von Fortbildungen könnten beispielsweise Fallvignetten besprochen werden, um das Personal zu unterrichten, wann Fixierungsmaßnahmen gerechtfertigt sind und wann nicht. Ebenso müssen Verdrängungs- und Verleugnungsmechanismen durchbrochen

werden, um ein neues Problembewusstsein auf Seiten des medizinischen Personals zu generieren [12]. Diese Art der Aufklärung könnte beispielsweise mithilfe von Statistiken erfolgen, die monatlich auf den jeweiligen Stationen im Krankenhaus ausgehängt und ausgewertet werden.

Ein wichtiges Schlagwort in diesem Zusammenhang ist die Vermeidung und damit einhergehend die Möglichkeit von alternativen Handlungsweisen. Leider hat der Zeitdruck einen wesentlichen Einfluss auf den Umgang mit den Patienten. Gerade der Mangel an Pflegepersonal verstärkt den Einsatz von Fixierungsmaßnahmen. Ziel sollte daher eine patientenorientierte Medizin sein, die den Patienten nur dann fixiert, wenn es wirklich nötig ist und seine Bewegungsfreiheit demzufolge so wenig wie möglich einschränkt. Generell sollte umfassend, öffentlich und institutionsintern darüber informiert werden, was im Vorfeld getan werden kann, um das konstitutionell garantierte Selbstbestimmungsrecht auch im Zustand fehlender Bewusstseinsklarheit ausüben zu können. Auf Bundesebene könnte dies zum einen mithilfe von Kampagnen des Bundesministeriums für Gesundheit geschehen, zum anderen innerhalb der medizinischen Institutionen durch Informationsveranstaltungen oder Flyer für Patienten. Ein besonderes Augenmerk sollte auch auf die Ausbildung des medizinischen Personals gelegt werden. Wenn die Fixierungsproblematik bereits zu Beginn der Ausbildung in das Bewusstsein aufgenommen wird, ist zu hoffen, dass sich dies auch auf die zukünftige Praxis auswirken wird.

### **Ergebnis und Schlussüberlegung**

Henke schreibt: „Fixierung ist niemals ein Pflegeziel, sondern stets ein aktuelles Pflegeproblem, welches bei der Pflegeevaluation als veränderungsbedürftig zu betrachten ist“, dennoch sind Fixierungsmaßnahmen zum jetzigen Zeitpunkt nicht aus Krankenhäusern wegzudenken. Bekanntermaßen handelt es sich um eine besonders einschränkende therapeutische Vorgehensweise im Medizinwesen, die einen ambivalenten Charakter hat. Oft wird den Patienten zu schnell eine fehlende Entscheidungskompetenz unterstellt [1]. Um herauszufinden, was für den betroffenen Patienten richtig ist, ist eine ganzheitliche Betrachtung nötig. Diese kann erfolgen, indem die derzeitige Lebenssituation, die Biographie, die Identität, Wertvorstellungen und der Wille in die Beurteilung einbezogen werden.

Nimmt die Autonomie des Patienten ab, erhöht sich die Sorgfaltspflicht des ärztlichen und pflegerischen Dienstes [1]. Auch wenn ein gesunder Mensch Schwierigkeiten hat, sich vorzustellen, welche Behandlungsarten und -möglichkeiten im Krankheitsfall für ihn in Frage kommen, ist es sehr wichtig, diesbezüglich einen persönlich gefestigten Standpunkt zu entwickeln. In Gesprächen mit Angehörigen – wie Partnern, Eltern, Geschwistern – oder Freunden, können die eigenen Vorstellungen und Wünsche jederzeit geäußert werden. Diese Informationen sind Hilfestellungen für das medizinische Personal, um die Durchsetzung des Patientenwillens zu gewährleisten.

Sollte das Thema Fixierungen in Krankenhäusern weiterhin einen verhältnismäßig geringen Stellenwert haben, kann davon ausgegangen werden, dass die Zahl der Grundrechtsverletzungen durch nicht genehmigte Fixierungsmaßnahmen zunehmen wird. Es ist wichtig, Menschen, die Gesundheitsberufe ausüben, weiter für diese Problematik zu sensibilisieren und ihnen die besondere Relevanz vor Augen zu führen. Nur die Bereitschaft aller Beteiligten, sich auf Neues einzulassen und

alte Verhaltensweisen kritisch zu überdenken, kann die gängige Praxis „Fixieren ohne (gerichtlichen) Beschluss“ ändern.

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## Chapter 7

### **The New Swiss Regulation on Restraint Measures on Medico-Ethical Trial/ Die neue Schweizer Gesetzgebung zu bewegungseinschränkenden Maßnahmen auf dem medizinethischen Prüfstand**

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## The New Swiss Regulation on Restraint Measures on Medico-Ethical Trial

### Summary<sup>1</sup>

Restraint measures are used in different medical institutions and care facilities to directly influence or change patients' behaviour. At the present time, especially people who suffer from dementia are affected. The increased vulnerability of certain patients makes it particularly important to examine circumstances and justifications for the application of restraint measures.

On 1 January 2013, a legal provision on the federal level addressing restraint measures came for the first time into force in Switzerland. Mobility restrictions can constitute a deprivation of liberty and justification is always needed. Also, indications for the application of restraint measures have to be clarified as their standard application should not be the aim in the health care treatment of patients'. Regarding this issue, legal regulations can be guidance for physicians in charge and the nursing staff and a supportive tool in times of uncertainty. The objectives of this paper are to analyse restraint measures from two different perspectives. This will be done by a medico-ethical discussion as well as by analysing the new legal regulation in Switzerland.

The main aim of this new regulation on restraint measures, article 383 et seq. of the Swiss Civil Code, is to strengthen autonomy and personal freedom of patients. Nevertheless, it is important to engage in a dialogue and to question regulations like this in order to reveal possible gaps while simultaneously offering solutions. Not only is awareness important, but the consequences for all involved persons need to be examined as the use of restraint measures can only rarely be ethically justified. Often, they contradict well-established principles of medical ethics (respect for autonomy, beneficence, non-maleficence) and care ethics (principle of welfare, human dignity, physician-patient relationship). Some deficiencies can also be found in this provision: a specific feature of this new regulation is, that physical and chemical restraints are separately regulated which cannot be ethically justified as both types of restraint have the same consequences for incapacitated patients and should therefore be treated equally. In order to be a truly supportive tool and a guiding instrument for health care staff, more clarity and accuracy in relation to certain time limits and the scope of application is needed. Unfortunately, this is not the case for all aspects of these new paragraphs.

Restraint measures should only be applied short-term and only under certain restricted conditions. Even though the introduced articles provide a detailed regulation about 'Restrictions of freedom of movement', not all existing regulatory gaps are filled. The new Swiss legislation can only be called a first step in the right direction. More information on the practical application is urgently needed and should be developed as soon as possible. Also, awareness needs to be further raised and alternatives to the use of restraints need to be promoted.

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<sup>1</sup> This paper was written and published in German, a concise English summary is therefore provided here. The entire German text can be found on the following pages.

# **Die neue Schweizer Gesetzgebung zu bewegungseinschränkenden Maßnahmen auf dem medizinethischen Prüfstand**

## **Zusammenfassung**

Bewegungseinschränkende Maßnahmen werden in verschiedenen medizinischen Institutionen angewendet, um das Verhalten von Patienten durch physische bzw. mechanische oder chemische Eingriffe zu beeinflussen. Solche Maßnahmen stellen eine Art der Freiheitsentziehung dar und bedürfen daher immer einer Rechtfertigung. Die Frage nach der Indikation für bewegungseinschränkende Maßnahmen ist abzuklären, da ein standardmäßiger Gebrauch nicht Ziel einer Behandlung sein sollte. Gesetze können als Richtschnur für behandelnde Ärzte und Pflegepersonal dienen. In der Schweiz ist am 1. Januar 2013 erstmals eine gesetzliche Regelung zu bewegungseinschränkenden Maßnahmen eingeführt worden. Hauptziel dieser neuen Artikel im Schweizerischen Zivilgesetzbuch (Artikel 383ff. ZGB) ist die Stärkung von Autonomie und persönlicher Freiheit von Patienten. Es ist wichtig, Vorschriften zu hinterfragen bzw. deren Auswirkungen für die betroffenen Personen zu analysieren und einen kritischen Dialog zu führen. Die vorliegende Publikation betrachtet bewegungseinschränkende Maßnahmen aus zwei verschiedenen Perspektiven: einerseits anhand einer medizinethischen Debatte, andererseits anhand einer Analyse der gesetzlichen Regelung in der Schweiz. Die neuen Artikel umfassen eine detaillierte Regelung zur „Einschränkung der Bewegungsfreiheit“. Dennoch schließen sie nicht alle bestehenden Regelungslücken. Die neue Schweizer Gesetzgebung kann daher nur als ein erster Schritt in die richtige Richtung betrachtet werden. Ausführungen zur praktischen Anwendung sind dringend nötig und sollten so schnell wie möglich ausgearbeitet werden.

## **Einleitung**

Bewegungseinschränkende Maßnahmen bei Patienten haben eine lange „Tradition“. Schon im Altertum wurden magisch-religiöse Heilmethoden eingesetzt, um geistige Erkrankungen mit Hilfe von Drogen und Beschwörungen zu heilen. Historiker vermuten, dass Patienten um 1.000 v. Chr. bereits mit Opium betäubt wurden [1]. Im Mittelalter kam es dann zu einem vermehrten Gebrauch dieser Praktik. Patienten wurden nicht mehr nur mit pflanzlichen Mitteln oder Medikamenten ruhig gestellt, sondern es wurde auf mechanische Hilfsmittel zurückgegriffen. Patienten wurden bspw. mit Zwangsstühlen, -jacken, Körpergurten oder Halsmanschetten am Bewegen gehindert. Im 17. Jh. verringerte sich der Gebrauch von körpernahen Fixierungen und betroffene Personen wurden vor allem in Gefängnissen und Armenhäusern untergebracht. Erst im 19. Jh. kam es zu einer Minimierung des Gebrauches von bewegungseinschränkenden Maßnahmen jeglicher Art [46]. Trotz dieser Wahrnehmungsänderung sind „humane Fixierungen“ bzw. Maßnahmen, welche die physische Bewegungsfreiheit von Patienten einschränken, seit vielen Jahren eine verbreitete Praxis [28]. Auch in der Schweiz war der demütigende Umgang mit Pflegebedürftigen zumindest bis ins 20. Jh. eine alltägliche Situation [55]. In der wissenschaftlichen Literatur zeichnet sich jedoch in den letzten Jahren eine zunehmend kritische Haltung gegenüber der Vornahme von Fixierungsmaßnahmen ab [7].

Flaherty geht sogar so weit zu sagen, dass eine medizinische Versorgung ohne Fixierungen der normative Standard sein sollte [17].

In der heutigen Zeit sind vor allem Menschen mit demenziellen Erkrankungen von bewegungseinschränkenden Maßnahmen betroffen [23]. Die ausgesprochene Vulnerabilität bestimmter Patientengruppen macht es besonders wichtig, Umstände und Rechtfertigungsgründe für Bewegungseinschränkungen zu untersuchen. Wie die Inhalte verschiedener Artikel [20,41] sowie die Notwendigkeit der In-Kraft-Setzung neuer gesetzlicher Regelungen zeigen, sind – trotz zunehmend kritischer Einwände – bewegungseinschränkende Maßnahmen nicht gänzlich aus Pflegeheimen, Krankenhäusern und/oder Privathaushalten verbannt. In der Schweiz ist zum 1. Januar 2013 im Rahmen der Revision des Schweizerischen Zivilgesetzbuches (ZGB) erstmals eine eidgenössische Regelung zu bewegungseinschränkenden Maßnahmen eingeführt worden. Bis zu diesem Zeitpunkt waren lediglich medizinische Richtlinien oder allenfalls interne Regularien vorhanden, welche die Vornahme von bewegungseinschränkenden Maßnahmen bei Patienten geregelt haben.

### **Definition von bewegungseinschränkenden Maßnahmen**

Um die Vornahme von bewegungseinschränkenden Maßnahmen beurteilen zu können, muss zuerst die Bedeutung des Begriffs geklärt werden. Dazu kann als Anhaltspunkt eine im Jahr 2005 veröffentlichte Richtlinie der Schweizerischen Akademie der Medizinischen Wissenschaften herangezogen werden. In dieser heißt es: „Von Freiheitsbeschränkung spricht man, wenn ausschließlich die Bewegungsfreiheit eingegrenzt wird (z.B. die Unterbringung in einer geschlossenen Abteilung). Schwerwiegende Freiheitsbeschränkungen sind die Fixierung (z.B. mit Gurten) oder die Isolation (z.B. in einem Isolierzimmer)“ [47].

Bei dem genannten Begriff der Fixierung handelt es sich um mechanische Bewegungseinschränkungen, zu denen körpernahe Freiheitsbeschränkungen mit Westen für den Oberkörper sowie Riemen oder Gurte für Becken, Hand- oder Fußgelenke gehören [22,4]. Bettgitter sind keine körpernahen Fixierungen, zählen aber gleichfalls zu mechanischen Bewegungseinschränkungen. Jedoch werden sie in vielen Studien und wissenschaftlichen Artikeln zu Fixierungsmaßnahmen nicht einbezogen [36,39]. Gurte, um einen Patienten am Bett zu fixieren, werden vom Pflegepersonal als restriktivste Maßnahme empfunden. Einseitige Bettgitter und Sensormatten dagegen als am wenigsten einschneidende Maßnahmen, während beidseitige Bettgitter als moderat eingestuft werden [24]. Die mechanische Bewegungseinschränkung ist die wohl am meisten verbreitete Form der Fixierung im medizinischen und pflegerischen Alltag. Daneben gibt es noch eine weitere Form: die chemische Bewegungseinschränkung. Die Vergabe von Sedativa, Neuroleptika und angstlösenden Medikamenten kann auch eine bewegungseinschränkende Maßnahme sein, wenn sie bewusst zur Verhaltenskontrolle eingesetzt wird [29]. Aufgrund der unterschiedlichen Wirkmodi [14] und der Schwierigkeit zu unterscheiden, ob es sich um eine indizierte Medikation handelt oder die Medikation allein dazu dient, Bewegungen des Patienten zu verhindern, wird diese Art der Fixierung oft aus Studien ausgeschlossen [37]. Die Autonomie, die Freiheit und das Recht des Patienten, Risiken einzugehen, werden hingegen durch beide Fixierungsarten eingeschränkt [35]. Außerdem haben sie die Verhaltenskontrolle von Patienten gemein. Die

mechanische und chemische Form der Fixierung unterscheidet jedoch der Weg dorthin. Während bei mechanischen Bewegungseinschränkungen die physische Bewegungseinschränkung im Vordergrund steht, ohne direkt Einfluss auf die mentalen Fähigkeiten des Patienten zu nehmen, hat die chemische Fixierung eine ganzheitliche Wirkung auf den Körper und schränkt den Patienten physisch und psychisch ein. Laut einer Studie werden chemische Fixierungen vor allem bei Patienten mit aggressivem Verhalten eingesetzt, wohingegen mechanische vorrangig zum eigenen Schutz des Patienten, bspw. vor Stürzen verwendet werden [48]. Häufig wird allein die mechanische Fixierung als eine echte Fixierung wahrgenommen [21]. Das fehlende Bewusstsein darüber, welche Maßnahmen in die Kategorie der Fixierung fallen, verdeutlicht die Notwendigkeit der Sensibilisierung für bewegungseinschränkende Maßnahmen. Nur mithilfe klarer Definitionen und der Klärung der Begrifflichkeiten ist dies möglich [30].

Neben dementiellen Erkrankungen zählen Aufgeregtheit, Verwirrtheit und vorangegangene Stürze zu den Dispositionen, welche die Wahrscheinlichkeit von Fixierungsmaßnahmen erhöhen [7]. Die Angst vor der Entfernung lebenswichtiger arterieller oder venöser Zugänge durch den Patienten, ist für Ärzt(innen) und Pfleger(innen) ein anderes wichtiges Motiv, bewegungseinschränkende Maßnahmen als notwendig zu erachten und zu veranlassen [37]. Studien belegen hingegen, dass es trotz mechanischer Fixierung zu Zwischenfällen kommen kann, bei denen sich die Patienten Zugänge entfernen, jedoch in den seltensten Fällen mit schweren bzw. lebensbedrohlichen Folgen [38]. Die fehlende Compliance bei mechanischen Fixierungen tritt insbesondere bei Patienten mit Demenzen auf, da diese die Notwendigkeit medizinischer Maßnahmen unter Umständen nicht mehr nachvollziehen können und sich aus einer für sie unangenehmen Lage befreien möchten [8].

Unter bestimmten Umständen können bewegungseinschränkende Maßnahmen als solche auch Verletzungen verursachen. Bettgitter vergrößern bspw. die Sturzhöhe und somit die Wahrscheinlichkeit für schwere Verletzungen [25]. Des Weiteren besteht vor allem bei mechanischen Fixierungen die Möglichkeit des Auftretens von Druckgeschwüren, Ödemen und Kontrakturen [11]. Die Gefahr von Inkontinenz, Verstopfung, Mangelernährung, Verringerung der Muskelkraft und des Gleichgewichts sowie eine verstärkte Abhängigkeiten bei alltäglichen Verrichtungen, die durch beide Arten der Fixierung hervorgerufen werden können, erhöht sich [8]. Ursache hierfür kann die unsachgemäße Anbringung durch das Personal sein oder der Versuch von Patienten, sich die Fixierung selbst zu entfernen. Aber auch die andauernde oder wiederkehrende Immobilisation [26] der Patienten durch mechanische oder chemische Bewegungseinschränkungen kann die aufgeführten Folgen haben.

### *Medizinethische Analyse*

Im Zusammenhang mit bewegungseinschränkenden Maßnahmen stellt sich die Frage, ob deren Durchführung ethisch vertretbar und zu rechtfertigen ist, und welche Bedeutung dies für die neue gesetzliche Regelung in der Schweiz hat. Es sollte hervorgehoben werden, dass die rechtliche Normierung einer bestimmten Handlung nicht gleichbedeutend mit deren ethischer Richtigkeit ist [53]. Demzufolge ist es wichtig, gesetzliche Regelungen zu hinterfragen und deren Auswirkungen für die betroffenen Personen zu analysieren. Die Angemessenheit des Einsatzes von

bewegungseinschränkenden Maßnahmen spielt eine bedeutende Rolle. Es ist zu klären, ob es Fälle gibt, in denen Bewegungseinschränkungen angebracht sind und falls ja, unter welchen Voraussetzungen. Auch wäre zu analysieren, ob solche Kasuistiken vom neuen Gesetz erfasst werden.

### *Prinzipienethik*

Im Rahmen der Prinzipienethik, deren Grundlagen 1979 durch das Buch von Beauchamp und Childress "Principles of Biomedical Ethic" gelegt wurden, können die folgenden Prinzipien zur Bearbeitung des Problems herangezogen werden: 1) Verpflichtung, keinen Schaden zuzufügen (Nicht-Schadens-Prinzip), 2) Verpflichtung, Gutes zu tun (Benefizienz) [3]. Demnach soll dem Patienten kein Schaden zugefügt werden und dessen Gesundheit, Wohlergehen sowie seine Sicherheit gefördert und selbstschädigenden Verhaltensweisen entgegengewirkt werden [58]. Das Fürsorgeprinzip soll den Patienten schützen. Eine zu starke Ausweitung dieser Pflicht kann allerdings unter Umständen zu paternalistischen Verhaltensweisen führen, welche die Autonomie des Patienten einschränken. Dieser Prinzipienkonflikt ist insbesondere im Fall von bewegungseinschränkenden Maßnahmen problematisch. Aus Angst, der Patient könnte sich durch das Entfernen eines arteriellen oder venösen Zugangs oder durch unkontrollierte Bewegungen verletzen oder schädigen, werden vorsorglich Fixierungen angeordnet [5]. Derartige Maßnahmen führen unter Umständen jedoch auch zu Schädigungen des Patienten, was ursprünglich verhindert werden sollte. Die – vor allem bei mechanischen Fixierungen – entstehenden Verletzungen können nicht nur körperlicher Art sein, sondern auch psychische Folgen haben, etwa Vertrauensverlust gegenüber Pflegekräften und medizinischem Personal bewirken oder Panikattacken auslösen [20]. Hier verdeutlicht sich das eigentliche Dilemma, welches das medizinische Personal zu bewältigen hat: Das Wohl des Patienten soll durch eine Maßnahme gewährleistet werden, gleichzeitig kann genau diese Maßnahme Sicherheit und Gesundheit des Patienten auf vielfältige Weise gefährden [7]. Solche Folgen widersprechen eindeutig der Verpflichtung, Gutes zu tun. Eine medizinische Maßnahme mit derart zwiespältigen Auswirkungen in Bezug auf das Wohlbefinden des Patienten sollte daher nur in sehr engen Grenzen durchgeführt werden.

Als dritter Punkt muss der Respekt vor der Autonomie des Patienten genannt werden<sup>2</sup>. Wiesemann stellt treffend fest, dass Autonomie als moralisches Recht zu einem Schlüsselbegriff moderner Gesellschaften avanciert ist [57]. Insbesondere im Rahmen der Entwicklung der modernen Medizinethik wurde das Konzept der Autonomie in den Vordergrund gestellt. Die Entscheidungsfreiheit des Patienten über medizinische Eingriffe jeglicher Art stellt die bedeutsamste und weitreichendste Neuerung der Selbstbestimmung dar. Menschliche Wesen sind keine Objekte, sondern Träger ihrer individuellen Entscheidungen [45] und Experten ihres eigenen Lebens [57]. Dies soll jedoch nicht heißen, dass sie Entscheidungen ohne Relation zu anderen Mitmenschen treffen müssen [2]. In Bezug auf die Vornahme von Fixierungsmaßnahmen kann insbesondere die Bedeutung der Autonomie als Abwehrrecht zum Tragen kommen [45]. Das Autonomieprinzip bekommt eine

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<sup>2</sup> Der vierte Punkt der Gleichbehandlung/Gleichberechtigung (Justice) spielt im Zusammenhang von bewegungseinschränkenden Maßnahmen nur eine untergeordnete Rolle und wird daher nicht in die Beurteilung einbezogen.

moralische Relevanz für das medizinische Personal, mit dem mögliche paternalistische Verhaltensweisen eingedämmt werden sollen [43]. Steinfath/Pindur betonen die Wichtigkeit der Einbeziehung des institutionellen und interpersonalen Kontextes, um die Fähigkeit von Patienten, autonom entscheiden zu können, zu stärken. Des Weiteren sollten die Persönlichkeit, der Charakter und die Fähigkeiten des Patienten eine besondere Bedeutung spielen, um dessen Wünsche und Verhaltensweisen besser nachvollziehen zu können, damit die Urteilsfähigkeit nicht vorschnell aberkannt wird [50]. Auch leiblichen Ausdrucksformen (Gesten/Bewegungen die z. B. Wohlbefinden/Unwohlsein, Ablehnung/Zustimmung ausdrücken können), sollte vor allem im pflegerischen Bereich mehr Beachtung geschenkt werden, da sie Befindlichkeiten und Willensbekundungen ausdrücken können, und sich die Selbstbestimmung ansonsten nur auf die Zustimmung zu helfenden Handlungen reduziert [31].

Nun ist fraglich, wie sich das Autonomiekonzept mit der Durchführung von Fixierungen bei Patienten vereinbaren lässt. Handelt es sich um eine Willensäußerung, wenn sich der Patient arterielle oder venöse Zugänge oder andere medizinische Hilfsmittel entfernt? Muss diese von Ärzten und Pflegepersonal respektiert werden, obwohl Zweifel an einer selbstbestimmten Entscheidung bestehen, weil sich der Patient in einem kritischen Zustand befindet oder bereits die Urteilsunfähigkeit festgestellt wurde? Oder ist eine derartige Überlegung das Ergebnis eines ausgefeilten Autonomieverständnisses? Fest steht, dass eine Willensäußerung nicht pauschal ausgeschlossen werden sollte. Es ist wichtig, dass allen Patienten das höchstmögliche Maß an Autonomie zugestanden wird. Zumindest solange, wie noch nicht an einem Testergebnis festgemacht werden kann, ob eine Handlung autonom ist oder nicht.

Die individuelle Beurteilung des Sachverhaltes aller äußeren Umstände und das Wohl des Patienten sollten für die abschließende Entscheidung für oder gegen eine bewegungseinschränkende Maßnahme ausschlaggebend sein. Schlussfolgernd kann gesagt werden, dass sowohl das Nicht-Schadens-Prinzip als auch das Prinzip, Gutes zu tun, und das Prinzip des Respekts der Patientenautonomie grundsätzlich gegen Fixierungsmaßnahmen sprechen.

### *Pflegeethik/Fürsorgeethik*

In der Pflegeethik spielt das Fürsorgeprinzip eine zentrale Rolle [18]. Gastmans et al. bezeichnen die Idee der „guten Pflege“ als das ultimative Ziel der pflegerischen Praxis. Pflege bedeute immer auch, die eigenen Fähigkeiten des Patienten zu fördern. Außerdem beschreiben die Autoren die Tugend der Fürsorge als einen inhärenten Bestandteil der moralischen Praxis in der Pflege [19]. Die Fürsorgeethik fokussiert sich auf Personen, welche in der Pflege in einer Beziehung zueinander stehen, und hebt somit das relationale Verhältnis zwischen Menschen hervor. Bei der Durchführung von bewegungseinschränkenden Maßnahmen spielt die Arzt<sup>3</sup>-Pfleger-Patient-Beziehung eine bedeutende Rolle und ist für die moralische Qualität ihres Handelns maßgeblich. Pflege ist eine Art, die andere Person anzuerkennen, und bezweckt hauptsächlich die Würde des Menschen [54].

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<sup>3</sup> Im Folgenden gelten die verwendeten Begriffe und Bezeichnungen in männlicher Form analog für Frauen.

### *Würde des Menschen*

Die Würde des Menschen ist unantastbar, sie kann nicht verloren gehen, nicht einmal durch Krankheit, Behinderung oder den nahenden Tod. Dennoch handelt es sich um einen Begriff, dessen Gehalt und Anwendungsbereich strittig sind [16]. Speziell die „Würdelosigkeit eines Zustandes“ und die Verletzung der Menschenwürde werden als Argumente für oder gegen bestimmte medizinische Handlungsweisen angeführt. Ein häufig zitiertes Beispiel ist einerseits die Debatte um die Sterbehilfe: Die gemutmaßte Würdelosigkeit einer schwer kranken, sterbenden Person verlangt demnach ein bestimmtes Handeln [15]. Andererseits stellt sich die Frage, ob die Durchführung einer bestimmten Maßnahme – der Fixierung – eine Handlung darstellt, welche die Würde des Menschen verletzt. Im Rahmen einer bewegungseinschränkenden Maßnahme ist es der betroffenen Person meist nicht möglich, einfache alltägliche Handlungen, wie z. B. sich an der Nase kratzen, aufzustehen oder etwas zu trinken, selbstständig durchzuführen.

Ungewiss ist, ob diese Kriterien genügen, damit eine Verletzung der Menschenwürde vorliegt. Denn durch die Bewegungseinschränkung wird verhindert, dass der Patient sich selbst Schaden zufügt. Der möglicherweise entwürdigenden Maßnahme steht also eine vermeintlich gesundheitserhaltende oder gesundheitsverbessernde Handlung gegenüber. Rechtfertigt dies eine, wenn auch nur kurzzeitige, Verletzung der Menschenwürde? Eine bewegungseinschränkende Maßnahme kann nicht per se als Würdeverletzung gelten, aber es kann Konstellationen geben, in denen dies zutrifft. Deshalb sollten Bewegungseinschränkungen als Maßnahmen, welche die Würde des Menschen einschränken können, eingestuft werden und nur angewandt werden, wenn es keine andere Lösung gibt, d. h. ein Patient auf keine andere Weise von selbst- und fremdschädigenden Handlungen abgehalten werden kann, wie z. B. ein Patient im Delir.

### *Informierte Einwilligung*

Wenn bewegungseinschränkende Maßnahmen in Betracht gezogen werden, muss der Patient so ausführlich wie möglich über deren Vorteile, aber auch deren mögliche Risiken informiert werden. Der betroffene Patient muss die Erläuterung verstehen und in die Maßnahme einwilligen. Daraus folgt, dass Bewegungseinschränkungen bei urteilsfähigen Personen immer erst nach Einwilligung erfolgen dürfen. Willigt der Patient nicht in eine Maßnahme ein, darf sie nicht durchgeführt werden. Für diese Art der Einwilligung im Zusammenhang mit Bewegungseinschränkungen gibt es keine gesetzliche Regelung.

Problematisch kann die Einschätzung der Urteilsfähigkeit sein. Bei urteilsunfähigen Patienten wird, laut Artikel 384 ZGB, die bei medizinischen Maßnahmen zur Vertretung berechtigte Person über die mechanische Bewegungseinschränkung informiert. Auch wenn die Einbeziehung von Vertretern in medizinische Entscheidungen gängige Praxis ist, kann sie ethische Probleme aufwerfen. Dies ist in besonderem Maße der Fall, da es sich um eine faktische Fremdbestimmung handelt und Missbrauchsrisiken nicht vollständig ausgeschlossen werden können [52]. Außerdem ist zu beachten, dass dem mutmaßlichen Patientenwillen durch den Stellvertreter nur mittelbar Ausdruck verliehen werden kann [51].

## **Analyse der gesetzlichen Regelung**

Bewegungseinschränkende Maßnahmen sind eine Art der Freiheitsentziehung und bedürfen daher immer einer Rechtfertigung. Die Frage nach der Indikation für eine Maßnahme ist abzuklären, da der standardmäßige Gebrauch in der medizinischen Versorgung von Patienten kein Behandlungsziel sein kann, sondern immer eine Ausnahme darstellen sollte [28]. Gesetze können in diesem Fall eine Richtschnur sein und für Klarheit sorgen.

Die Bewegungsfreiheit wird in der Schweizer Bundesverfassung (BV) gemäß Artikel 10 Absatz 2 geschützt. Fraglich ist daher, aus welchem Grund, trotz einer vorhandenen bundesgesetzlichen Regelung, eine zusätzliche zivilgesetzliche Regelung eingeführt wurde. Das Ziel, welches mit dieser neuen gesetzlichen Regelung zu bewegungseinschränkenden Maßnahmen verfolgt wird, ist die Autonomie und die persönliche Freiheit von Patienten zu stärken [10]. Außerdem soll sie einen verstärkten Schutz urteilsunfähiger Personen in Heimen gewährleisten [42]. Es kann demgemäß geschlussfolgert werden, dass die ursprüngliche gesetzliche Regelung auf Bundesebene die nötigen Schutzanforderungen nicht gewährleisten konnte, welche für diesen sensiblen Bereich notwendig sind.

Der neue Artikel 383 ZGB beinhaltet eine detaillierte Regelung der „Einschränkung der Bewegungsfreiheit“:

1. *Die Wohn- oder Pflegeeinrichtung darf die Bewegungsfreiheit der urteilsunfähigen Person nur einschränken, wenn weniger einschneidende Maßnahmen nicht ausreichen oder von vornherein ungenügend erscheinen und die Maßnahme dazu dient:*
  1. *eine ernsthafte Gefahr für das Leben oder die körperliche Integrität der betroffenen Person oder Dritter abzuwenden; oder*
  2. *eine schwerwiegende Störung des Gemeinschaftslebens zu beseitigen.*
2. *Vor der Einschränkung der Bewegungsfreiheit wird der betroffenen Person erklärt, was geschieht, warum die Maßnahme angeordnet wurde, wie lange diese voraussichtlich dauert und wer sich während dieser Zeit um sie kümmert. Vorbehalten bleiben Notfallsituationen.*
3. *Die Einschränkungen der Bewegungsfreiheit wird so bald wie möglich wieder aufgehoben und auf jeden Fall regelmäßig auf ihre Berechtigung überprüft.*

Der Artikel besteht aus drei Absätzen: Der erste Absatz bezieht sich auf die Voraussetzungen für die Einschränkung der Bewegungsfreiheit bei urteilsunfähigen Personen. Dies liegt darin begründet, dass urteilsfähige Personen selbst in die Maßnahme einwilligen können und daher keiner gesetzlichen Regelung bedürfen. Der Artikel bezieht sich explizit auf die Einschränkung der Bewegungsfreiheit in Wohn- oder Pflegeeinrichtungen. Hierbei ist anzumerken, dass demzufolge bewegungseinschränkende Maßnahmen in Krankenhäusern und im Rahmen der häuslichen Pflege nicht unter diese Regelung fallen. Zumindest lässt sich auf den ersten Blick nicht erkennen, wie der Begriff Wohn- oder Pflegeeinrichtung auszulegen ist und ob Krankenhäuser im Rahmen einer weiten Auslegung als Pflegeeinrichtung eingestuft werden können. Das gleiche gilt für den Begriff Wohneinrichtung im Fall der häuslichen Pflege. Des Weiteren darf eine bewegungseinschränkende Maßnahme nur ergriffen

werden, wenn die urteilsunfähige Person entweder ihr eigenes Leben, ihre körperliche Integrität oder Dritte ernsthaft gefährdet, oder wenn sie das Gemeinschaftsleben auf schwerwiegende Weise stört. Das heißt, dass die normativen Kriterien für eine Maßnahme dieser Art sehr eng sind.

Im zweiten Absatz des Artikels ist die Aufklärung des Patienten gesetzlich festgeschrieben, womit auch der Respekt vor urteilsunfähigen Personen deutlich gemacht wird. Demnach werden bewegungseinschränkende Maßnahmen nicht einfach angeordnet und durchgeführt, sondern der Patient wird trotz seiner Urteilsunfähigkeit über das Prozedere informiert. Im Rahmen einer vertrauensvollen Arzt-Patienten- bzw. Pfleger-Patienten-Beziehung ist die Förderung der Kommunikation bei der Durchführung von bewegungseinschränkenden Maßnahmen ein wichtiger Bestandteil.

Im dritten Absatz wird die zeitliche Begrenzung für Bewegungseinschränkungen angesprochen. Die Aussagen bleiben dabei allerdings sehr vage und es gibt keine Zeitangaben, wann und wie oft eine Maßnahme überprüft werden muss. Insbesondere bleibt unklar, was so bald wie möglich/regelmäßig bedeutet. Dies kann für Pflegende ein praktisches Problem werden, da es im Gesetz keine Hinweise auf Maximalzeiträume gibt. Demnach scheint es momentan in der Verantwortung der Betreuenden zu liegen, wann und wie oft eine bewegungseinschränkende Maßnahme überprüft wird.

In einem weiteren Artikel (384 ZGB) wird zum einen die Protokollierungspflicht (Name der anordnenden Person, Zweck, Art und Dauer der Maßnahme) für bewegungseinschränkende Maßnahmen, zum anderen die Informationspflicht gegenüber der bei medizinischen Maßnahmen zur Vertretung berechtigten Person beschrieben. Daraus lässt sich schließen, dass die alleinige Übermittlung einer Information kein Mitspracherecht beinhaltet. Um die Legitimität von Fixierungen mit Gurten etc. bei Urteilsunfähigkeit zu gewährleisten, dürfte nicht nur die Mitteilung über die Durchführung der Maßnahme ausreichen, sondern es müsste eine Einwilligung durch die zur Vertretung berechnete Person erfolgen. Eine solche Regelung wäre Ausdruck für den Respekt vor der Autonomie und der Würde des Patienten [15]. Zwar liegt im Wirken eines Stellvertreters stets auch ein Moment der Fremdbestimmung, die Privatautonomie würde dadurch dennoch stärker gewahrt als durch die Fremdbestimmung durch Dritte (Ärzte, gerichtlich bestellte Betreuer) [33]. Ob die aktuelle gesetzliche Regelung den gängigen ethischen Standards in der medizinischen Praxis entspricht, ist deshalb in Frage zu stellen. Zwar ist die schriftliche Anrufung der Erwachsenenschutzbehörde gemäß Artikel 385 ZGB jederzeit möglich, dessen ungeachtet ist damit ein administrativer Aufwand verbunden, welchen nicht alle Menschen gleichermaßen zu bewältigen vermögen. Der Gesetzgeber sollte folglich auf die individuellen Lebenssituationen der Angehörigen Rücksicht nehmen. Im Zuge der Umsetzung der Gesetzesnovelle zu bewegungseinschränkenden Maßnahmen könnten Anlaufstellen eingerichtet werden, die Betroffenen konkrete Unterstützung anbieten und bspw. telefonische Anfragen entgegen nehmen.

Eine Besonderheit der aktuellen Gesetzgebung stellt die getrennte Regulierung von Bewegungseinschränkungen durch mechanische Hilfsmittel und durch sedierende Medikamente dar. Der Gesetzgeber hat sich dafür entschieden, die beiden Arten der Bewegungseinschränkung nicht gleichartig zu behandeln. Dies kann Vorteile und Nachteile haben. Auf der einen Seite wird deutlich,

dass mechanische und chemische Bewegungseinschränkungen gleichermaßen einen Regelungsbedarf erfordern, auf der anderen Seite macht diese höhere Vorschriftendichte die praktische Arbeit im pflegerischen Alltag diffiziler, da unterschiedliche Regelungen beachtet werden müssen. Chemische Fixierungen fallen demnach nicht unter Artikel 383 ZGB. Bei der chemischen Bewegungseinschränkung findet Artikel 377 ff. ZGB Anwendung und die vertretungsberechtigte Person wird in die Entscheidung einbezogen [9]. Diese Zweiteilung vermittelt den Eindruck, dass für den Gesetzgeber die medikamentöse Bewegungseinschränkung einen grundlegend anderen Charakter aufweist, als die Bewegungseinschränkung mit Hilfe von Fixierungsgurten, Gittern oder Netzen. Ob dies eventuell an möglichen Nebenwirkungen bei der Gabe von sedierenden Medikamenten liegt, bleibt aufgrund des Gesetzestextes unklar.

### **Bewertung**

Bewegungseinschränkende Maßnahmen in der Medizin sollten ausschließlich oder mindestens immer im Interesse des Patienten sein. Dabei kann es sich um Notfallmaßnahmen oder um präventive Maßnahmen handeln. Der Nutzen dieser medizinischen Maßnahmen ist indes nicht klar, da es sich um eine bisher nicht-validierte Therapie handelt [5]. Das persistierende Fehlen eines Nachweises der Effektivität in der klinischen Praxis verdeutlicht die Brisanz der Maßnahmen. Qualitativ hochwertige wissenschaftliche Studien zur Minimierung von Fixierungen wären notwendig, um zu untersuchen, ob die Verringerung von Fixierungen nicht automatisch mit dem Risiko von Therapieunterbrechungen verbunden sein muss bzw. ob das Risiko von Verletzungen durch Fixierungen selbst viel höher ist [37].

Gesetzliche Regelungen können die weitere Entwicklung in diesem Bereich beeinflussen, wie Beispiele aus Schottland und Dänemark zeigen, wo die Fixierung älterer Menschen verboten ist [23]. In Österreich betreffen die Regelungen des „Heimaufenthaltsgesetzes“, welches 2005 in Kraft getreten ist, chemische und mechanische Bewegungseinschränkungen gleichermaßen [34]. Ein besonderes Merkmal der gesetzlichen Regelung in der Schweiz hingegen ist, wie oben bereits erwähnt, die Trennung von mechanischen und chemischen Fixierungen. Ethisch ist diese Trennung kaum zu rechtfertigen, da beide Arten der Bewegungseinschränkung die gleichen Konsequenzen für urteilsunfähige Patienten haben und daher auch gleich behandelt werden sollten. Eine einheitliche Lösung im Umgang mit bewegungseinschränkenden Maßnahmen hätte zudem zu einer Harmonisierung beigetragen und wäre auch deshalb vorzuziehen gewesen.

Wie medizinethische Analysen zeigen, lassen sich bewegungseinschränkende Maßnahmen nur sehr selten ethisch rechtfertigen. Oftmals widersprechen sie den gängigen medizin- und pflegeethischen Prinzipien. Die therapeutischen Vorteile wiegen die negativen Auswirkungen in den wenigsten Fällen auf. Folglich ist die moralische Vertretbarkeit der Anwendung einer Maßnahme an sich nicht gegeben. Die mechanischen oder chemischen Fixierungen von Patienten werden teilweise aus Gründen wie Zeit-, Personal- oder Ressourcenmangel durchgeführt, können diese aber keinesfalls rechtfertigen [9]. Eine einfache Lösung für viele Probleme scheint gängige Attitüde gegenüber Fixierungsmaßnahmen im Rahmen der Gesundheitsversorgung zu sein [13].

Ferner wäre es sinnvoll gewesen, mit Hilfe dieser gesetzlichen Regelung einen einheitlichen Standard innerhalb und auch zwischen verschiedenen Einrichtungen einzuführen. Patienten, die von Fixierungen betroffen sind, sollten nicht aufgrund von subjektiven oder vielleicht sogar willkürlichen Einschätzungen des medizinischen und pflegerischen Personals ungleich behandelt werden. Eindeutige Zeitangaben im Zusammenhang mit der Überprüfungspflicht der Fixierungsmaßnahmen gemäß Artikel 383 ZGB erster Halbsatz hätten Unsicherheiten in diesem Bereich vermieden. Die Aufhebungspflicht (regelmäßige Überprüfung der Maßnahme) laut Artikel 383 ZGB zweiter Halbsatz lässt sich weiterhin nur mit Blick auf den konkreten Einzelfall verantworten. Ohne strikte Vorgaben zur Regelmäßigkeit der Überprüfung und der damit verbundenen möglichen Aufhebung der Fixierung wird das Wohl der Patienten in die Hände der Verantwortlichen gelegt. Dies könnte die Wahrscheinlichkeit von Missbrauch in Einrichtungen mit personeller Unterbesetzung erhöhen. Der Gesetzgeber überlässt damit den Gerichten die genaue Definition der fraglichen Begrifflichkeiten und zeitlichen Begrenzungen, sollte es diesbezüglich zu einem Rechtsstreit kommen, und entzieht sich in diesem Fall in gewissem Maße seiner Verantwortung. Überdies ist ungewiss, ob die Fähigkeit der involvierten Personen, diesbezüglich eine adäquate Entscheidung treffen zu können, überhaupt vorausgesetzt werden kann. Es ist zu vermuten, dass der Gesetzgeber davon ausgeht, dass Personen, die bewegungseinschränkende Maßnahmen durchführen, dazu in der Lage sind, die zeitlichen Überprüfungsabstände richtig einzuschätzen. In einem hochsensiblen medizinischen und pflegerischen Bereich kann eine Annahme dieser Art jedoch zu ungewollten Zuständen führen.

Eine bewegungseinschränkende Maßnahme kann nur dann angemessen sein, wenn eine Güterabwägung zeigt, dass es keine andere Möglichkeit als die Bewegungseinschränkung gibt, um den Patienten vor sich selbst oder anderen Personen zu schützen oder wenn der Patient in die Maßnahme einwilligt, da er/sie sich beispielsweise mit einem Bettgitter in der Nacht sicherer fühlt [27]. Generell dürfen ohne die Prüfung der Verhältnismäßigkeit keine Bewegungseinschränkungen durchgeführt werden. Konkret muss begutachtet werden, ob die Maßnahme notwendig und proportional ist und nicht durch eine andere Maßnahme ersetzt werden kann. In Anlehnung an eine Entscheidung des deutschen Bundesverfassungsgerichtes zu Zwangsbehandlung im Maßregelvollzug sollten bewegungseinschränkende Maßnahmen gegen den Willen des Patienten demnach „nur dann eingesetzt werden, wenn sie im Hinblick auf das Behandlungsziel, das ihren Einsatz rechtfertigt, Erfolg versprechen und für den Betroffenen nicht mit Belastungen verbunden sind, die außer Verhältnis zu dem erwarteten Nutzen stehen.“ [6]. Ein besonders wichtiger Punkt ist hierbei die Kommunikation mit dem Patienten [12], um dessen Verständnis für die Maßnahme und somit seine Compliance zu erhöhen. Auch wenn Freiheitsbeschränkungen kaum aus dem Pflegealltag wegzudenken sind [25], sollte deren Anwendung grundsätzlich nur in Ausnahmefällen in Betracht gezogen werden (ultima ratio). Sie sollten nicht als Routinemaßnahme eingesetzt werden und die am wenigsten eingreifende Maßnahme muss Vorrang haben. Diese Aspekte werden in den neuen Artikeln des ZGB berücksichtigt, finden jedoch nach der Wortlautauslegung nur Anwendung für Wohn- oder Pflegeeinrichtungen. Folglich werden, zumindest nach dem Wortlaut, Krankenhäuser oder psychiatrische Einrichtungen ausgeschlossen.

Alternativen zur Fixierung können bspw. die Verwendung von Hüftprotektoren, Anti-Rutsch-Matten usw. darstellen. Des Weiteren rücken viele Studien Bildungsmaßnahmen wie Workshops oder Seminare, Fallbeispiele und Diskussionen zur Minimierung von Fixierungen in den Vordergrund. Leider sind deren Herangehensweisen und die Ergebnisse sehr unterschiedlich, ein eindeutiger und langfristiger Effekt lässt sich daher nicht attestieren [40].

Das Joanna Briggs Institute hat bereits 2002 eine Auflistung von Fixierungsalternativen erarbeitet. Es werden unter anderem: a) Veränderungen in der Umgebung mit beispielsweise verbesserten Lichtverhältnissen, rutschfesten Bodenbelägen, barrierefreie Raumarchitektur; b) Sicherheit im Bett mit konkaven Matratzen, Einsatz von Seitenschläferkissen, Matratzen vor dem Bett als Abfederung bei Stürzen; c) Aktivitäten und Programme wie Physio- und Ergotherapie, Fitnessübungen, Beschäftigungen/Betreuungsmöglichkeiten für Nachtwandler; d) Änderungen in der Pflege, wie z.B. Erhöhung des Personalspiegels, gefährdete Patienten in der Nähe der Pflegestation, schnellstmögliches Entfernen von Kathetern, Drainagen etc., vorgeschlagen [32]. Auch das Abdecken von Zugängen durch Mullbinden wäre eine Möglichkeit, das Entfernen derselben zu verhindern [8], bzw. würde dem Pflegepersonal genügend Zeit lassen einzugreifen, falls sich der Patient unwohl fühlen sollte.

### **Schlussüberlegung**

Die Güterabwägung zeigt, dass bewegungseinschränkende Maßnahmen nur kurzfristig und nur unter ganz bestimmten Voraussetzungen durchgeführt werden sollten. Die neue gesetzliche Regelung in der Schweiz kann als ein erster Schritt in die richtige Richtung betrachtet werden. Sie gibt eine Orientierung für das medizinische Personal, aber auch für Angehörige von betroffenen Patienten. Leider bestehen Regelungslücken, welche Unsicherheiten oder Unklarheiten in der Praxis hervorrufen können und so einen schweizweiten, einheitlichen Gebrauch erschweren. Eine Möglichkeit zur Vorbeugung wäre z. B. eine Liste mit spezifischen Indikationen, wann Fixierungsmaßnahmen angewendet werden dürften [49]. Bewegungseinschränkende Maßnahmen sollten generell nur so wenig wie möglich angewendet werden, um Grundrechtsverletzungen zu vermeiden. Außerdem sollte das medizinische Personal zu dieser Thematik geschult werden, um die Aufmerksamkeit für das Problem und die Pflegequalität zu erhöhen [56]. In Einrichtungen, in denen genügend Personal zur Verfügung steht und in denen es eine flexible Organisationsstruktur gibt, sind Fixierungen in den seltensten Fällen nötig, wie das Beispiel des Alters- und Pflegeheims in Stana, Kanton Wallis, belegt [44]. Ein Mittel zur Vorbeugung gegen bewegungseinschränkende Maßnahmen, und ergo ein Garant für den respektvollen Umgang mit pflegebedürftigen Patienten, wäre ausreichend Zeit.

### **Interessenkonflikt**

W. Bretschneider gibt an, dass kein Interessenkonflikt besteht.

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# General Discussion

## Introduction

Due to their constant growth, ageing prisoners as a group attract more and more attention. In the late 1970s and early 1980s, the first<sup>1</sup>, occasional scientific articles or book chapters about this “new” group in prison were published [1,46-48]. In the past years, attention for this group of prisoners has grown and the debate about how to meet their various needs has gained importance [2,6,27-31,34,39,40,58,61,62,64,65]. The variety of new challenges is manifold. How to best deal with the new challenges in an ethical way is still not entirely clear and it will most probably take more time to find solutions and proof their practical advantages.

The aims of this thesis are to provide information on the current health care situation of ageing prisoners in Switzerland, to better understand the legal and practical settings of health care provision for ageing prisoners and to analyse the ethical issues that arise from the need to provide adequate health care to inmates in the context of an increasingly ageing prison population.

Therefore, the following research goals were pursued and met:

- 1) Development of a theoretical overview about ethical issues in prisons relating to ageing prisoners.
- 2) Examination of the legal framework and regulations that address’ the health care for ageing prisoners.
- 3) Identification and investigation of stakeholders’ attitudes from three European countries regarding equivalent health care for ageing prisoners. The results thereof shall be used to identify the difficulties that stakeholders see in the provision of equivalent health care for older offenders.
- 4) Exploration and comparison of the somatic disease burden of younger and older prisoners in Switzerland based on their medical records. Followed by an examination of the results whether possible differences can be explained by age group and/or time served in prison.
- 5) Analysis of ethical issues and legal regulations of restraint measures in different (health) care establishments in Germany and Switzerland in order to see how this matter is addressed in an institutional context. These findings could serve as an example for health care provision outside prisons when applying the principle of equivalence.

The main conclusions and the key findings of the research project are presented and discussed in this final part of the thesis. In addition to that, the limitations and strengths of the applied research methods are delineated along with an outlook on implications for future research and practice.

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<sup>1</sup> One single article by Moberg [42] dates back to 1953.

## Main Conclusions

This PhD thesis has notably added value to the debate on health care for ageing prisoners by providing a critical overview on the ethical issues that prison systems have to reflect upon when confronted with the constantly growing number of ageing prisoners. This dissertation is embedded in the SNSF-project “Agequake in Prisons: Reality, Policies and Practical Solutions Concerning Custody and Health Care for Ageing Prisoners in Switzerland”, which is the first of its kind and provides a unique insight into an under-researched area. The empirical focus was mainly put on Switzerland due to the fact that there were no empirical data available to lead the national discussion in an evidence based way, the theoretical part on the contrary also incorporated the international context.

The main goal of this work was to analyse the status that ageing prisoners have in institutions from a theoretical and empirical angle detecting barriers for the adequate health care provision for ageing prisoners. The term status includes the status of their health, the status of their health care provision and their status in our society in a political and legal sense. This thesis combines theoretical and empirical research and aims at capturing and understanding the current health care provision for ageing prisoners by identifying regulatory gaps and barriers to equivalent health care provision in correctional institutions.

Five main conclusions can be drawn:

- 1) The growing population of ageing prisoners poses new challenges for the prison systems worldwide, but also for the prison system in Switzerland. Here, the number of detainees older than 50 years nearly doubled (absolute numbers) from 320 (9.41% of the average prison population in Switzerland) in 1999 to 616 (13.18% of the average prison population in Switzerland) in 2013<sup>2</sup>. The accommodation of older prisoners and end-of-life care/death in prison are two particularly important topics for this group that need to be addressed. The principle of equivalence of care is a helpful tool to support the process of finding new solutions in order to improve the health care for ageing prisoners by adapting and mirroring measures offered to patients outside prison as described in **Chapter 1** and **Chapter 5**. It can be concluded that currently the health care needs of ageing prisoners are not sufficiently met in this regard and that there is a strong need for a structural change towards better health care provision for older prisoners in correctional facilities.
- 2) After examining the existing regulations and laws on health care for ageing prisoners, it became evident that the status of prisoners, such as their age, is seldom considered as presented in detail in **Chapter 2**. Up to now, no international regulation speaks explicitly about health care for older prisoners or acknowledges their special needs. This lack of regulation could also be a reason for their largely unaddressed health care needs and could contribute to the non-compliance with the principle of equivalence in certain areas. Even though

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<sup>2</sup> In 1984, the percentage of prisoners (average prison population) above the age of 50 in Switzerland was only 6.57%.

international human rights law imposes the principle of equivalence, health care provision in prisons is not always equivalent to healthcare provision in the general community like described in **Chapter 3**. In order to minimise these deficiencies, which could also be based on a general lack of knowledge about the principle of equivalence or its exact meaning – especially with the existing lack of professional training that includes ethical and legal education for health care staff or prison directors – a new legal framework could fix these gaps and ensure or at least support the provision of equivalent health care for (ageing) prisoners in correctional facilities.

- 3) Variability within correctional systems, the presence of gatekeepers (for example nurses or correctional officers) and gatekeeping protocols, the lack of personnel (health care and correctional staff), and delays in the provision of care were named as reasons for difficulties with the realisation of equivalent health care for ageing prisoners as shown in **Chapter 3**. Experts from three different countries recounted similar aspects and reasons, while also pointing out that health care for ageing prisoners can be very good in some prisons and on the contrary not adequate or equivalent in other correctional settings. This indicates that problems related to the implementation of the principle of equivalence of care are not country-specific, but a phenomenon that can be transnationally identified. Therefore, it is required to investigate possible causes for these different situations in order to increase the quality of health care provision in those prisons where equivalent health care is not yet realized.
- 4) The analysis of medical records from 380 male prisoners (one half being older than 50 years, the other half younger than 49 years) revealed that older prisoners in Switzerland are suffering from more somatic diseases than detainees from the younger group and that the total number of diseases, excluding mental health problems, increases significantly from the younger to the older group. Overall, ageing prisoners have a higher health care burden. Even though, they have, on average, lived in prison for double the amount of time compared to their younger counterparts, the higher disease burden cannot be directly linked to the time spent in prison. The number of diseases did not increase with the number of years spent in prison, but was dependent on the age of the prisoner as discussed in **Chapter 4**. It can be concluded that further investigations regarding prison conditions, the adequacy of the prison health care system as well as the provision of health care for aging prisoners need to be undertaken in order to see if the number of diseases is related to the quality of health care for ageing prisoners.
- 5) Restraint measures are still frequently used in nursing homes and hospitals. Also, the use of restraint and the use of shackles is common practice in correctional facilities. Their application is difficult to justify as they often contradict well-established principles of medical ethics (respect for autonomy, beneficence, non-maleficence) and care ethics (principle of welfare, human dignity, physician-patient relationship). Even though, there are legal regulations

addressing restraint measures, they often lack clarity and accuracy leaving health care staff in uncertainty while using restraint measures. It can be concluded, that the use of restraints should only be performed after a thorough assessment of the health of the patient and a transparent and standardised system of documentation of restraint measures should be implemented. This should be the case in institutions such as hospitals as well as, according to the principle of equivalence of care, prisons. In correctional facilities, restraint measures are mainly applied for security reasons as they reduce the burden of responsibility for the staff. They are an easy way to ensure safety, but it puts an extra burden on prisoners when restraints are applied. Here, the restriction of freedom as punishment and not humiliating treatment during the utilisation of health measures needs to be the premise. In order to reduce the use of restraint measures, more information about the critical consequences should be provided to the one's applying it. Medical personnel – but also correctional staff – should be better educated and alternatives to the use of restraints need to be promoted as argued in **Chapter 6** and **Chapter 7**. If this is applied, a reduction of restraint measures for all – patients in hospitals/nursing homes and prisons – could be achieved. Even though the reduction of restraint measures in general may seem to be burdensome for the staff, it should be seen as a positive challenge and a motivation to decrease its use to a minimum.

In the course of this research, it was confirmed that the principle of equivalence of care is one of the key aspects of medical ethics in the prison context with regard to ageing prisoners as specific (national or international) legal regulation for this group are missing. Still, it also became evident that several strengths and weaknesses can be found in the course of implementing this principle in the correctional setting and that it will be challenging to improve its application and thereby the health care for ageing prisoners. These findings raise questions of how the implementation of the principle of equivalence care could be moved forward.

## Discussion of Key Findings

### Ageing Prisoners and the Principle of Equivalence of Care

Detainees are deprived of their freedom but should not be punished in other ways, for example not by providing poor medical health care to them [43]. As early as 1976, the Swiss Federal Court established in a judgement that prisoners are entitled to “impeccable medical care”<sup>3</sup> [9] based on the unwritten fundamental right of personal liberty [8]. In order to ensure that the health care needs of prisoners are met, the principle of equivalence of care was introduced in 1982 by the United Nations and subsequent recommendations followed for example from the Council of Europe [15,16,56]. However, they do not have a binding character (soft law) [5,20,43]. An increase in awareness about the special health care needs of prisoners and particularly ageing prisoners is also reflected in the growing literature on this topic [30], but not yet considered accordingly in practice.

The demands of ageing prisoners are not completely different from their peers in the community outside prison [17], but the living conditions of prisoners compared to outside prison vary immensely due to the fact that prison architects put their primary emphasis on security [25]. This may have been reasonable for reasons of punishment and convenience of prison staff [25], but the population change with the growing number of ageing prisoners in place will require a different approach that is based on humanity and the principle of equivalence and not on convenience. Based on the research findings presented in this thesis, the following structural changes are proposed: (1) empowerment of prisoners and prison staff through education about the meaning of the principle of equivalence of care and ageing prisoners health care needs, (2) implementation of a (national) legal regulation that addresses the health care needs of ageing prisoners, and (3) a shift from only treating diseases of ageing prisoners to prevention.

#### *The Need for Empowerment*

As described in **Chapter 1**, the process of imprisonment for ageing prisoners begins with the adaptation to the new setting. This change in environment is already challenging for younger prisoners but can be even more difficult for older prisoners [49], who were used to their usual environment and who have to deal with an increasing lack of flexibility due to their age [10,60]. Prisoners have to adjust to a massive restriction of movement with, amongst other things, small and narrow cells [38], fixed facilities such as dining halls, sanitation as well as health services. Further, they have to accept that they are under constant observation [25]. Particularly, the daily structure in prison is predetermined with a comprehensive regulation of all spheres of life, ranging from the morning wake-up call to the choice of clothing and food [43]. In a study conducted by Loeb and Steffensmeier [38], the following challenges for older prisoners to maintain their health were identified: “cost issues, prison personnel and policies, food concerns, fellow inmates, and personal barriers”. Nevertheless, these ageing prisoners also engaged in some self-care strategies by “accessing resources and support; staying positive; managing diet and weight; engaging in physical activity; and protecting self [sic]” [38]. Even

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<sup>3</sup> „einwandfreie ärztliche Betreuung“

though these self-care strategies are very positive, such behaviour is not self-evident. It cannot and should not be taken for granted that every older prisoner can make use of these strategies as it is something very personal and some older prisoners may have fewer resources and coping strategies than others. One way to (further) enhance their own self-care abilities maintaining their health would be through the empowerment of ageing prisoners and thereby enabling them to claim their rights. By doing so, they would be attracting more attention inside and probably even outside prison. Fetterman describes this in the following way:

“Self-determination, defined as the ability to chart one’s own course in life, forms the theoretical foundation of empowerment evaluation. They include the ability to identify and express needs, establish goals or expectations and a plan of action to achieve them, identify resources, make rational choices from various alternative courses of action, take appropriate steps to pursue objectives, evaluate short-and long-term results (...), and persist in the pursuit of those goals. (...) This individual ability exists in varying degrees and is enhanced or diluted by developmental factors (including age and maturity), type or degree of disability, and environmental conditions. For example, a supportive provider and a supportive school environment generate opportunities and encourage risk taking, exploration, and the development of abilities. The absence of these supportive environmental features limits opportunities, creates obstacles, and fosters dependency and/or despondent behaviour” [24].

At present, the prison setting creates and promotes dependencies leading to prisonisation [43,44] which is counterproductive for achieving equivalence of care in prison. In order to achieve equivalence it is necessary that the population – ageing prisoners – that is affected claims for it and not only external groups such as human rights organisations or scientists. Some universal factors of prisonization as suggested by Clemmer are, for example, inmates acceptance of an inferior role, adaptation to the regulations and structure of the prison, and passiveness about one’s own needs [12]. These factors work against the empowerment of ageing prisoners and prisoners in general and at the same time against the full implementation of the principle of equivalence of care. It may not be sufficient to offer preventive measures and better equipped cells as these actions could prove futile, if older prisoners do not verbalise their needs and if active participation in preventive health care of older prisoners and other services are not encouraged. Assisting ageing prisoners to help themselves will be much more efficient in the long run than just providing “development aid”. This comparison might seem to be peculiar, but the relationship between prisoners and health care/security staff in prison is also characterized by asymmetric power relationships like in the case of high-income and low-income countries. The existing lack of equivalence in certain prison settings due to the environment and the prison organisation itself makes it even more important to provide them with sufficient and appropriate tools in order to enable ageing prisoners to normalise their (in the majority of cases a long-term) stay [43]. The provision of information about health related issues such as advance directives [3], end-of-life care or assisted suicide in prison as discussed in **Chapter 5**, should be put forward to promote the

formation of an opinion about topics that gain relevance with age. This is imperative for accomplishing equivalence in prison, but also to facilitate re-integration into the community in case of release from prison.

Another important factor in this regard is the empowerment of the personnel working in prison. The Swiss penal system with its different hierarchical levels such as cantons, concordats, law enforcement departments and different institutional regulations makes it particularly challenging for the prison personnel to be well informed [5,4]. In addition to that, there are even more recommendations and standards issued by intergovernmental organisations which should also have an impact on the health care provision inside prison. Adherence to public international law and national regulations is only possible if it is known, but Brägger points out that they are either not at all or inadequately known in Switzerland [4]. Besides that, to address grievances and to ensure the full respect of ethical principles (if they are known) in a closed institution separated from the outside world can be a major challenge for prison staff and health care personnel working in such institutions. This is particularly the case for staff that has been working in this system for decades. It is possible that habituation effects occur, or that even the prisonization of prison staff has taken place which means that new challenges or changes arising in the daily routine could be overlooked quite easily. These are additional factors that can interfere with existing knowledge about the needs of ageing prisoners. Yet, health care or security staff are in direct contact with the prisoner most of the times and thus best placed to form an opinion about his or her needs. Therefore, health care and correctional staff should be aware of and try to avoid these habituation effects. Employees working inside prisons need to reflect on the moral identity of their profession as they shall not only care (in a medical and safety-related way) for ageing prisoners, but also fulfil their other duties and if needed, act as their mouthpiece, too. Unfortunately, prison employees are not in the position of decision-makers and proposed changes from their side may be dismissed and rejected. Still, it is very important to educate the health care and correctional staff in correctional facilities about the meaning and implications of the principle of equivalence of care to eventually change the existing unethical conditions inside prison. The two halves of empowerment of ageing prisoners and prison staff are necessary to increase the likelihood of achieving a greater whole: the principle of equivalence of care.

#### *The Need for a Legal Regulation*

Switzerland, England and Wales, and the US were chosen as examples to investigate the current health care situation of ageing prisoners from a theoretical point of view. This analysis revealed the lack of regulations and legal documents that protect ageing prisoners' health, proving once more that (ageing) prisoners are a vulnerable and neglected group [52] even in this regard. It could be argued that there is no need to introduce a legal regulation in order to guarantee adequate health care for ageing prisoners as this is to be assumed by the principle of equivalence of care. Still, other vulnerable groups/populations are also protected by special national laws even though international guidelines and recommendations are in place. Persons with disabilities or children, adolescents and adults lacking capacity are protected by laws such as the Federal Act on the Elimination of Discrimination

against People with Disabilities [54] and the Federal Act on Research involving Human Beings, Chapter 3, section 1, in Switzerland [55]. This implies that there can be a need for a detailed and national legal regulation to adequately protect certain groups. It cannot be guaranteed that it is always sufficient to simply apply or refer to the principle of equivalence to ensure adequate health care provision for ageing prisoners. For this reason, there is also a need for special protective measures or special policies concerning ageing prisoners or like Ginn [27] phrases it: “a national strategy is long overdue”. A detailed legal regulation or at least a Swiss framework legislation would be an additional safeguard for the vulnerable group of prisoners and specifically for ageing prisoners that is desirable to ensure that the principle of equivalence is respected in the correctional setting. A national regulation would also enable ageing prisoners to bring actions to assert his/her rights before national courts and to claim for a minimum level of care and quality of life in prison when these conditions are not fulfilled. By establishing an enforceable legal claim, the chance for timely legal proceedings would increase as compared to proceedings before the European Court of Human Rights where all available means of legal redress in the country concerned must have been used (that could provide compensation for the situation complaining about, for example in case of torture and inhuman or degrading treatment or punishment) before an application can be lodged [14]. The lack of court judgements could either be an indication for the unproblematic health care for aging prisoners or a proof for the high threshold to begin legal action against the responsible bodies. Furthermore, subsequent national rulings could represent precedents that could influence future behaviour and actions of officials who bear responsibility for the correctional system. Older prisoners represent a small percentage of the overall prison population and their status of being old and criminal renders them twofold disadvantaged [25]. Being a minority, they do not have a high-priority status, neither in society nor in prison [25]. The lack of an enforceable right is aggravated by a lack of legal knowledge and a lack of legal support on the side of the (ageing) prisoner. Here, it is again essential to emphasize the importance of empowerment and a legal provision could be a step towards this goal.

After identifying the regulatory gap concerning the health care for ageing prisoners, an investigation was undertaken whether, and if so how, the principle of equivalence of care is realised in the prison setting. Based on these findings, opinions of stakeholders who work with or in the correctional system on the health care provision of ageing prisoners were investigated. It was discovered that the principle of equivalence cannot be implemented completely in all prisons due to a range of barriers that prison health care staff has to face reinforcing the need for a legal framework. Achieving the objective of equivalent health care in practice seems to be impeded by major obstacles as several barriers, such as the variability within correctional systems, the presence of gatekeepers and gatekeeping protocols, the lack of personnel, and delays in the provision of care, to equivalent health care for ageing prisoners were mentioned in the interviews with experts. Once barriers are identified it will be much easier to change procedures or make alterations and to develop possible solutions. Still, the insufficient provision of equivalent health care that occurs (partially) demonstrates the importance to act as it cannot be guaranteed that their fundamental rights (right to equality, right to health) are fully respected. While there have been attempts to improve the ageing prisoners' position in Switzerland,

such as the opening of the 60plus unit in the 'Zentralgefängnis Lenzburg' [33], none of them as yet led to substantial changes. There seem to be no defined conditions or factors on how equivalent health care in prison can be best achieved. A solution to prevent mal-treatment of ageing prisoners in general could be: firstly the adoption of an international standard and/or secondly the introduction of national legal regulations to acquire subjective rights. In this way, prisoners themselves or health care staff could invoke the rights of ageing prisoners when shortcomings regarding their health care are detected. Like mentioned before, up to now, there are only guidelines or recommendations [15,53]. In the light of the theoretical findings in **Chapter 2**, combined with the empirical findings described in **Chapter 3**, it is urgently necessary to design a specific recommendation or guideline for the health care treatment of ageing prisoners as "there are no advocacy groups lobbying for changes for incarcerated elderly" [25].

Summarizing the above, health care in prisons is not always equivalent to health care that is offered in the general community, but equivalent health care is possible and exists in some prisons. Variability of health care in different prisons appears to be due to the lack of detailed standards regarding the exact meaning of equivalence of care, such as staffing quota, delays of treatment, and acceptable gatekeeping systems that may be used to allocate access to health care. In this regard, as an intermediate step and until a legal rule is adopted, other cantons or prisons could be good examples to solve these issues, but also solutions that can be found abroad could be a source of inspiration and supportive in achieving equivalent health care for ageing prisoner extensively.

#### *The Need for Prevention*

Another important factor that could affect the achievement of the principle of equivalence of care could be the way health care is provided to ageing prisoners. Nowadays, economic consideration play an even greater role as prisons budgets have to follow cost-benefit ratios. For this very reason, it is important to take into account the current costs as well as the potential long-term savings when considering future options and possibly legal obligations regarding the health care for ageing prisoners. The expenses for the penal system in Switzerland amounted in 2010 to 993 million CHF which is 0.67% of the total expenditures of 147.1 billion CHF (an increase of 24% from 2005) [23]. Numbers from 2010 also indicate that one day in a Swiss prison (open or closed) costs 390 CHF per person compared to 243 CHF for a day in a remand prison [23]. These costs have increased by 58 CHF and 34 CHF respectively in the past 5 years [23]. Compared to data from Germany where in 2008, the national average was about 93 € per day and person [41]. The overall running costs for the penal system in Germany was 2.4 billion in 2007 [50]. With higher occupancy rates [4] and an increasing number of ageing prisoners, the costs for health care are likely to rise even more [40]. Unfortunately, there were no numbers available on the health care expenditures of the penal system in Switzerland or Germany, but a rise in health care spending has already happened in the USA between 2001 and 2008, increasing by 52% [57]. As shown in **Chapter 4**, older prisoners have higher health care burdens and therefore are more frequent users of health care services [59], which could become a cost trap for correctional facilities in Switzerland also if they are unwilling or unable to halt or avert

this development. The high utilization of expensive health care is already now putting more strains on the prison budgets [38,51,57], and the resources needed to deliver health care to older prisoners' are likely to exceed the costs for public health care services in the general ageing population. An adequate allocation of resources to and within prison systems is consequently necessary to enable the responsible prison management to modify and improve existing structures. This could be done by focussing more on preventive measures and not on a curative approach. Using this new approach, it could be possible to prevent the manifestation of chronic diseases and save treatment costs. Even though, some prisons already offer preventive measures for their detainees, it is not routinely and systematically done as the following quotes from Stakeholders that were interviewed during the qualitative part of the study indicate:

Maybe it would also be necessary to have specific offers, for example preventive measures, which is a great example. If we assume that men 50plus do a preventive colorectal cancer screening, hence have to do a colonoscopy, and we have an increasing number of people like this in prison, then maybe it should be part of such a concept/approach [for aging prisoners]. As far as I know, there are, well we clearly have nothing like that at all, and probably in most other [correctional] institutions that is also not the case. (2 C1b, PA<sup>4</sup>)

That's an issue that has been highlighted, that aged men are getting the screening that men should be getting at that age. Things like aortic aneurism screening, bowel cancer screening, this isn't being done routinely. And I know that's the same for women in terms of elderly female prisoners not getting mammograms or cervical screening. (17 C2, HCP)

Likewise, Stojkovic [52] states that: "In the non-incarcerated population, we have seen targeted efforts to address early signs of these illnesses and to develop appropriate treatment protocols. In the prison, more often than not, this is not the case". Given the cost-reducing effect that is very highly regarded relating to prevention, health promotion and health protection, this is very surprising also because websites like "Health Promotion Switzerland" offers information and downloads that are accessible online and free of charge [26]. Especially, nutrition (offering high-protein products and vegetables (soups)) and movement (purchasing devices and equipment, for example for balance training, such as balance discs) of ageing prisoners are factors that could be adjusted relatively easy inside prisons without an increase of costs. The application of the principle of equivalence even in this regard could prevent the aggravation of diseases and the need for long-term care.

### *Outlook*

In the current state and most likely in the future, it is necessary to find individual solutions for ageing prisoners which is always much more complex than a one-fits-all solution. For this reason, training

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<sup>4</sup> For coding scheme, please see Chapter 3, first paragraph of the Result Section.

programs for staff members working with ageing prisoners [11,36] should be developed to facilitate the performance of their new tasks and to carry out a satisfying and meaningful job. The ability to detect deteriorating health conditions of older prisoners is also of great importance for correctional staff [63] in order to initiate early treatment and act as an bridging element. The possibility to access physicians trained as geriatricians [13] should also be guaranteed in Swiss prisons that house older prisoners. The aim of these visits would be to provide support for the older prisoners and the health care and correctional staff equally. Another subject that is related to health care for ageing prisoners is end-of-life care. Correctional facilities are not the ideal environment to offer end-of-life care due to their design and equipment (staffing and other medical aids/devices). To care for old, frail, sick and disabled persons is a time-intensive, expensive and challenging task, doing it in prisons without staff that has experience in this field is even more demanding [52]. Concentrating on compassionate release for older prisoners posing no threat to society could be one option to facilitate the challenge of end-of-life care in correctional facilities. If older prisoners do not pose a threat to society, it would according to Human Rights Watch be a violation of “human rights, common sense, and fiscal prudence” not to release them [35] or like Curran phrases it: „If the humane aspect of the elderly inmate's dying without dignity behind bars doesn't tug at their heart strings, then maybe tugging at their purse strings will“ [18]. The choice and attempt to realize compassionate release more often may be linked with additional administrative effort at the beginning, but once procedures have been established and contacts to outside care facilities have been set up, it should continue to become a normal process with a likewise decreasing workload. Changes in the prison system should be directed at long-term performance to achieve a stable and ethical evolution in the health care provision for ageing prisoners.

## Strengths and Limitations of Research Methods

The data presented in this thesis were collected as part of the exploratory research project “Agequake in Prisons: Reality, Policies and Practical Solutions Concerning Custody and Health Care for Ageing Prisoners in Switzerland”. This project was the first Swiss-wide study (excluding Ticino) in correctional facilities. It was designed applying a mixed-methods approach due to the complexity of the research questions and lack of available data. By collecting quantitative and qualitative data, the range of aspects of health care provision for ageing prisoners in institutions investigated was increased and could be exploited in more detail. This range was further expanded by involving different peer groups in the interview process in order to investigate different perspectives on ageing prisoners’ health care. An inclusion of (health care) providers and (health care) users made it possible to confront individual perspectives. While, the comparison of stakeholders’ viewpoints with prisoners’ viewpoints cannot be found in this thesis, it was still used in the overall project and depicts an important strength of the “Agequake in Prisons” study design.

The sampling method for prisons included compiling a list of all correctional facilities in Switzerland, sorted by canton, facility name, type of function (different types of detention) and capacity. Based on this list, the inclusion criteria: (i) prisons housing older prisoners, (ii) prisons with more than 20 places, and (iii) long term prisons (>1.5 years imprisonments), and the exclusion criteria: (i) juvenile detentions, (ii) semi-detentions, (iii) remand prisons, (iv) deportation centres, (v) other prisons holding less than 20 places, (vi) prisons that do not house older prisoners, which are described in more detail in **Chapter 4**, were applied. Out of 26 prisons that fulfilled the inclusion criteria and did not meet the exclusion criteria, eleven prisons refused participation in this research project due to lack of resources and time. For this reason, the final sample for the quantitative data collection included 15 prisons: four prisons from the French speaking region and eleven from the German speaking region in Switzerland, representing 122 and 284 medical records respectively. The Italian speaking region of Switzerland was not included due to language barriers. Switzerland has an overall population of 6,923 detainees [7] and although a randomised sampling method was not applied, those 15 prisons that agreed to participate had a capacity of 2,198 places, representing 76.35% of the eligible population. Still, the findings of this study cannot be transferred to those prison types that were excluded (i.e. remand prisons, juvenile detention), because of their different characteristics and particular prison populations.

The quantitative sample comprised a retrospective study of data from 406 prisoner medical records (203 from prisoners younger than 49 years and 203 from prisoners above the age of 50, for more details see **Chapter 4**) and is relatively large for a small country like Switzerland, representing 18.5% of the prison population that fulfilled our inclusion criteria. Based on the design of our study, there are limitations to the generalizability of the presented study results that are applicable to the overall “Agequake in Prisons” research project as the Swiss context with its 26 cantons and 26 different penitentiary law regulations is very specific. Even though, theoretical approaches in different parts of Europe may be mirrored in the cultural context in the French, German and Italian speaking parts of Switzerland. Still, the findings of the quantitative part of the study provide a picture of the status quo in

Switzerland and support the process of identifying the health status and health care access of ageing prisoners, but they are mainly unique. Nevertheless, they add important new information on this topic that can be interpreted and related to other quantitative studies in this field and by doing so, stimulating the debate abroad.

Furthermore, standardised questionnaires and data collection sheets were not employed. This was due to the fact, that there exist enormous differences in prison settings not only in between countries, but also within one country. But it was still possible to use some validated research tools for a minor part of the study. For the qualitative part, two semi-structured interview guides were designed. This was necessary to adjust to the circumstances and realities of the very distinct groups of prisoners and stakeholders. For the geriatric evaluation, which was part of the interviews with prisoners, the SF-12 (Functional Health and Well-being), MMSE (Mini Mental State Examination), CDT (Clock Drawing Test), Barthel Index (of Activities of Daily Living), MNA (Mini Nutritional Assessment) and the GDS-15 (Geriatric Depression Scale) were used. While these tools are in general well-validated instruments, this is not the case for the use in correctional settings. However, only minimal changes were necessary and adhering to the principle of equivalence, a particular focus was put on using these assessment tools for this study.

For the qualitative part of the study, a convenience sampling technique was applied and interviews were conducted with stakeholders from three different European countries on the one hand and prisoners from Switzerland on the other hand. Details about the sampling methods for the group of stakeholders are described in detail in **Chapter 3** of this thesis. Due to the multi-cultural society that can be found in Switzerland, prisoners also had different cultural backgrounds. The participants studied differed regarding their age, race, religious, professional and political background, thereby broadening the scope of investigation. As qualitative interviews aim at investigating opinions and perceptions in an exploratory way and not at quantifying study results [45], it must be noted that these study results are not generalizable. This was enhanced by their diverse backgrounds. Still, those 40 experts from three different European countries described similar aspects and reasons why the provision of equivalent health care in prison can be difficult. This is an indication that problems related to the implementation of the principle of equivalence of care regarding ageing prisoners are not country-specific, but something that can be found transnationally. Certainly, these results constitute an important contribution to current international knowledge in the field of (equivalent) health care provision for ageing prisoners.

Based on this examination, conclusions can be drawn concerning the design of future research projects. Some aspects that will be addressed in the further course of this project and new topics that would be worthwhile investigating are described in the following.

## **Implications for Future Research**

Due to the specific circumstances in the prison setting such as high security standards combined with limited or time consuming access procedures for researchers from outside, the preparations for data collection and the data collection itself were very lengthy. Nevertheless, it was possible to collect a large amount of quantitative and qualitative data which will be further analysed beyond this thesis in the “Agequake in Prisons” project. By continuing this work, other relevant topics such as the accommodation of older prisoners, their nutritional needs, the transportation to outside health care facilities and work and pension of ageing prisoners will be addressed.

Particularly for ageing prisoners it is essential that equivalent health care inside prison is delivered since they suffer from poorer health conditions compared to their younger inmates [21,22]. From the quantitative part of the “Agequake in Prisons” study, it is possible to compare the differences between the somatic disease burden of the younger and older age group of prisoners. Still, these findings do not allow to judge about how adequate the health care provision for ageing prisoners really is and it will be difficult to verify the prevalence of short-comings in the health care provision with the data obtained. Therefore, it would be desirable to design a subsequent study that could prove the denounced short-comings that can be found in the literature. Here, case studies of medical records of ageing prisoners and their analysis by external reviewers in cooperation with the treating medical staff could be a new approach.

Another option for such further investigation would be to carry out a health care intervention with ageing prisoners in the prison environment. Currently, quantitative data on the number and types of diseases and health care usage by ageing prisoners in Switzerland has been collected as part of the “Agequake in Prisons” project and so far partially evaluated, but no data on the effect of health care interventions is available. As a further step it would be helpful to analyse whether the provision of preventive measures, such as physical and/or occupational therapy, or adaptations to the prisons cells, such as special mattresses, better lighting concept, age-appropriate seating, of older prisoners have positive outcomes and increases ageing prisoners’ health and well-being. For the implementation of new health care interventions and adaptations to the environment in prisons, it would be of great advantage to provide empirical evidence that demonstrates their positive effect. This would enhance the chances of implementing these kinds of quality improvements for future practice.

Further research projects should also include other types of facilities, such as remand prisons and prisons with less than 20 places, to gain knowledge on the situation of ageing prisoners in these institutions. This could also enable a comparison between different types/groups of correctional facilities, if certain similar characteristics, such as size/number of places, type of health care provision (nurse, physician based or mixed), are fulfilled. The “Agequake in Prisons” research project focussed on long-term imprisonment. However, in the course of data collection, especially during the interviews, it became evident that the time in pre-trial detention, where prisoners on remand are being locked-up in a cell for up to 23 hours a day can impact the health status, especially of older prisoners severely.

During this time, which can last several months, their bodily activity and social interactions are significantly restricted. The impact of this period in prison has not yet been looked at and should thus be researched in a follow-up study.

## Implications for Practice

Although the major interest of this project lies in its explorative approach on equivalent health care in prisons, it also has some practical implications for the correctional system in Switzerland. The provision and the access to equivalent health care for ageing prisoners is essential for them and constituted in their right to health [37,66]. Older prisoners require special attention and support by security and health care staff likewise to prevent that they are forgotten [28,32]. Attention also needs to be paid to the minimization of the negative effects of barriers to health care access. Currently, ageing prisoners still have to face major challenges in navigating the prison environment and in getting the health care they need. Therefore, it is very important to create more awareness on this topic and to introduce changes to existing practices.

First, special health programs need to be established for the population of ageing prisoners in all Swiss prisons that house prisoners above the age of 50 years. On admission, a first health assessment which goes beyond the usual medical check-up should take place. This is necessary in order to detect health related deficiencies already from the first day in prison. Health assessments should take place on a regular basis to adjust to potentially arising declines in the health conditions of ageing prisoners. The introduction of quality standards could define precisely how older prisoners should be treated and could promote equal standards in different correctional facilities and different cantons. This would be an advantage for prisoners when they are being transferred to another prison as well as for the health care staff as both sides would be informed about their rights and obligations with similar standards in all prisons.

Secondly, it is imperative to educate health care, security as well as administrative staff about the special characteristics of older prisoners. When prisoners require health care, in the majority of cases, they are dependent on the health care staff inside prisons and the services they offer to them. Without knowledge about the special needs of ageing prisoners, change is more difficult to be achieved. Therefore, the Swiss Education Centre for Staff Working in the Penal System (Schweizerisches Ausbildungszentrum für das Strafvollzugspersonal)<sup>5</sup> should offer workshops or courses for correctional staff that maintain direct contact with ageing prisoners regularly to improve their mode of operation. Staff that is sensitized for the work with older prisoners and is informed about preventive measures, the principle of equivalence and its meaning can improve the work setting to a setting where older prisoners are treated and cared for according to their needs and equivalent to their peers outside prison. Brägger [19] also argues for the need to employ highly specialized personnel as they are a cornerstone for a well-functioning prison system. Well-trained staff represents the preconditions for a system where ageing prisoners are not neglected.

Thirdly, a person-focused approach rather than a group-focus approach should be applied when caring for older prisoners. As mentioned before, older prisoners are a very heterogeneous group and a one-fits-all approach would not take into account their individuality. Especially, at the end-of-life,

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<sup>5</sup> <http://www.prison.ch/de/>

measures that are tailored to the specific situation and adapted to the special demands that older prisoners have at that time are of great relevance.

Fourthly, the prison administration needs to realise that even with the present resources, important improvements and changes are possible. Usually, the reluctance to change the conditions in correctional facilities is excused by the lack of resources. But like mentioned before, an active approach with preventive measures offered to ageing prisoners in contrast to a passive approach where diseases are treated when they occur would not imply an increase in cost for health care treatment but could rather lead to minimising the costs. In the first place it would be a shifting of costs and not an increase. The release of ageing prisoners at their end-of-life or if they do not pose a threat to society anymore would contribute to easing the burden on staff and on the prison budget and would be an option to minimise the housing costs for ageing prisoners [18].

Finally, Switzerland has three penal system concordats (Strafvollzugskonkordate). It should be considered to add a separate paragraph in each of the concordat agreements, handbooks and/or guidelines in order to address the needs of this currently neglected group and to make it a central task to improve the (health care) situation of ageing prisoners in Swiss prisons. The implementation of minimum standards could guarantee uniform treatment of ageing prisoners.

## **Conclusion**

The main goals of this thesis were to identify areas of concern in the health care provision for ageing prisoners: (1) their current health care situation, (2) the legal and practical settings of health care provision and (3) the ethical issues that arise from the need to provide adequate health care. The preceding chapters provide an insight into some of the most challenging aspects of old age inside prisons such as the provision of equivalent health care. Binding legal or other (national) regulations which protect ageing prisoners and their health are missing. These gaps are very concerning and it is therefore suggested to introduce a specific legal provision to ensure equivalent health care for ageing prisoners comprehensively. Although, the delivery of health care for ageing prisoners does meet the standard of equivalent health care in certain prisons, the findings also suggest that it is not achieved in every Swiss prison according to the Stakeholders that were interviewed. This thesis also adds evidence that the disease burden of ageing prisoners compared to younger prisoners in Switzerland is higher, but it is not clear if this higher disease burden is due to a lack of sufficient health care provision for ageing prisoners. The question, whether there is a correlation between the quality of health care and the health status of ageing prisoners could not be answered and leaves room for future research. Now, health care providers, prison administrators and politicians need to face the reality of the structural change in the prison population and it is proposed that the educational framework is adjusted accordingly. It is important for correctional facilities to check current policies and practices in order to improve cost-effectiveness as the high costs that are related to the health care provision in prisons may also have negative consequences for other members in society or society as such (i.e. less money for education). The first priority is to reduce the barriers to health care for ageing prisoners and to ensure that the principle of equivalence is self-evidently applied in the prison system. The growing population of ageing prisoners requires an urgent change in attitudes as the fundamental rights of ageing prisoners have to be respected. The future development concerning the health care for ageing prisoners and the time it will take to implement the proposed changes may also be influenced by the question: "Which way do we want to go: back to retribitional punishment or further along the humanitarian way?".

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## Appendix

## Agequake in Prisons – Stakeholder Interview Guide

Dear Participant, You are taking part in a study that concerns health, well-being and ethical care of older adults living in prison. We are inviting you to take part in this study because of your experience working in prison and/or your expert knowledge in this field. During this interview, I will ask you questions concerning health care received by older prisoners and if and why in your opinion something should be done regarding the situation of older prisoners. In addition, I will ask questions concerning alternative management solutions that would not only help the prisoners but also the prison administration.

*\*Questions in Red may not be applicable for researchers.*

*\*\*The interview guide was designed keeping prison doctors, prison administrators, researchers, and prison scholars in mind. Questions must be adapted for each profession.*

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**If you are fine with the purpose of the study and the reasons we are here (talking) today, I would first like to start with your experiences:**

1. Can we first begin with your past and current working experiences in the prison context:
  - How long have you worked in the prison context and/or with prisoners?
  - Could you please explain what type of work/research have you done in those years?
  - Are you currently still engaged in the prison context? What type of issues are you working on?
2. What is your general experience working in/with the prison system?
3. So far, what has been your experience/understanding regarding the state of older prisoners?
4. Have you personally known any prisoner? If so, how long have you known some of them?

**The next questions concern older prisoners' general health care access:**

5. Could you please tell me about your experiences dealing with older prisoners' health care issues?
  - Please provide a recent example of a situation (if possible).
6. How do you perceive the quality of health care services provided to older prisoners in your state/country?
  - Can you provide a recent example?
7. Please describe the health care services provided to older prisoners in your state/country: take for example a 60-year old prisoner with multiple morbidities such as diabetes, hypertension and heart disease.

8. How often do older prisoners have access to health care specialists such as nurses, doctors, therapist und other specialists?
9. What type of health insurance do older prisoners have (in your state/country)? (Or how are the health care cost of older prisoners financed?)
10. How often do older prisoners get access to additional care such as those provided by dentists, additional emergent care and/or in-patient care?
11. Are additional health care insurance for these treatments provided or possible?
12. Are preventative health care measures such as educational programs on exercise, smoking and drug abuse, yearly medical assessment, HIV test, etc. provided by the prison?
  - Please describe when and how often?
13. What specific aspects of care are considered for older prisoners who are dependent on drugs?
14. Is physical abuse or violence against older prisoners a problem? Please explain.

**I would now like to pose questions related to how health care is provided to older prisoners, if you are OK with it?**

15. Could you please describe to me what happens when an older prisoner suffering from the flu or has chest pain needs medical care - particularly, who provides the first consultation and where does it take place?
16. If after the consultation, it is deemed that the patient must be provided with in-patient care in a hospital, how does that process work?
17. In addition, is there monitoring during the transport and/or in the hospital? How is that organized?
  - Monitoring by security personal?
  - Medical monitoring by nurse?
18. In case an out-patient treatment is recommended for which the older prisoner must be shuttled a few times a week between the prison and the hospital, how is that service provided?

19. Who provides these services and are health care personnel such as a nurse available if there were to be problems and health care complains during the transfer?
20. If the treatment was to take place in prison, would special or additional health care personnel be arranged to provide the medical care, if it was necessary?
21. Who pays for the different costs associated with health care delivery, including transportation of prisoners (i.e. insurance, prison or the state?)
22. Have you had experience with such circumstances? If yes, please give an example.
23. In your opinion, how accessible is medical care in prison for older prisoners?
24. How long does it take to get to the medical service, how far is it from a prison cell, how many doors and security checks does a prisoner have to pass?
25. Could you give an example of a situation where you thought the health care provision to an older prisoner was managed well?
  - Is this example recent (within the last year) or relatively older?
26. Could you give an example of a situation where you thought the health care provision to an older prisoner was managed poorly?
  - Is this example recent (within the last year) or relatively older?
27. In the last few years, have you changed the handling of the medical care of older prisoners or has the medical care of older prisoners changed? (*specific to medical doctors*)

**The following questions will concern barriers faced by older prisoners in obtaining health care:**

28. Are there/do you see problem(s) in the provision of health care to older prisoners?
  - If yes, what are the 3 biggest problems that older prisoners face in relation to health care?
29. What solutions do you see for these problems with which the health care providers are confronted when providing care to older prisoners?
30. Do you receive support for the care of prisoners in general and older prisoners in particular?
31. Could you please describe what type of support do you receive?

32. From whom do you receive the support?

33. Are there legal guidelines in your state/country describing the criteria for the provision of health care for older prisoners and their care at the end-of life?

- Please name the guidelines and/or laws that you are aware of and what influence do they have on your work?

34. Would you wish to have more continued education to better work with the different challenges faced with older prisoners?

**The following questions assess the topic “Ageing in Prison”, particularly to see the circumstances of older prisoners:**

35. Are there guidelines concerning (a) payment for work that older prisoners perform in prison, (b) their ability/right to retire when they reach 65 years, and (c) entitlement to old age pensions?

36. In your opinion, what are possible meaningful and appropriate jobs, duties, and/or activities for older prisoners?

37. Do you think that full-time work for older prisoners is useful? Please explain.

- If no, what alternatives do you propose?

38. What services should prisons provide to improve the quality of life of older prisoners?

39. Do you think that older prisoners would use these services and/or would profit from them? Please explain.

40. In your expert opinion, what should “aging well” in prison comprise?

41. What is your opinion about a separate prison unit for older prisoners?

42. Do older prisoners have access to services like nursing care, palliative care, or hospice care? Explain: who provides these services, who pays for it, how easy is it to receive those services.

- If not, why are these services not provided?

43. What minimal criteria are considered for provision of end-of-life care for a terminally ill older prisoner?

44. What minimal criteria are considered for early release of a terminally ill older prisoner?

45. Is there anything else that you would like to add on the topic of ageing prisoners?

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**Now, I would like to ask some questions regarding cost-benefit analysis:**

1. Are following equipment for treatment of illnesses available in prison  
(1 = yes, available in prison; 2 = available outside of prison, transport to hospital or different institution necessary)?
  - Respiratory assistance (respirator, aspirator, oxygen therapy)
  - Treatment for circulatory problems (compression tights)
  - Treatment for abdominal hernias (bandage)
  - Dialysis equipment
  - Materials for injection (IV, Insulin)
  - Material for basic tests (urine analysis, blood pressure)
  - Heart stimulator (defibrillator)
  - Anti-sore materials (pillows, mattresses)
  - Physical therapy equipment
  - Other treatment equipment: \_\_\_\_\_
  
2. If these medical aids are not available in prison, how far does an older prisoner must be transported in order to get his/her treatment? Which means of transportation are used?
  
3. How likely is it that the prison would build an elevator (expected cost: CHF 500.000) to make it easier for older prisoners with mobility problems.
  
4. Would it be possible to designate or built a prison section (estimated cost: 5 - 10 million) for older prisoners to ensure their safety and improve their quality of life?

## Agequake in Prisons – Stakeholder Vignettes

Based on the vignettes provided, please answer the following questions.

**Vignette 1:** Mr. Müller is 65 years old and has lived in prison A for the last 10 years. He is suffering from diabetes and hypertension. He receives prescribed medications for his chronic conditions. Until his recent fall, Mr. Müller was healthy and was able to conduct his daily activities independently. As a result of the fall, he now has a broken hip and a broken wrist, making him dependent on constant care from others.

1. Mr. Müller needs help with his daily activities such as feeding, showering, dressing, using the bathroom and walking. How will the prison handle a case like this?
2. Who is likely to aid him with these daily activities?
3. Mr. Müller needs occupational therapy for practicing activities of daily living and preventing further falls. How likely is it that he would receive this therapy?  
 Very likely       Likely       Unlikely       Very unlikely  
What factors would affect the likelihood of receiving the therapy?
4. In this case, what kind of therapy would most likely be first offered to Mr. Müller? Please explain your reason.
5. In your opinion, what preventive measures would be taken to avoid future falls of Mr. Müller and other older prisoners like him (e.g., installing shower bars, ensuring the floors are not slippery, providing assistive devices)?

**Vignette 2:** Mrs. Gerbert is 72 years old and has lived in Prison B for 32 years. It is expected that she would not live for more than 12 months due to her terminal cancer. She has severe pain and has been requesting stronger pain medications and narcotics. She has no family members outside the prison and is well liked by other prisoners and prison staff members.

1. What would you recommend for this case?
  - If she should be released, what would the reasons be?
  - How would the decision-making process for such release take place? Who would be involved in these decisions?
  - Would she receive hospice care or other end-of-life related care?
  - Who would be responsible for taking care of these end-of-life care services?

2. Would she be provided with hospice care or other end-of-life care? Describe the circumstances and barriers that you would face when accessing such care for Mrs. Gerbert?
3. Will Mrs. Gerbert have access to stronger pain medication/narcotics?
4. Is access to narcotics a problem for older prisoners? Please explain.

**Participant Demographic Information:**

1. Age and Sex:
2. Profession:
3. Highest Educational Qualification:
4. Country:

Thank You!

## Agequake in Prisons – Medical Records Data Extraction Sheet

\*NA = information not available in medical record

Patient Number:

Institution Number:

### 1. Demographic Information:

- a. Age: \_\_\_\_\_ Year of birth: \_\_\_\_\_
- b. Sex:  1 Male  2 Female
- c. Nationality:  1 Swiss  
 2 Western Europe  
 3 Eastern Europe  
 4 African  
 5 American  
 6 South-American  
 7 Asia  
 8 Oceania  
 Other, specify:  
 111 NA
- d. Languages:  1 German  
 2 French  
 3 Italian  
 4 English  
 5 Other
- e. Occupation at the time of offence:  1 Employed  
 0 Unemployed  
 2 IV-Pensioner  
 3 Retired  
 4 Housewife/Husband  
 5 Self-employed  
 111 NA
- f. What kind:
- g. Job/duty in prison:  1 Yes  0 No Job/duty  111 NA
- h. What kind:

- i. Marital status:  1 Married  
 2 Divorced  
 3 Widowed  
 4 Separated  
 5 Never Married/Single  
 6 Other, specify:  
 111 NA
- j. Number of children:  111 NA
- k. Number of grandchildren:  111 NA
- l. Number of siblings:  111 NA
- m. Are parents still alive:  1 Both alive  
 2 Both dead  
 3 Mother dead  
 4 Father dead  
 111 NA
- n. Other remarks concerning family:
- o. Education:  1 No qualification  
 2 Up to 6 years of school  
 3 More than 6 years of school  
 4 Primarschule  
 5 Realschule  
 6 Sekundarschule  
 7 Gymnasium  
 8 Berufsschule/Lehre  
 9 University degree  
 111 NA
- p. Religion:  1 Protestant  
 2 Catholic  
 3 Muslim  
 4 No religious denomination  
 Other (specify):  
 111 NA

- q. Living situation in prison:  1 Alone in a cell  
 2 Alone in cell/WG  
 3 In group with other prisoners  
 4 Other, specify:  
 111 NA

## 2. Incarceration Information:

- a. Is this the first incarceration:  1 Yes  0 No  111 NA

a2. If no, number of times incarcerated:

- b. Date entry:

- c. Date exit:  1 Yes  0 No (measure)  333 Not applicable (i.e. vorzeitiger Strafvollzug)  111 NA

c2. If yes 2/3: Date: Total:

If no, please check one or more of the following categories if they apply to the participant:

- Art. 19 I StGB (Criminal responsibility):  1 Yes  0 No  111 NA  
 Art. 19 II StGB (Reduced criminal responsibility)  1 Yes  0 No  111 NA  
 Art. 59 StGB (In-patient treatment):  1 Yes  0 No  111 NA  
 Art. 60 StGB (In-patient treatment drug-abuse):  1 Yes  0 No  111 NA  
 Art. 61 StGB (For young adults)  1 Yes  0 No  111 NA  
 Art. 63 StGB (Out-patient Treatment):  1 Yes  0 No  111 NA  
 Art. 64 StGB (Safe custody):  1 Yes  0 No  111 NA

- d. Crime(s) for which imprisoned:

Main: **(only one choice possible)**

1. Gewaltdelikt:

- 1.1 Mord (Art. 112 StGB)  
 1.2 vorsätzliche Tötung (Art. 111 StGB)  
 1.3 Totschlag (Art. 113 StGB)  
 1.4 Fahrlässige Tötung (Art. 117 StGB)  
 1.5 Schwere Körperverletzung (Art. 122 StGB)  
 1.6 Einfache Körperverletzung (Art. 123 StGB)  
 1.7 Tätlichkeit (Art. 126 StGB)  
 1.8 Drohung (Art. 180 StGB)  
 1.9 Nötigung (Art. 181 StGB)

## 2. Sexualdelikt:

- 2.1 Sexuelle Handlungen mit einem Kind (Art. 187 StGB)
- 2.2 Sexuelle Handlungen mit einem Abhängigen ( Art. 188 StGB)
- 2.3 Sexuelle Nötigung (Art. 189 StGB)
- 2.4 Vergewaltigung (Art. 190 StGB)
- 2.5 Schändung (Art. 191 StGB)
- 2.6 Pornographie (Art. 197 StGB)
- 2.7 Inzest (Art. 213 StGB)

## 3. Eigentum:

- 3.1 Diebstahl (Art. 139 StGB)
- 3.2 Raub (Art. 140 StGB)
- 3.3 Veruntreuung (Art. 138 StGB)
- 3.4 Sachbeschädigung (Art. 144 StGB)
- 3.5 Betrug ( Art. 146 StGB)
- 3.6 Betrügerischer Missbrauch (Art. 147 StGB)

## 4. Other:

- 4.1 Verstoss gegen das Betäubungsmittelgesetz
- 4.2 Beschimpfung (Art. 177 StGB)
- 4.3 Hausfriedensbruch (Art. 186 StGB)
- 4.4 Verstoss gegen das Transportgesetz
- 4.5 Verbreitung menschlicher Krankheiten (Art. 231 StGB)
- 4.6 Brandstiftung (Art. 221)
- 4.7 Verstoss gegen das Ausländergesetz
- 4.8 Widerhandlung gegen das Waffengesetz
- 4.9 Verstoss gegen das Strassenverkehrsgesetz
- 4.10 Other:
- 111 NA

4b. Attempted?  1 Yes  0 No

Others: (more than one choice possible)

- |  |                                 |
|--|---------------------------------|
| 1. Gewaltdelikt:   | Versuch (i.V.m. Art. 22 I StGB) |
| <input type="checkbox"/> 1.1. Mord (Art. 112 StGB)                                     | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.2. Vorsätzliche Tötung (Art. 111 StGB)                      | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.3. Totschlag (Art. 113 StGB)                                | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.4. Fahrlässige Tötung (Art. 117 StGB)                       | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.5. Schwere Körperverletzung (Art. 122 StGB)                 | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.6. Einfache Körperverletzung (Art. 123 StGB)                | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.7. Tätlichkeit (Art. 126 StGB)                              | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.8. Drohung (Art. 180 StGB)                                  | <input type="checkbox"/>        |
| <input type="checkbox"/> 1.9. Nötigung (Art. 181 StGB)                                 | <input type="checkbox"/>        |
|  |                                 |
| 2. Sexualdelikt:   |                                 |
| <input type="checkbox"/> 2.1 Sexuelle Handlungen mit einem Kind (Art. 187 StGB)        | <input type="checkbox"/>        |
| <input type="checkbox"/> 2.2 Sexuelle Handlungen mit einem Abhängigen ( Art. 188 StGB) | <input type="checkbox"/>        |
| <input type="checkbox"/> 2.3 Sexuelle Nötigung (Art. 189 StGB)                         | <input type="checkbox"/>        |
| <input type="checkbox"/> 2.4 Vergewaltigung (Art. 190 StGB)                            | <input type="checkbox"/>        |
| <input type="checkbox"/> 2.5 Schändung (Art. 191 StGB)                                 | <input type="checkbox"/>        |
| <input type="checkbox"/> 2.6 Pornographie (Art. 197 StGB)                              | <input type="checkbox"/>        |
| <input type="checkbox"/> 2.7 Inzest (Art. 213 StGB)                                    | <input type="checkbox"/>        |
|  |                                 |
| 3. Eigentum:   |                                 |
| <input type="checkbox"/> 3.1 Diebstahl (Art. 139 StGB)                                 | <input type="checkbox"/>        |
| <input type="checkbox"/> 3.2 Raub (Art. 140 StGB)                                      | <input type="checkbox"/>        |
| <input type="checkbox"/> 3.3 Veruntreuung (Art. 138 StGB)                              | <input type="checkbox"/>        |
| <input type="checkbox"/> 3.4 Sachbeschädigung (Art. 144 StGB)                          | <input type="checkbox"/>        |
| <input type="checkbox"/> 3.5 Betrug ( Art. 146 StGB)                                   | <input type="checkbox"/>        |
| <input type="checkbox"/> 3.6 Betrügerischer Missbrauch (Art. 147 StGB)                 | <input type="checkbox"/>        |
|  |                                 |
| 4. Other:  |                                 |
| <input type="checkbox"/> 4.1 Verstoss gegen das Betäubungsmittelgesetz                 | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.2 Beschimpfung (Art. 177 StGB)                              | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.3 Hausfriedensbruch (Art. 186 StGB)                         | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.4 Verstoss gegen das Transportgesetz                        | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.5 Verbreitung menschlicher Krankheiten (Art. 231 StGB)      | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.6 Brandstiftung (Art. 221)                                  | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.8 Verstoss gegen das Ausländergesetz                        | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.8 Widerhandlung gegen das Waffengesetz                      | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.9 Verstoss gegen das Strassenverkehrsgesetz                 | <input type="checkbox"/>        |
| <input type="checkbox"/> 4.10 Other  | <input type="checkbox"/>        |

111 NA**4. General Physical Health Information:**a. Condition of teeth:  1 Saniert  2 Kariös  111 NAb. Dentures:  0 No  
 1 Upper Jaw  
 2 Lower Jaw  
 3 Both  
 111 NAc. Eye sight problem:  1 Yes  0 No  111 NAc1. If yes: Glasses used:  1 Yes  0 No  111 NAc2. Lenses used:  1 Yes  0 No  111 NAd. Hearing disability:  1 Yes  0 No  111 NAd1. If yes: Hearing aid used:  1 Yes  0 No  111 NA

e. e1. Height: e2. Weight:

f. Latest recorded blood pressure:  1 Yes  0 No  111 NA

f1. If yes, when:

**5. Diseases - Specify Diagnosis and Symptoms:**

Present? Yes/No	Description medical record	Classification

**5.1. Allergies:**

1 Yes                       0 No                       111 NA

a. Which:

**6. Preventative Measures Offered:** (Record educational and other preventive measures provided such as exercise, nutrition, smoking and drug use)

- |   |         |
|---|---------|
| <input type="checkbox"/> 1 Vaccination                                    | Date:   |
| <input type="checkbox"/> 2 Nutrition (e.g. diabetes diet)                 | Date:   |
| <input type="checkbox"/> 3 Exercise                                       | Date:   |
| <input type="checkbox"/> 4 Counselling alcohol/drug/medication withdrawal | Date:   |
| <input type="checkbox"/> 5 Counselling chronic diseases                   | Date:   |
| <input type="checkbox"/> 6 Consultation infectious diseases               | Date:   |
| <input type="checkbox"/> 7 Consultation hygiene (teeth)                   | Date:   |
| <input type="checkbox"/> 8 Weight monitoring                              | Period: |
| <input type="checkbox"/> 9 Blood pressure                                 | Period: |
| <input type="checkbox"/> 10 None  |         |
| <input type="checkbox"/> 111 NA   |         |

**7. Screening and Diagnosis Tests Performed:**

(Record test name, when performed: e.g. TB - 13.11.19xx; HIV - 13.11.19xx)

1. Infectious diseases:  1 Yes                       0 No

- |  |       |
|--|-------|
| <input type="checkbox"/> 1.1 HIV           | Date: |
| <input type="checkbox"/> 1.2 Hep B         | Date: |
| <input type="checkbox"/> 1.3 Hep C         | Date: |
| <input type="checkbox"/> 1.4 Tbc (Mantoux) | Date: |

2. Blood test:                       1 Yes                       0 No (Space for values outside range)

- |       |                       |
|-------|-----------------------|
| Date: | Values outside range: |

## 3. Drug screening

3.1 Urine test:  1 Yes  0 No 3.1.1 THC 3.1.2 AMP 3.1.3 COC 3.1.4 MET 3.1.5 MOR 3.1.6 BZO3.2 Alcohol test:  1 Yes  0 No Date:4. Imaging methods:  1 Yes  0 No 4.1 X-ray Date: 4.2 MRT Date: 4.3 CT Date: 4.4 Sonography Date: 4.5 Angiography Date: 4.6. Other Date:5 ECG:  1 Yes  0 No Date:6 Gender specific screenings/diagnose tests:  1 Yes  0 No 6.1 PSA-Prostate Date: 6.2 Mammography Date: 6.3 Pap Smear/Thin Prep Date: 6.4 Pregnancy test Date: 6.5 Other Date: 7 Ophthalmologist check-up Date: 8 Endoscopy Date: 9 Other Date: 10 None 111 NA



- c. Suicide attempted:  1 Yes  0 No  111 NA  
 d. When?

**11. Substance Use:**

- a. Tobacco smoking (now):  1 Yes  0 No  3 Former smoker  
 111 NA

a1. If yes, cigarettes smoked in a day: or Units per year:

a2. Remarks from physician:

- b. Alcohol (before incarceration):  1 Yes  0 No  111 NA

b1. If yes, amount of alcohol consumed:

b2. Remarks from physician:

- c. Drugs:  1 Yes  0 No  111 NA

- i. Cannabis/THC:  1 Yes  0 No  111 NA

c1. If yes, frequency before.....during .....incarceration

c2. Remarks from physician:

- ii. Cocaine:  1 Yes  0 No  111 NA

d1. If yes, frequency: ; way of use:  1 injection  2 smoking  
 3 sniffing

d2. Remarks from physician:

- iii. Opiates:  1 Yes  0 No  111 NA

e1. If yes, frequency: ; way of use:  1 injection  2 smoking  
 3 sniffing

e2. If yes, indicate if substitution treatment and doses per day:

e3. Remarks from physician:

- iv. Benzodiazepine:  1 Yes  0 No  111 NA

f1. If yes, medication and doses:

f2. Remarks from physician:

- v. Other drugs:  1 Yes  0 No  111 NA

g1. If yes, Name of drug:

g2. Frequency:

g3. Remarks from physician:

**12. Visitation With a Medical Health Provider in the Last 6 Months:**

a. Number of times general physicians visited:

Reason	Code	Outcome	Code

b. Number of visits to specialized physician:

Type of Physician	Diagnosis/Reason	Code	Outcome	Code

c. Number of visits to a psychiatrist/psychologist:

Reason	Code	Outcome	Code

## d. Number of visits to a dentist:

Diagnosis/Reason	Code	Outcome	Code

## e. Number of visits to a nurse:

Diagnosis/Reason	Code	Outcome	Code

## f. Physio- or occupational therapy:

- Number of visits to a physio- or occupational therapist:

Diagnosis/Reason	Code	Outcome	Code	Type of therapy

**13. Hospital and Nursing Care Visitation in the Last 6 Months:**

a. Number of visits to a hospital:

Diagnosis/Reason	Code	Outcome	Code

b. Total number of days spent in hospital:

c. Number of visits to a nursing facility:

Diagnosis/Reason	Code	Outcome	Code

d. Total number of days spent in a nursing facility:

**14. Fall Risk:**

a. Has the patient suffered a fall in the last 6 months?

 1 Yes     0 No     111 NA

b. If yes, how many times and what actions were taken:

**15. Select Yes, if Problems are Recorded with Any of the Following Activities of Daily Living.** *\*Assistance: indicates that the person performs the activity with support from a carer or an assisted device.*

 1 Yes     0 No     111 NA

15a. If yes,

Bathing/shower:  1 Yes     0 No     111 NA     2 AssistanceGrooming:  1 Yes     0 No     111 NA     2 AssistanceEating and drinking:  1 Yes     0 No     111 NA     2 AssistanceDressing:  1 Yes     0 No     111 NA     2 AssistanceToilet use:  1 Yes     0 No     111 NA     2 AssistanceBowels:  1 Yes     0 No     111 NA     2 AssistanceBladder:  1 Yes     0 No     111 NA     2 AssistanceMobility (walk 3 meters):  1 Yes     0 No     111 NA     2 AssistanceWalk up stairs:  1 Yes     0 No     111 NA     2 Assistance

Transfer (From bed to chair and back):

 1 Yes     0 No     111 NA     2 Assistance

Participant #

Date:

Cleaning cell:     1 Yes     0 No     111 NA     2 Assistance  
Making telephone calls:  1 Yes     0 No     111 NA     2 Assistance  
Handling money:     1 Yes     0 No     111 NA     2 Assistance

**16. Work Capacity:**

- a.    1 Full     2 Partly  
b. How much?    None     111 NA

**17. Health Insurance:**

- a.    1 Yes     0 No     111 NA    Which?  
b. Paid by:  1 Self     2 Social services     3 Prison     4 Other  
               111 NA

**18. Other Relevant Information Noted in the Record:**

(e.g. assisted devices used; since when limitations and disabilities exist, information concerning orientation (space, time, etc.), if injured as a result of violence) etc.)

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**19. Relevant Information Concerning Medical Record in General:**

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# Curriculum Vitae



## Wiebke Bretschneider

*Home Address* Ringstr. 23, 79576 Haltingen, Germany  
*E-mail* wiebke.bretschneider@unibas.ch  
*Date of Birth* 5 January 1984  
*Country of Birth* Germany

### Professional Experience

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Date	05/2011 - Present (100%)
Job description	Research Assistant
Name/address of employer	Institute for Biomedical Ethics Bernoullistr. 28, University of Basel, Switzerland
Area	Research
Date	01/2010 – 04/2011 (part-time)
Job description	Health Care Assistant
Name/address of employer	Cum laude GmbH (outpatient nursing) Elsa-Brändström-Str. 181, 06110 Halle/Saale, Germany
Area	Health Care

### Education

---

05/2011 - present	PhD Candidate in Medical and Health Ethics Swiss National Science Foundation Project: “Agequake in Prisons: Reality, Policies and Practical Solutions Concerning Custody and Health Care for Ageing Prisoners in Switzerland” Institute for Biomedical Ethics, University of Basel, Switzerland
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#### PhD Committee:

*Referee:* Prof. Dr. Bernice Elger, University of Basel, Institute for Biomedical Ethics

*Co-Referee:* Prof. Dr. Alexander Capron, University of Southern California Gould School of Law

*Co-Referee:* Dr. Roberto Andorno, University of Zurich, Institute of Law

*External Expert:* Prof. Dr. Winfried Kluth, Martin Luther University Halle-Wittenberg, Institute of Public Law

- 10/2008 - 03/2011 M.mel., "**Medicine, Ethics and Law**", Martin-Luther University Halle-Wittenberg, Halle (Saale), Germany, "*magna cum laude*"
- Master thesis: "*Restraint of Intensive Care Patients. A Medical, Philosophical and Constitutional Analysis*"
- 10/2005 - 09/2008 LL.B., "**Comparative and European Law**", University of Bremen, Hanse Law School, Grade: 2,3
- Bachelor thesis: "*Should Deaf Parents be Able to Choose a Deaf Child? A Comparative Law Approach to the Practice of Pre-Implantation Genetic Diagnosis in the United Kingdom and Germany*"
- 09/2007 - 01/2008 Erasmus Programme, University of Groningen, Netherlands
- 09/2004 - 08/2005 European Voluntary Service (EVS)/Diaconal year abroad, Viljandi, Estonia
- 08/2001 - 07/2004 Wirtschaftsgymnasium, Grade: 1,0, Stendal, Germany
- 08/2000 - 06/2001 Student exchange, AFS (American Field Service) Intercultural Programs, Escola Interativa Coopema, Barra do Garças, Brazil
- 08/1994 - 07/2000 Markgraf-Albrecht Gymnasium, Osterburg, Germany

### Internships

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Date	01/2009 - 04/2009 (100%)
Job description	Intern
Name/address of employer	Landgericht Halle Hansering 13, 06108 Halle/Saale, Germany
Area	Judicial
Date	10/2008 - 01/2008 (100%)
Job description	Intern
Name/address of employer	Universitätsklinik für Anästhesiologie und Operative Intensivmedizin, Ernst-Grube-Str. 40, 06120 Halle/Saale, Germany
Area	Health care

Date	02/2007 -04/2007 (100%)
Job description	Intern
Name/address of employer	Silvia Schmidt, MdB, Behindertenbeauftragte der SPD-Bundestagsfraktion, Deutscher Bundestag, Platz der Republik 1, 11011 Berlin, Germany
Area	Local and health care politics
<b>Project Funding and Scholarships</b>	
08/2013 - 04/2015	OPO-Stiftung „Die Medikation von älteren Gefangenen: Eine detaillierte Analyse in den Einrichtungen des Freiheitsentzuges in der Schweiz“ (45.000 CHF)
10/2012 - 09/2012	Hans und Eugenia Jütting-Stiftung Stendal (6.000 €)
09/2007 - 01/2008	Erasmus Programme (Mobility Grant)
09/2004 - 08/2005	Jugend in Aktion - Europäischer Freiwilligendienst (EVS)

#### Teaching/Tutoring

02/2015 – 07/2015	Coordinator and lecturer for the seminar: <i>“Contemporary Debates in Bioethics: Insights into Prisons”</i> , University of Basel, Switzerland
Contributions to teaching (part of a lecture)	
04/2013	<i>“Begutachtung von Forschungsprojekten, Grundlagen, Organisation und Arbeitsweise der Ethikkommissionen”</i> , Forschungsethik, University of Basel, Switzerland
Tutorials given	
12/2012	<i>„Fürsorgerische Unterbringung“</i> , Themenblock <i>“Körper-Subjekt-Umwelt”</i> , University of Basel, Switzerland
03/2013	<i>Themenwoche “Wissenschaft und Ethik”</i> , University of Bern, Switzerland
04/2013	<i>„Grundlagen der Ethik für Studierende der Biologie und Pharmazeutischen Wissenschaften“</i> , University of Basel, Switzerland
05/2013	<i>Themenblock „Psyche-Ethik-Recht“</i> , University of Basel, Switzerland

### Peer-reviewed Journal Articles

---

1. **Bretschneider, W.**, “*Restraints in hospitals - A sore point*” (Fixierungsmaßnahmen in Krankenhäusern - Ein wunder Punkt). (2012), *Das Gesundheitswesen*, 74(12):812-817.
2. **Bretschneider, W.**, Elger, B., Wangmo, T., *Ageing Prisoners' Health Care: Analysing the Legal Settings in Europe and the United States*. (2012), *Gerontology*, 59(3):267-275.
3. Handtke, V., **Bretschneider, W.**, Wangmo, T., Elger, B., *Facing the challenges of an increasingly ageing prison population in Switzerland: In search of ethically acceptable solutions*. (2012), *Bioethica Forum*, 5(4):134-141.
4. **Bretschneider, W.**, “*The new Swiss regulation on restraint measures on medico-ethical trial*” (Die neue Schweizer Gesetzgebung zu bewegungseinschränkenden Maßnahmen auf dem (ethischen) Prüfstand). (2014), *Ethik in der Medizin*. DOI: 10.1007/s00481-014-0317-5. published online.
5. **Bretschneider, W.**, Elger B., *Expert Perspectives on Western European Prison Health Services: Do Ageing Prisoners Receive Equivalent Care?*. (2014), *Journal of Bioethical Inquiry*, 11(3):319-332.
6. Handtke, V., **Bretschneider, W.**, *Will I stay or can I go? Assisted suicide in prison*. (2014), *Journal of Public Health Policy*. DOI: JPHP.2014.43, published online.
7. Wangmo, T., Meyer, A., **Bretschneider, W.**, Handtke, V., Kressig, RW., Gravier, B., Büla, C., Elger, B., *Ageing prisoners' disease burden: Is being old a better predictor than time served in prison?* (2014). *Gerontology*. DOI: 10.1159/000363766, published online.
8. Handtke, V., **Bretschneider, W.**, Elger, B., Wangmo, T., *Easily forgotten: Elderly Female Prisoners*. (2015). *Journal of Aging Studies*, 32:1-11.
9. Wangmo, T., Meyer, A., Handtke, V., **Bretschneider, W.**, Biller-Andorno, N., Page, J., Sommer, J., Stuckelberger, A., Aebi, M., & Elger, B., *Ageing prisoners in Switzerland: An analysis of their access to healthcare utilization* (2015) *Journal of Aging and Health* (accepted).
10. Handtke, V., Wangmo, T., Elger, B., **Bretschneider, W.**, *New guidance for an old problem: Early release for seriously ill and elderly prisoners in Europe*. (2015) *The Prison Journal* (accepted).
11. Submitted: Handtke, V., **Bretschneider, W.**, Elger, B., Wangmo, T., *The collision of care and punishment: ageing prisoners' view on compassionate release*. *Punishment & Society*.

### Book Chapters

---

1. **Bretschneider, W.**, Wangmo, T., Elger, B., *Notfallsituation*. In: Ethik und Recht in Medizin und Biowissenschaften - aktuelle Fallbeispiele aus Biologie, klinischer Praxis und Forschung, Eds. Elger, Biller-Andorno, Rüttsche, De Gruyter, 2014.
2. Engel, S., **Bretschneider, W.** *Gentechnik*. In: Ethik und Recht in Medizin und Biowissenschaften - aktuelle Fallbeispiele aus Biologie, klinischer Praxis und Forschung, Eds. Elger, Biller-Andorno, Rüttsche, De Gruyter, 2014.

### Conference Oral Presentations

---

1. Handtke, V., **Bretschneider, W.**, Wangmo, T., Elger, B., *Closing the research gap: Analysing the health care for women in prisons*. European Association of Centres of Medical Ethics Conference (EACME). Bristol, UK. September 2012. Oral Presentation.
2. **Bretschneider, W.**, *Agequake in prisons*. Schweizerische Gesellschaft für Biomedizinische Ethik - Autumn seminar. Bigorio, Switzerland. November 2012. Oral Presentation.
3. **Bretschneider, W.**, Handtke, V., Wangmo, T., Elger, B., *Becoming Old in Prisons: An Overview of the Swiss National Study of Ageing in Prisons*. 13th Annual Conference of the ESC (Eurocrim). Budapest, Hungary. September 2013. Oral Presentation.
4. **Bretschneider W.**, Handtke V., Elger B., Wangmo T., *No second chance? Consequences of the 2004 introduction of life long custody in Switzerland*. 69th Annual Meeting of the American Society of Criminology. Atlanta, USA. November 2013. Oral Presentation.
5. **Bretschneider W.**, Handtke V., Meyer L., „*Strafvollzug und demografischer Wandel - Herausforderungen für die Gesundheitssicherung älterer Menschen im Vollzug*“, 7th European Conference on Health in Prisons. Bonn, Germany. March 2014. Workshop.
6. **Bretschneider, W.**, Handtke, V., Wangmo, T., Elger, B., *How do older prisoners perceive their health? An analysis of geriatric evaluation*. 14th Annual Conference of the ESC (Eurocrim). Prague, Czech Republic. September 2014. Oral Presentation.

### Conference Poster Presentations

---

1. **Bretschneider, W.**, Handtke, V., Ritter, C., Büla, C., Gravier, B., Kressig, R., Wangmo, T., Elger, B., *The pattern of health care use of older prisoners in Switzerland*. 80<sup>th</sup> Annual Meeting of the Swiss Society of General Internal Medicine (SGIM). Basel, Switzerland. May 2012, Poster Presentation.

2. Handtke, V., **Bretschneider, W.**, Wangmo, T., Elger, B., *Easily forgotten: Elderly women in prison*. 11th World Congress of Bioethics, International Association of Bioethics (IAB). Rotterdam, Netherlands. June 2012. Poster Presentation.
3. **Bretschneider, W.**, Wangmo, T., Handtke, V., Elger, B., *Ageing Prisoners Healthcare: Analysing the Legal Settings in Europe and the United States*. 12th annual conference of the European Society of Criminology (Eurocrim). Bilbao, Spain, September 2012. Poster Presentation.
4. Elger, B., **Bretschneider, W.**, Handtke, V., Wangmo, T., *Health Care of Elderly Female Prisoners: Is Age Specific Treatment Necessary?*. Gerontological Society of America (GSA), 65th Annual Scientific Meeting. San Diego, USA. November 2012. Poster Presentation.
5. **Bretschneider, W.**, Wangmo T., Handtke V., Elger B., *Ageing Prisoners Healthcare: Analysing the Legal Settings in Europe and the United States*. Gerontological Society of America (GSA), 65th Annual Scientific Meeting. San Diego, USA. November 2012. Poster Presentation.
6. **Bretschneider, W.**, Stuckelberger, A., Page, J., Ritter, C., Wangmo, T., Elger, B., *Aging behind Bars: The Medication of Older Prisoners in Switzerland*. Handtke V., Gerontological Society of America (GSA), 65th Annual Scientific Meeting. San Diego, USA. November 2012. Poster Presentation.
7. **Bretschneider, W.**, Wangmo, T., Handtke, V., Büla, C., Elger, B., *Understanding the health and healthcare needs of older prisoners: A national study of older prisoners in Switzerland*. 66th Annual Scientific Meeting of the Gerontological Society of America. New Orleans, USA. November 2013. Poster presentation.

#### **Educational Training (34 ECTS)**

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- “Angewandte Statistik I”, Autumn Semester 2011, University of Basel, Switzerland, **2 ECTS**.
  - “Einführung in das politische System der Schweiz”, Autumn Semester 2011, University of Basel, Switzerland, **3 ECTS**.
  - “Biomedical Ethics”, Autumn Semester 2011, University of Basel, Switzerland, **3 ECTS**.
  - “Bioethics Research: Contemporary Debates”, Autumn Semester 2011, University of Basel, Switzerland, **2 ECTS**.
  - “Empirical Research in Bioethics: Qualitative and Quantitative Methods I”, Autumn Semester 2011, University of Basel, Switzerland, **2 ECTS**.
  - “Empirical Research in Bioethics: Qualitative and Quantitative Methods II”, Spring Semester 2012, University of Basel, Switzerland, **2 ECTS**.

- “The Development of Biomedical Ethics”, Autumn Semester 2012, University of Basel, Switzerland, **4 ECTS**.
- “Systematische Theologie/Ethik. Religiöse Erfahrung und moralische Identität”, Autumn Semester 2012, University of Basel, Switzerland, **2 ECTS**.
- “Ethik in der Pflege: Basiskompetenzen und aktuelle Fragestellungen”, Autumn Semester 2012, University of Basel, Switzerland, **3 ECTS**.
- “Qualitativ Forschen”, Spring Semester 2013, University of Basel, Switzerland, **3 ECTS**.
- “Advanced Research Methods in Bioethics - Specialised Topics”, Spring Semester 2013, University of Basel, Switzerland, **2 ECTS**.
- “PhD-Retreat”, 1-3 July 2013, University of Zurich, Switzerland, **2 ECTS**.
- “Advanced Research Methods in Bioethics - Specialised Topics”, Spring Semester 2014, University of Basel, Switzerland, **1 ECTS**.
- “Summer School I Empirical Bioethics”, Spring Semester 2014, University of Zurich, Switzerland, **3 ECTS**.

#### Other Skills

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German	Mother tongue
English	Fluent (spoken and written)
Portuguese	Basic knowledge
Dutch	Basic knowledge
Estonian	Basic knowledge
MS Office	Good knowledge
SPSS	Basic knowledge
MAXQDA	Good knowledge

#### Memberships

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04/1995	Protestant Church
07/2001	AFS (American Field Service) Intercultural Programs
01/2006	Förderverein “Fachwerkkirche St.Lorenz” Rathslieben e.V.
07/2011	meris e.V. (Association to promote the interdisciplinary scientific discourse)



Picture taken in 2013 by Wiebke Bretschneider in the Eastern State Penitentiary, Philadelphia (USA).